QUALITY OF LIFE IN PATIENTS WITH PSORIASIS

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DECLARATION

I, Mercedes Morrison, declare that this research report is my own work. It is being submitted for the degree of Master of Medicine in the branch of Dermatology at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Name: Mercedes S.

Surname: Morrison

Date: _____

Signature: _____

DEDICATION

Dedicated to my husband, son and family for their continued love and support.

ABSTRACT

Background

Psoriasis(PsO) is a chronic skin disease that is often associated with impaired health-related quality of life (HRQoL). To date there are limited data on HRQoL in South Africans with PsO.

Objective

The aim of the present study was to assess HRQoL in patients with PsO in urban Gauteng, South Africa.

Patients and Methods

A cross-sectional study was conducted in patients with PsO attending Dermatology clinics at three hospitals of the Wits Academic Complex, Johannesburg. Data collection included demographics, Psoriasis area and severity index (PASI) and two dermatology HRQoL questionnaires, namely the Dermatology life quality index (DLQI) and PsO-specific, Psoriasis disability index (PDI).

Results

Of the 105 patients who participated in the study, there was almost an equal number of men and women, with a mean (SD) age and disease duration of 53,04 (14.65) years and 15 (20) years, respectively. Most patients had plaque type PsO (98.1%) and 30,5% had psoriatic arthritis. The median (IQR) PASI, DLQI and PDI scores were 5,5(10,4), 8(10) and 10(15), respectively. Predictors of worse DLQI and PDI scores were PASI>10 ($p=0.011$ and $p=0.002$), respectively, and younger age ($p=0.002$ and $p=0.000$), respectively. In addition, DLQI was also negatively affected by marital status, genital involvement of psoriasis and smoking status.

Conclusion

Patients with PsO from Johannesburg, South Africa seem to have impaired HRQoL as assessed by both DLQI and PDI and more so with moderate to severe skin involvement and in younger patients, findings that are similar to those reported in other populations.

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ABBREVIATIONS

BSA	Body surface area
CADI	Cardiff acne disability index
CASPAR	Classification criteria for psoriatic arthritis
CDLQI	Children's dermatology life quality index
DLQI	Dermatology life quality index
EDI	Eczema disability index
GHQ	General health questionnaire
HAQ	Health assessment questionnaire
HCRU	Healthcare resource use
HRQOL	Health related quality of life
IL	Interleukin
IMPACT	Impact of skin disease scale
KMPI	Koo mentor psoriasis instrument
LS/PGA	Lattice system/Physicians' global assessment
NHP	Nottingham health profile
PASI	Psoriasis area and severity index
PDI	Psoriasis disability index
PLSI	Psoriasis life stress inventory
proSPI	Professional simplified psoriasis index
PsA	Psoriatic arthritis
PSO	Psoriasis
PSORS1	Psoriasis susceptibility 1 gene
PUVA	Psoralen ultraviolet A
QES	Questionnaire on experience with skin complaints

QoL	Quality of life
SAPASI	Self -administered psoriasis area and severity index
saSPI	Self -assessment simplified psoriasis index
SF-36	Short form 36 health survey
SIP	Sickness impact profile
SPI	Salford psoriasis index
SWLS	Satisfaction with life scale
TNF	Tumour necrosis factor
T2DM	Type 2 diabetes mellitus
UVA	Ultraviolet A
UVB	Ultraviolet B
WHO	World Health Organization

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

1 CHAPTER ONE: INTRODUCTION AND LITERATURE REVIEW

I am silvery, scaly

Puddles of flakes form wherever I rest my flesh

Lusty, though we are loathsome to love

Keen-sighted, though we hate to look upon ourselves

The name of the disease, spiritually speaking, is Humiliation

John Updike *in* Journal of a Leper(Updike, 1976)

1.1 Introduction

Psoriasis (PsO) is a chronic immune-mediated inflammatory condition that affects predominantly the skin and to a lesser extent the joints. It has an estimated global prevalence of around 2% with a strong familial tendency (Christophers, 2001) It affects physical, emotional, psychological and social functioning thereby impacting on an individual's overall health-related quality of life (HRQoL). It tends to run an acute on chronic course, and its unpredictability proves very difficult for many patients. The economic burden for patients with PsO is significant in all parts of the world (Javitz et al., 2002, Sohn et al., 2006)

1.2 History

Von Hebra in 1841 was the first to distinguish the cutaneous clinical features of PsO from those of leprosy, whereas for many centuries previously, PsO was grouped with leprosy (Bolognia J, 2008). Hence in earlier times, PsO patients were given the same brutal treatment as those with leprosy, isolated from their communities, rejected and even killed. Even in modern times, numerous studies have reported on the

stigmatization that PsO patients suffer, and the negative impact the disease has on their HRQoL (Ginsburg and Link, 1993).

1.3 Epidemiology

Psoriasis is estimated to affect approximately 2% of the general adult population, but the prevalence varies in different populations (Christophers, 2001). It is generally thought to occur more commonly in Caucasian patients than in non-Caucasians. In North- America the prevalence varies from 2% up to 4,7% in White Americans. The disease is reported to be less common in Africans, African-Americans and Asians, around 0.4- 0.7%. In more recent studies the prevalence of PsO was found to be 1.3-1.9% in African Americans (Gelfand et al., 2005). Lower prevalence rates have also been reported in Asian countries, 0.44% in Sri Lanka, 0.23% in Taiwan and 0.35% in China (Parisi et al., 2013).

In Africa, differences in prevalence rates have been observed between west African countries, such as Nigeria (0.8%) and east African countries, like Kenya (2,6%) (Obasi, 1986, Verhagen and Koten, 1967). In a survey of 7029 patients attending Dermatology Clinics in Johannesburg, PsO was the most common skin condition in South Africans of Indian origin with a prevalence rate of 9.6%.(Hartshorne, 2003)

The disease occurs equally in males and females and can occur at any age. There are two peaks of age of onset. Type I PsO occurs in younger patients, beginning on or before age 40, and accounts for more than three-quarters of all cases, Type II PsO is seen in older patients with age of onset usually after 40 years (Henseler and

Christophers, 1985) . The prevalence of PsO in children is lower and shows a linear increase with age (Augustin et al., 2010).

1.4 Pathogenesis

Psoriasis is an immune-mediated inflammatory disorder with a strong genetic association. The disease is a predominantly Th1-mediated disease with resulting increase in the cytokines, IFNY and IL2 (Krueger and Bowcock, 2005). Th 17 cells are another subset of T-cells driven by IL23, producing IL17 and IL22, which further induces keratinocyte proliferation(Di Cesare et al., 2009).The complex interactions between T-cells, granulocytes and macrophages result in upregulation of cytokines, TNF and IFNY, resulting in epidermal hyperplasia and proliferation of vascular endothelial cells.

Given that patients with PsO have a family history of the disease in approximately 40% of cases, it is not surprising that several genetic loci have been associated with the disease (Andressen C, 1982). Thus far genetic studies have identified over 40 loci thought to be associated with PsO. The commonest replicated locus in PsO, termed PsO susceptibility 1, PSORS1 (Trembath et al., 1997). The pathogenesis of PsO is beyond the scope of this review.

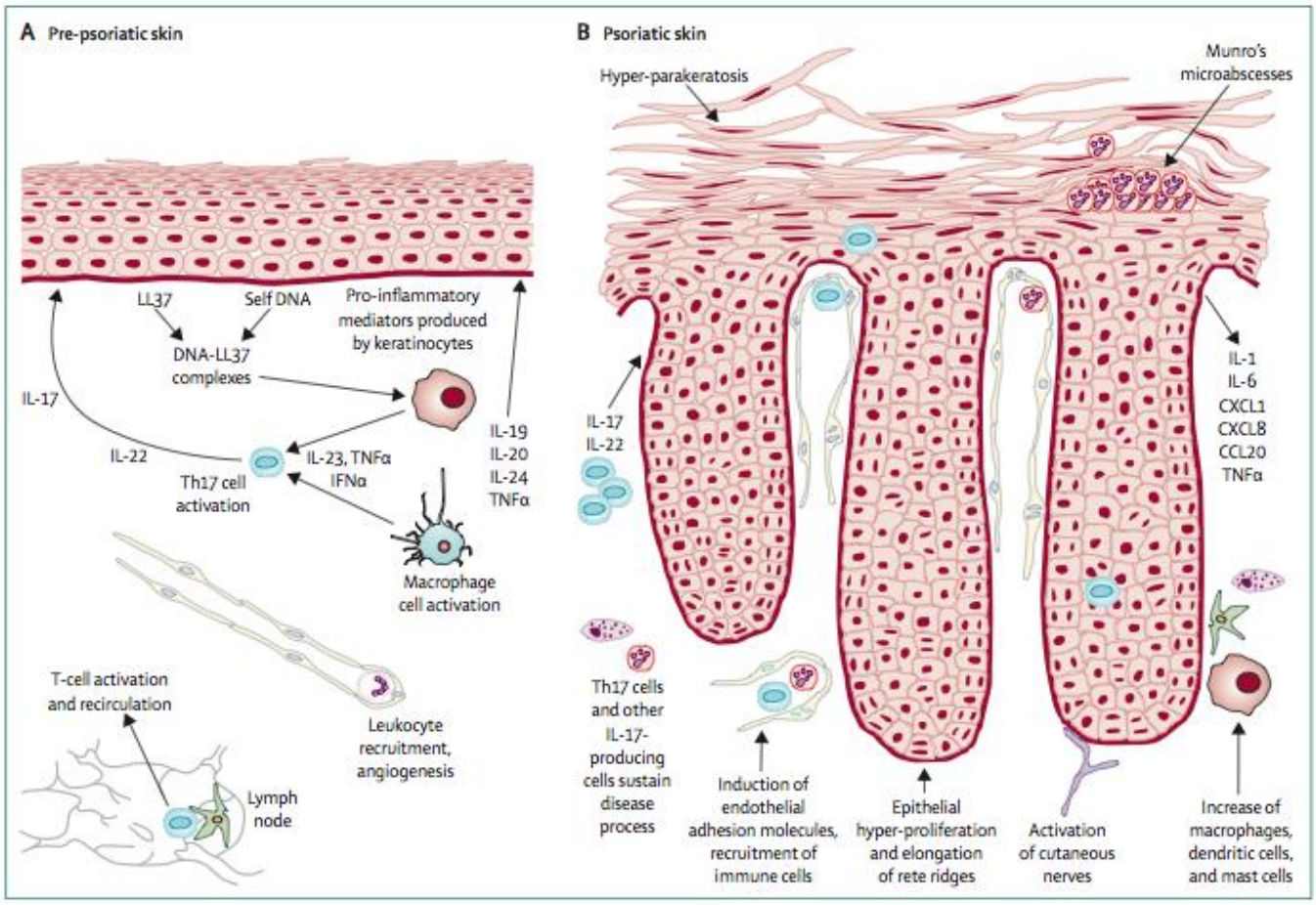

Figure 1.1 Pathogenesis of PsO (Boehncke and Schon, 2015)

1.4.1 Exacerbating factors

Several factors are known to trigger the onset or exacerbate PsO including: infections, stress, drugs and smoking. Streptococcal infections have been implicated, especially in the onset of guttate PsO (Skov and Baadsgaard, 2000). HIV has been associated with an increase in the severity of PsO (Morar et al 2010). Psychogenic stress has long been an accepted trigger for PsO (Gupta et al., 1989). Drugs such as β blockers, lithium and anti-malarials have been implicated as precipitants of PsO (Tsankov et al., 2000). Smoking has also been implicated as a trigger for PsO (Herron et al., 2005)

1.5 Clinical features

Psoriasis is characterized clinically by thick, sharply demarcated, erythematous plaques with thick white scale, predominantly involving the extensor surfaces, scalp and nails but it can be widespread. The course of the disease is chronic with remissions and unpredictable flares. Symptoms include bleeding, pruritus, pain and discomfort. There are 5 types of Cutaneous PsO:

1. Plaque PsO being the most common and accounts for over 90% of cases.
2. Guttate PsO which occurs most commonly in children, and present with smaller scattered plaques.
3. Inverse PsO presents as shiny erythematous plaques in the intertriginous areas.
4. Pustular psoriasis has two main clinical variants, the generalized form and localized palmoplantar pustulosis. The generalized pustular form of the disease can be life threatening.
5. Erythrodermic PsO is a serious complication. In a South African series of patients, the erythrodermic form of the disease was found to be more prevalent in patients with HIV (Morar et al., 1999)

Nail involvement is seen most commonly with plaque PsO and is characterised by pitting, leukonychia, onychorrhexis, crumbling, subungal hyperkeratosis, splinter haemorrhages, onycholysis and the pathognomic yellowish-brown discoloration or so-called ‘oil spot’ sign. These changes result from inflammatory changes in the nail bed and nail matrix. Fingernails and toenails can be involved and found to be as high as 83% in patients who have psoriatic arthritis (PsA). The severity of nail involvement often correlates with the severity of skin and joint disease (Williamson et al., 2004).

Nail bed changes such as onycholysis, splinter haemorrhages, oil spots and subungal hyperkeratosis are associated with higher swollen joint counts (Sandre et al., 2015).

Psoriatic Arthritis

Psoriatic arthritis was first recognized as being distinct from rheumatoid arthritis by Wright and Moll, 1973 (Moll and Wright, 1973). It is a chronic inflammatory arthritis classified as a seronegative spondyloarthropathy, affecting 5-30% of patients with cutaneous PsO (Christophers, 2001). Cutaneous disease tends to precede PsA in 60-80% of patients by about a decade, in some cases the skin and joint disease present simultaneously, and rarely joint disease precedes the onset of the cutaneous disease.

1.6 Diagnosis

The diagnosis of PsO is primarily based on finding the typical clinical features. A key physical sign is the Austpitz sign, where pinpoint bleeding is seen after removal of a thick scale from a psoriatic plaque.

A skin or nail biopsy is sometimes necessary to confirm the diagnosis. The histopathological features of PsO are shown in Figure 2. They include confluent parakeratosis, hyperkeratosis, neutrophils in the stratum corneum (‘Munro microabscesses’) and spinulosum (‘spongiform pustule of Kogoj’) and hypogranulosis. Other features are suprapapillary thinning of epidermis over dermal papillae, regular acanthosis, dilated capillaries in dermal papillae and perivascular lymphocytes (Rapini, 2012)

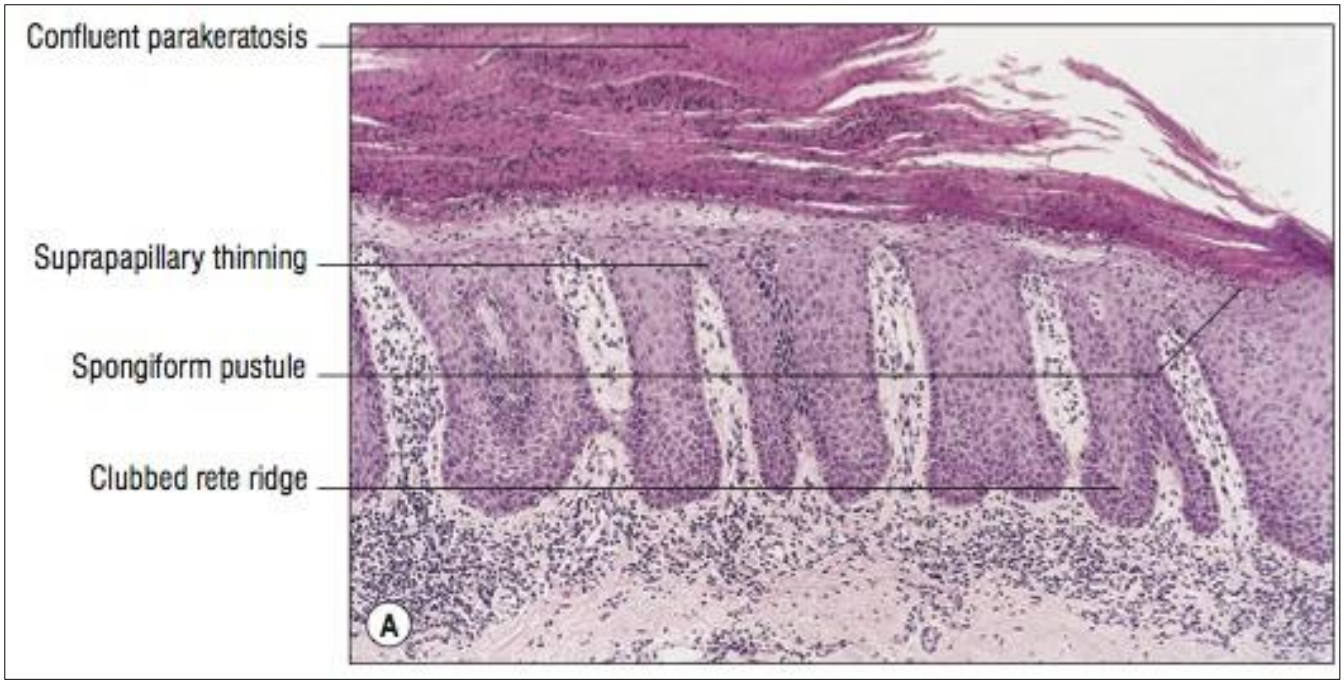

Figure 1.2 Histology of PsO (Rapini, 2012)

The focus of our study will be mainly based on the effects of cutaneous psoriasis on quality of life in patients.

1.7 Cutaneous Psoriasis Severity Scores

Several severity scores have been developed for assessing plaque PsO (Table 1.1).

Table 1-1. Clinical severity scoring instruments for cutaneous PsO

Score	Erythema Scaling Infiltration	BSA	Psychosocial Impact	Calculated by
PASI **PsO Area and Severity Index**	+	+	-	Physician
BSA **Body Surface Area**	-	+	-	Physician
PGA **Physicians Global Assessment**	+	-	-	Physician
LS/PGA **Laatice System Physicians Global Assessment**	+	+	-	Physician
SPI **Salford PsO Index Simplified PsO Index**	+	+	+	Physician
saSPI **self –assessment Simplified PsO Index**	+	+	+	Patient
proSPI **professional Simplified PsO Index**	+	+	+	Physician
SAPASI **Self Administered PASI**	+	+	-	Patient

Adapted from (Oji and Luger, 2015) *BSA Body surface area , +includes, - excludes

Table 1.1 illustrates a number of different clinical severity scoring instruments used for cutaneous psoriasis. Some of these are administered by physicians, others self-administered by patients. The psoriasis area and severity index (PASI) is the most widely used in clinical trials. Body Surface Area is used as a clinical scoring instrument on its own, however alongside, erythema, scaling and infiltration it is used in other instruments to determine extent of clinical disease. A few of these instruments also incorporate psychosocial impact

1.8 Treatment

The treatment of PsO is determined by the severity of disease as well as by patient preference and availability and access to various therapies. Cost is another major factor determining treatment choice. Mild disease is generally treated with topical agents whereas moderate to severe disease is often treated with systemic agents (Table1.2). Phototherapy is a good treatment option for those who are unable to take systemic agents (Gupta et al., 1999).

Treatments for psoriasis if used appropriately and safely can make a marked improvement in disease severity. These treatments however also come with their own challenges. Topical treatments can be irritating to the skin and can cause staining to clothes and linen. Phototherapy is not always practical, as it is very time consuming, individuals often needs daily treatment sessions for weeks at designated treatment centres. Systemic drugs need to be monitored regularly for organ toxicities, immunosuppression as well as for drug interactions.

A detail review of treatment is beyond the scope of this research report.

Table 1-2 Treatment modalities for psoriasis

TOPICALS	SYSTEMIC AGENTS	PHOTOTHERAPY
Vitamin D analogues	Methotrexate	UVB
Corticosteroids	Cyclosporine	Narrowband UVB
Anthralin	Retinoids	UVA
Retinoids	Mycophenolate Mofetil	PUVA
Salicylic Acid	Sulfasalazine	Photo(chemo)therapy
Coal Tar	Apremilast	
Calcineurin inhibitors		
Keratolytics		
Salt water Baths	**Biologic agents**	
	Etanercept	
	Infliximab	
	Adalimumab	
	Ustekinumab	
	Secukinumab	

UVA= Ultraviolet A, UVB =Ultraviolet B, PUVA= Psoralen Ultraviolet A

The severity of psoriasis is a determinant for which treatment modality is being utilized. It can be suggested that those on systemic treatment has more severe disease. Disease severity together with treatment-type can therefore influence HRQoL.

1.8.1 Newer emerging treatments and impact on health-related quality of life

There has been limited number of studies evaluating changes in HRQOL with traditional therapeutic agents and phototherapy. It is only recent years that overall HRQoL has been considered to be an outcome measure in PsO. For example, treatment with cyclosporine showed declines in DLQI scores of -9,58 after 12 weeks

of treatment. Cyclosporine has also been shown to have similar efficacy to Methotrexate in improving SF-36 scores (Heydendael et al., 2003, Touw et al., 2001) Gupta et al showed that 100 consecutive patients treated with narrowband UVB showed an improvement of median baseline PDI scores from 40 to 30 at 3 months (p= 0,001)(Gupta et al., 1999). DLQI is commonly used as a measurement tool for assessing the efficacy of the newer biological agents. In randomized trial with Etanercept, significant improvements of DLQI scores were seen. At 12 weeks improvements in DLQI scores of 70% for 50mg twice weekly doses, 64% for 25mg twice weekly doses and 6% for placebo was observed.

1.9 Comorbidities

1.9.1 Infections

A range of comorbidities are known to be more prevalent in patients with PsO. Guttate PsO, which occurs more commonly in children, is often associated with streptococcal infection (Skov and Baadsgaard, 2000).

1.9.2 HIV and psoriasis

Psoriasis has been increasingly reported in association with HIV infection, and often with severe and extensive skin involvement (Morar et al., 2010). Whilst some studies have suggested that the prevalence of PsO in HIV infected patients is similar to that of the general population, around 1-3 %(Uthayakumar et al., 1997, Duvic et al., 1987), other studies that have reported higher prevalence rates of 5-6,4% (Garbe et al., 1994)

In the setting of HIV infection, new-onset PsO typically occurs five years after the diagnosis of HIV infection, and in the case of pre-existing PsO, the skin disease can

get worse, especially with progression of the HIV infection (Morar et al., 2010).. Various clinical types of PsO can occur in HIV positive patients. Plaque PsO have been reported as being the most common presentation. In a South African series of patients, the erythrodermic form of the disease was found to be more prevalent in patients with HIV (Morar et al., 1999)

Treatment for patients with PsO infected with HIV is often more challenging, as the usual systemic treatments used for PsO induce further immunosuppression.

1.9.3 Cardiometabolic disorders

Cardiometabolic disorders such diabetes, hypertension, dyslipidaemia and obesity are more common in PsO patients (Gisondi et al., 2007). Other studies suggest that PsO is an independent risk factor for cardiovascular diseases such as myocardial infarction, coronary artery disease and cerebrovascular disease, and that patients with severe PsO are at increased risk of cardiovascular mortality (Gelfand et al., 2007, Ludwig et al., 2007).

1.9.4 Psychological impact of psoriasis

Due to the visible nature of the PsO rashes, especially the erythema and scales on exposed parts of the body, this often results in patients experiencing feelings of embarrassment, shame and a low self-esteem. This is amplified by the chronic nature of the disease. Patients with PsO are more likely to suffer from depression than the general population. Depression is a consequence of living with the disease. (Hayes and Koo, 2010). In one study as many as 10% of PsO patients had contemplated suicide(Gupta et al., 1993)

Patients with psoriasis also experienced higher levels of stigmatization than patients with other dermatological conditions. This leads to feelings of humiliation when exposing their bodies. The result is a limitation of social activities requiring physical exposure , social isolation and also a negative effect on personal intimate relationships (Ginsburg and Link, 1993).

1.10 Financial burden of disease

The total overall (direct and indirect) annual cost of PsO has been estimated in the United States to be around 1.6 and 4.3 billion dollars in 1997 and a direct cost of treatment around 649.6 million dollars.(Bhosle et al., 2006). A study in Germany reported that the cost per patient for moderate to severe PsO is on average over 6000 euros annually (Sohn et al., 2006). Cost of care is related to outpatient visits, hospitalization, dermatologic prescription medication, phototherapy as well as over the counter medication.

Moreover, approximately 60% of patients reported missing on average 26 days a year directly related to their PsO. And 8% indicated that PsO had prevented them from working outside the home(Finlay and Coles, 1995). Patients with severe disease often visit multiple practitioners as well as suffering from a decrease in income (Gelfand et al., 2004). The expenses in caring for PsO was greater for those with severe disease, as well as being associated with a lower QoL. Sato et al in a study conducted in five European countries, found that healthcare resource use by PsO patients, independent of clinical severity, was greater for those with poorer QoL(Sato et al., 2011).

Physical and emotional effects of PsO also have a significant negative impact at the workplace for PsO patients, and have higher rates of unemployment compared to the general population.(Horn et al., 2007). Patients who are in employment have greater time lost from work, resulting in loss of productivity, loss of income and psychosocial impairment in the workplace (Pearce et al., 2006, Finlay and Coles, 1995).

1.11 Health Related Quality of Life

Up until recently, the impact of chronic diseases like PsO were only viewed with respect to morbidity and mortality. Increasingly healthcare professionals and healthcare funders are looking to better understand the socio-economic implications of chronic diseases.

The constitution of the World Health Organization (WHO) defined health as “A state of complete physical, mental and social wellbeing, not merely the absence of disease or infirmity…”. It defines Health Related Quality of Life (HRQoL) as a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features in their environment.

The terms Health Related Quality of Lile and Quality of Life are often used interchangeably. The concept of HRQoL emerged in the 1970’s. It narrows QoL to aspects relevant to an individuals’ health and is an assessment of how the individuals’ well-being may be affected over time by a disease, disability or disorder. Various HRQoL instruments capture mainly the bio-physical consequences or morbidity of the diseases, especially chronic diseases.

Measures of HRQoL can provide important information to physicians regarding their patients' response to treatment, as well as a guide for physicians needing to implement certain medications. For healthcare funders, employers, insurers and governments, health economic data derived from HRQoL studies provides insights into cost-effective delivery of healthcare. Hence HRQoL measures are included as outcome measures and have been utilized in new randomized controlled clinical trials by researchers.

1.11.1 Quality of Life in Psoriasis

The psychological impact of PsO has been studied as early as 1946 (Wittkower, 1946). Since then there have been several studies using validated questionnaires to assess HRQoL in patients with PsO.

1.11.2 Demographic Aspects and Impact on Quality of Life

The impact of PsO on HRQoL appears to be greater in younger patients compared to those of the elderly. Patients aged between 18 and 45 years have been found to be more severely affected by their disease(Gupta and Gupta, 1995) .Similarly patients between 18-34 years and 35-55 years have reported a greater impact of PsO on psychosocial aspects than those aged 55 years and older (Krueger et al., 2001).

Whilst Gupta et al observed no gender differences in areas related to appearance and socialization, a number of other studies indicate that female patients are more severely affected(Gelfand et al., 2004). African and Hispanic patients reported a poorer Quality of life than Caucasian patients with PsO. Married patients reported less impairment than those living alone(Zachariae et al., 2002). The degree of financial distress due to

PsO was more evident in those from a lower socio-economic group(Krueger et al., 2001, Schmitt and Ford, 2006).

1.11.3 Disease Characteristics and Impact on Quality of Life

Symptoms, such as itch, pain, scaling and bleeding influence HRQoL (Yosipovitch et al., 2000, Schmitt and Ford, 2007). Involvement of certain sites, especially, the hands and feet, axillae and genitals have a more profound negative effect on activities of daily living. Sensitive sites such as the face and genital areas, are also associated with impaired HRQoL (Schmitt and Ford, 2007, Dubertret et al., 2006).

Skin pain and discomfort have a negative effect on sleep, mood and enjoyment of life. More severe, extensive disease is associated with greater reductions in HRQoL (Gelfand et al., 2004). The chronic and recurring nature of PsO was associated with feelings of hopelessness, as patients feel they have no control over their disease(Vardy et al., 2002).

Studies evaluating the relationship between disease severity and QoL have not been consistent. In a US study body surface area was found to be the most important factor related to QoL in psoriasis patients(Gelfand et al., 2004). There was also a significant correlation found between Psoriasis Area and Severity Index (PASI) and DLQI and PDI in an Iranian study, higher PASI scores were associated with higher disability scores.(Aghaei et al., 2009). However in a larger study done in Nordic patients, the affected body surface area of psoriasis patients were found to not be a significant predictor of QoL (Zachariae et al., 2002)

1.12 Instruments Used to Measure Health Related Quality of Life in Dermatology

Several instruments have been developed to assess HRQoL in dermatology in general, and specifically PsO. These instruments are becoming increasingly important in assessing disease outcomes, both in daily clinical practice and and the research setting. While clinical measures like body surface area (BSA) affected by PsO are commonly used to assess disease severity in clinical trials, some experts argue that HRQoL measures are better determinants of disease severity and outcome. It has however been noted by some that cross-cultural inequivalences of these tools exists (Nijsten et al., 2007)

The HRQoL questionnaires/ instruments are categorized as follows;

1. PsO specific instruments, e.g., PsO disability Index (PDI)
2. Skin specific instruments, e.g. Dermatology life quality index (DLQI)
3. Generic HRQoL instruments, e.g., the Short Form 36
4. Mixed measures

PsO specific and skin specific being the most sensitive, however the later 2 allow comparison with other diseases (Table 1.3).

Table 1-3 Quality of Life Measurement Tools in Dermatology

Measurement Tool	Reference
PsO-specific measures	
PsO Disability Index (PDI)	Finlay and Coles (1987)
PsO Life Stress Inventory (PLSI)	Gupta and Gupta (1995)
PsO Index of Quality of Life (PSORIQoL)	McKenna et al (2003)
Other dermatological disease-specific measures	
Eczema disability index (EDI)	Salek et al (1993)
Cardiff acne disability index (CADI)	Motley and Finlay (1992)
Dermatology-specific measures	
Impact of skin disease scale (IMPACT)	Wessley and Lewis (1989)
Dermatology life quality index (DLQI)	Finlay and Khan (1994)
Questionnaire on Experience with Skin Complaints (QES)	Schmid-Ott et al (1998)
Skindex	Chren et al (1996)
General health measures	
Sickness Impact Profile (SIP)	Berger et al (1981)
Short Form-36 item Health Survey (SF-36)	Ware and Sherbourne (1992)
General Health Questionnaire (GHQ)	Goldberg and Hillier (1979)
Nottingham Health Profile (NHP)	Hunt et al (1989)
Health Assessment Questionnaire (HAQ)	Fries et al (1978)
Satisfaction with Life Scale (SWLS)	Diener et al (1985)
Mixed Quality of life measures	
Salford PsO Index (SPI)	Kirby et al (2000)
Koo-Mentor PsO Instrument (KMPI)	Feldman et al (2004)

Adapted from (Finlay, 1997)

Table 1.3 illustrates the wide variety of HRQoL instruments. This is disadvantageous as it makes comparison of different measuring tools being used in various studies difficult. Identifying which tool to use for a specific group of patients can be confusing. The use of simple universal measuring tools will make their use more common by clinicians and allow for greater comparison between studies

Mixed QoL tools such as the Salford PsO Index and the Koo Mentor PsO Instruments include aspects of disease severity, quality of life as well as some aspect of treatment options and history.

We selected the DLQI and PDI tools as it is the most widely used measuring tools. It has been used in a similar study on patients with psoriasis, which was conducted in Durban, South Africa. (Hariram et al 2011). It is important to maintain uniformity as it allows for better comparison.

1.13 South African Perspective

From the African continent, very little information regarding quality of life and PsO has been documented.

In Cape Town, South Africa Jobanputra and Buchmann ,looked at quality of life in 607 patients with various skin conditions from different ethnicities at Groote Schuur Hospital. Patients with contact dermatitis scored the highest DLQI scores compared to those with psoriasis. They found that risk factors for higher disability scores were severity of skin diseases as determined by physician, younger age, unemployment as

well as language. In their study 109 patients with PsO, the mean DLQI was only 6 (range 0-23).They added additional questions to the DLQI relating to anxiety and depression.(Jobanputra and Bachmann, 2000).

In a cross-sectional study of 69 patients in Stanger, KwaZulu-Natal, about 50% of patients had a DLQI score between 11 and 20, showing that psoriasis had a very large effect on quality of life. The study found a weak correlation between Body surface area affected and QoL (DLQI and PDI), but found that if the site of involvement included 'sensitive sites'- head/neck, hand/foot and genitalia/groin all areas of QoL were affected. They found no significant difference between QoL of different ethnic groups, although 75% of their sample were Indian(Hariram et al., 2011)

1.14 Study Aims

The broad aim of the study was to assess the impact of psoriasis on HRQOL in patients seen in dermatology clinics in the Wits Academic Complex of Hospital, Johannesburg, Gauteng.

1.15 Study Objectives

The specific objectives were:

1. To determine the demographics, clinical type and severity of PSO
2. To investigate HRQoL using two validated QoL instruments.
3. To investigate the relationship between the severity of psoriasis in relation to HRQoL measures
4. To investigate other factors that impact on HRQoL in patients with psoriasis

1.16 Summary

Psoriasis has a significant impact on all areas of an individuals' life (Bhosle et al., 2006).Studies around the world have shown how it can negatively affect an individuals' physical, psychological, emotional, inter-personal relationships as well social life(Finlay and Coles, 1995, Krueger et al., 2001).In one study, 79% of patients reported that psoriasis has a negative impact on their lives(Krueger et al., 2001).Patients with severe psoriasis in the United Kingdom, lost on average 26 working days per year due to their disease and one third of patients not working attributed this to their psoriasis(Finlay and Coles, 1995)

There has however only been one study looking specifically at QoL in patients with psoriasis in South Africa. (Hariram et al 2011) Therefore our aim is to qualitatively evaluate the impact of psoriasis on the quality of life in patients from Johannesburg as well as to determine the relationship between factors including disease severity and quality of life.

2 CHAPTER TWO: PATIENTS AND METHODS

2.1 Study Design

A cross-sectional study of consenting adult patients, 18 years or older, diagnosed with cutaneous psoriasis were recruited from the Dermatology clinics at 3 hospitals (Chris Hani Baragwanath Academic Hospital, Helen Joseph Hospital and Charlotte Maxeke Johannesburg Academic Hospital) from the University of the Witwatersrand Academic Complex in Johannesburg. The diagnosis of psoriasis was made on the basis of typical clinical features and in some cases requiring histological confirmation.

2.2 Study Instruments

The study instruments that were utilized included 1) Data Collection Sheet

2) PASI score

3) DLQI score

4) PDI score

2.2.1 Data Collection Sheet / Demographic and Clinical Data

Demographic data that was recorded included age, gender, race, marital status, employment status, duration of disease and family history of PsO. Other variables included a smoking history, comorbidities of type 2 diabetes mellitus (T2DM), hypertension, ischaemic heart disease, cerebrovascular accidents, dyslipidaemia. It also included whether an individual was a smoker, non- smoker or ex-smoker. The type of treatment systemic vs topical treatment was also documented.

Clinical features that were documented included the weight and height (for calculating the body mass index (BMI), the presence of inflammatory joint disease or psoriatic

arthritis (PsA) Clinical and demographic data were recorded on a Data Collection Sheet (Appendix 1).

2.2.2 PASI Score

The extent and severity of the cutaneous PsO was recorded using the PASI method (Appendix 2).

The PASI scoring method was developed in 1978 by Fredriksson and Pettersson, to evaluate the efficacy of retinoid treatment in PsO (Fredriksson and Pettersson, 1978). To calculate PASI score, areas affected; the head, trunk, upper extremities, and the lower extremities are assessed, corresponding to 10%, 20%, 30% and 40% of the body area, respectively. The plaques are also scored for erythema, thickness and scaling. The PASI score ranges from 0 to 72, with a higher score correlating to more severe disease. A PASI score of ≤10 together with a DLQI score of ≤ 10 and BSA≤ 10 is defined as mild disease and PASI, BSA and DLQI scores >10 are deemed as moderate to severe disease (Mrowietz et al., 2011). Schmitt and Wozel have proposed a different severity scale with mild disease as a PASI<7, a score of 7-12 as moderate and >12 as severe chronic plaque PsO (Schmitt and Wozel, 2005).

2.2.3 Dermatology Life Quality Index

The dermatology life quality index (DLQI) was first published in 1994 (Finlay and Khan, 1994). It was developed in the United Kingdom but has been used in at least 20 countries including developing countries like Guyana, India, Iran, South Africa and Tanzania. It is fairly simple and easy to use. (Lewis and Finlay, 2004). It has been translated into over 21 languages, at the time of our study, only Afrikaans and Xhosa

as African languages were available. There were over 85 peer reviewed research articles and 52 published abstracts describing the used of the DLQI in 2004. (Lewis and Finlay, 2004)

It consists of 10 questions, each question consists of a 4 point scale (from not at all, scoring 0, to very much scoring 3). The minimum score for DLQI is 0, and the maximum score is 30.

The DLQI relates to the impact on QoL of a patient over the last week. Questions relate to 6 subsections; symptoms and feelings, daily activities, leisure, work, and school, personal relationships and treatment.

The scores are interpreted as follows:

0-1 no effect at all on patient's life,

2-5 small effect on patient's life

6-10 moderate effect on patient's life

11-20 very large effect on patient's life

21-30 extremely large effect on patient's life

DLQI Subsections and questions:

1. Symptoms and Feelings : Questions 1 and 2
2. Daily activities : Questions 3 and 4
3. Leisure : Questions 5 and 6
4. Work and School : Question 7
5. Personal relationships : Questions 8 and 9
6. Treatment : Question 10

(Appendix 3)

A paediatric version of the DLQI, the Children's Dermatology Life Quality Index (CDLQI) as well as a cartoon version of the DLQI has been described(Lewis-Jones and Finlay, 1995).

2.2.4 Psoriasis Disability Index

The PsO disability index (PDI) was developed by Finlay and Kelly in 1985 and updated in 1990 (Finlay and Kelly, 1987). It has been used globally and in developing countries like Egypt, Iran, Romania, South Africa and Thailand. It has been translated into over 16 languages(Lewis and Finlay, 2005).

It consists of 15 questions, each question consists of a 4-point scale (from, not at all, scoring 0, to very much scoring 3). The minimum score is 0, and the maximum score is 45. The higher the score the more impaired the quality of life. PDI can be expressed as percentage of the maximum possible score.

The PDI questions relate to impact on quality of life over the last 4 weeks. It explores general practical aspects of an individual's daily life but no questions concerning emotions are included in the PDI.

Scale for PDI severity effect on quality of life:

0 No effect

1-4 Little effect

5-9 Moderate effect

10-18 Large effect

>18 Very large effect

PDI Subsections and questions :

1. Daily activities	questions 1,2,3,4,5
2. Work/ School	questions 6,7,8
3. Personal relationships	questions 9,10
4. Leisure	questions 11,12,13,14
5. Treatment	questions 15

2.3 Process of Recruitment

The main investigator approached all patients with psoriasis in the clinics. The clinics that the patients were recruited from was determined by the days at which the researcher was at the various clinics.

Informed consent(Appendix 6) was obtained from the patients after explaining to them the purpose of the study as well as what it entailed. Information sheet (Appendix 7)

2.3.1 Sample size

Convenient sample collection was done. The proportion of sample by hospital was not allocated specifically.

2.3.2 Inclusion Criteria

1. All patients with either a clinical diagnosis of psoriasis or psoriasis confirmed on histology
2. 1Patients 18 years and older

3. Patients who were able to consent to participate in the study

2.3.3 Exclusion Criteria

1. Patients who are unable to consent to the study
2. Any patient younger than 18 years of age

2.4 Data Collection Process

The questionnaires were administered by the primary researcher. The language that was used was English. The mode of questions was paper based. Patients who were literate, read and answered the questions by themselves. Those who stated that they had visual problems or who were unable to read, and or unable to read English were assisted. In these instances, the researcher read the questions and answers to the patient.

The instruments are available in Afrikaans, Zulu and Xhosa, but was not utilized as full linguistic validation at the time of our study was not done. For full linguistic validation, a minimum of two parallel independent forward translations, then co-operate agreement followed by two backward translations are required. There is also a process of further forward and backward translations until the Cardiff Dermatology Quality of life Team are satisfied that the translation is as accurate as possible.

Afrikaans has validation as of 24 January 2017, however not Zulu, or Xhosa.

The questions were captured on a questionnaire by the researcher.

Period of data collection was January 2015 until December 2015.

Data was stored in a paper based filing system and information was tranfered to an excel spreadsheet and stored electronically.

2.5 Statistical methods

Data were captured on an Excel spreadsheet. Descriptive statistics for categorical variables are presented as frequencies and percentages and median and interquartile range for continuous variables. The non-parametric Wilcoxon and Kruskal Wallis tests were used to compare PDI and DLQI scores between groups as the data were non-normally distributed. All statistical analyses were conducted using STATA 13.0 at a significance (P) level of <0.05.

Multivariate Poisson Regression analysis was applied to determine the independent predictors of the DLQI and PDI scores.

2.6 Ethical Considerations

The study was approved by the HREC of the University of the Witwatersrand (M140509) (Appendix 5)

Information was provided to patients detailing the purpose of the study via an information sheet. (Appendix 7) All data was kept confidential and each patient was assigned a numerical number. Informed consent was obtained from all patients that partook in the study (Appendix 6).

3 CHAPTER THREE: RESULTS

The findings of our study will reflect the demographics and clinical characteristics of our study sample of psoriasis patients. The comorbidities as well as the treatment that patients received will be reported on. The Quality of life instruments DLQI and PDI will be discussed in greater detail and their relationship to PASI score. Factors influencing these scores will also be reported on. These will be presented in tables, figures and graphs.

3.1 Demographics and Clinical characteristics

One hundred and five patients met the inclusion criteria. There was almost an equal number of male (49.5%) and female (50.5%) patients (Table 3.1). The mean(SD) age of the patients was 53.0 (43;63) years. There was a disproportionate number of patients of mixed ancestry and Indian decent (70,5%). In spite of the majority patients attending the Dermatology Clinics being Black African, they accounted for 16,2% of this cohort.

The majority of patients were married 57,1%. The rest comprised of patients who were widowed, single, divorced and those in a relationship. Only a minority were in formal employment (40%). Over half, 57.2% of the group were either smokers or gave a history of previously smoking.

As shown in Table 3.1, most patients had plaque PsO (98,1%). The median (IQR) PASI score was 5,5(10,4) with the majority (71,4%) of patients having mild disease of ≤10.

Of note 41,9% of patients had a positive family history of PsO. A third (30,5%) of patients had psoriatic arthritis. The mean (SD) age of onset of PsO was 36,04 (16,73) years. The median (IQR) duration of disease was 15(20) years.

Table 3-1 Demographic and clinical features of patients with psoriasis in Johannesburg

Variable	**n (%)**
F:M ratio	1.05:1
Ethnicity	
Black	17(16.2)
White	14(13.3)
Mixed ancestry (Coloured)	36(34.3)
Indian	38(36.2)
Marital status	
Single	14 (13.3)
Married	60 (57.1)
Divorced	10 (9.5)
Widowed	15 (14.3)
In a relationship	6 (5.7)
No of patients in gainful employment	42 (40)
Age - mean (SD)	53(14.65)
Disease duration - median (IQR)	15 (20)
PASI - median (IQR)	5.5 (10.4)
Moderate-severe PsO (PASI ≥10)	30 (28.6)
Type of PsO	
Plaque	103 (98.1)
Pustular	2 (1.9)
Nail involvement	48(45.71)
Inflammatory arthritis	32 (30.5)
BMI ≥ 30	51(48.57)

(BMI=body max index, F=females, M=males, PASI-psoriasis area and severity index)

3.2 Comorbidities

Hypertension (38%) followed by dyslipidaemia (29%)and T2DM (23%) were the commonest (Fig. 3.1) comorbidities and only a minority of patients (4.8%) had HIV infection.

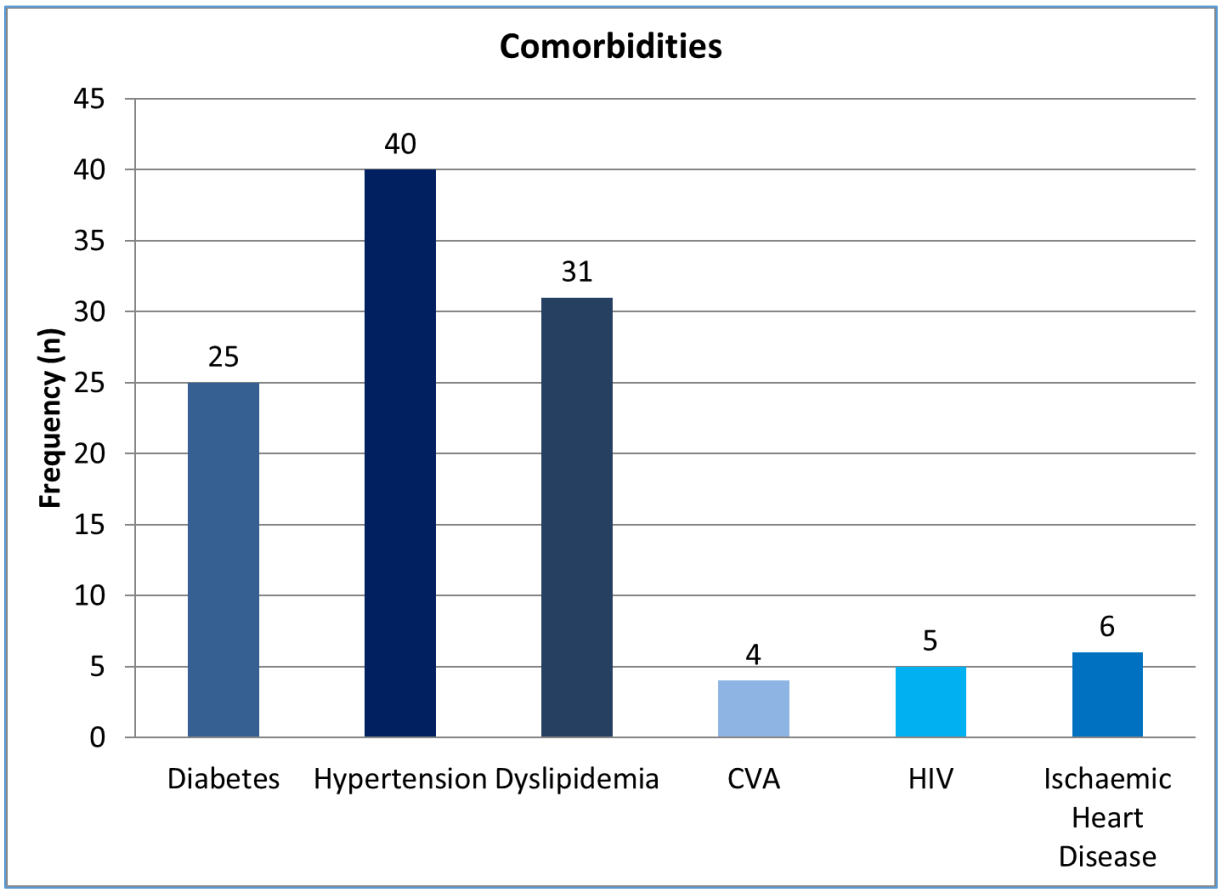

Figure 3.1Comorbidities of study sample

3.3 Medical Treatment

More than a third (39%) of patients were on systemic treatment, the majority on methotrexate (26,7%), followed by neotigason (9,5%). (Table 3-2). Of note is that there were no patients on phototherapy due to the lack of available working equipment in any of the Wits Academic Complex of hospitals at the time of the study.

Table 3-2 Treatment modalities used by 105 psoriasis patients

Treatment Type	**n(%)**
Systemic treatment	41 (39)
Methotrexate	28(26.7)
Neotigason	10(9.5)
Leflunomide	1(1)
Cyclosporine	1(1)
Other/Combination treatment	1(1)
Topical treatment	64(61)

3.4 Quality of life scores

Both the generic dermatology DLQI and the PsO-specific PDI showed that the PsO had at least a moderate effect on HRQoL. As shown Fig,3.2 there was a strong correlation between the scoring methods. The Pearson correlation coefficient was 0.837.

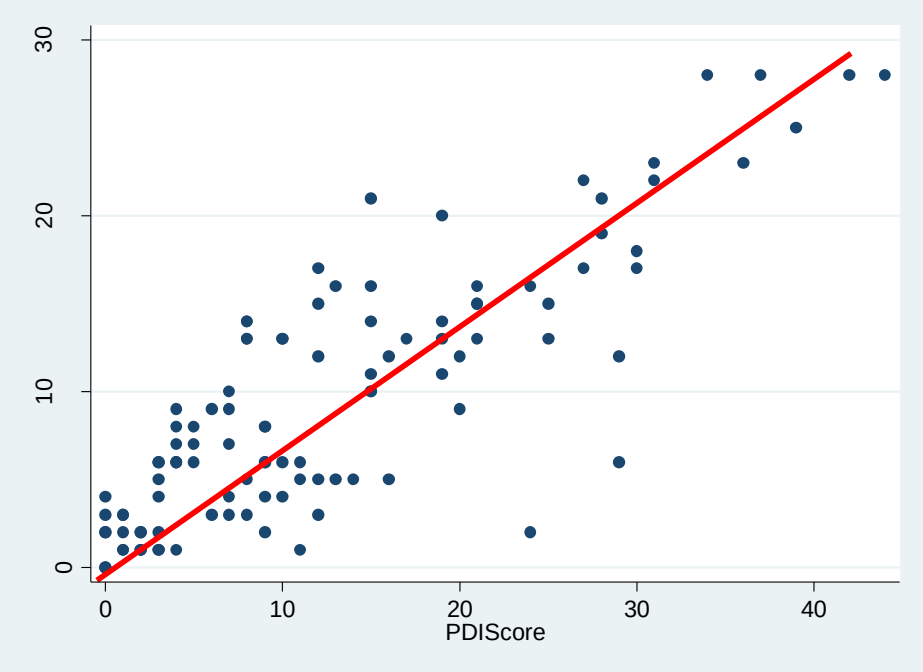

Figure 3.2. Two-way scatterplot of Dermatology life quality index versus Psoriasis disability index scores

3.4.1 Dermatology Life Quality Index

A closer look at the DLQI scores shows that in 40% of patients, PsO had very large to extremely large effect on HRQoL (Table 3.3). The greatest negative effects were due symptoms and feelings (53%) and daily activities (39%), and the least effect on work 16% (Fig. 3.3)

Table 3-3 DLQI scores of 105 psoriasis patients

Median (IQR) DLQI scores	8 (10)
Number (%) of patients with DLQI >10	43 (40.9)
DLQI by effect size -	**n (%)**
No effect	10 (9.5)
Small effect	27(25.7)
Moderate effect	25(23.8)
Very Large effect	32(30.5)
Extremely large effect	11(10.5)

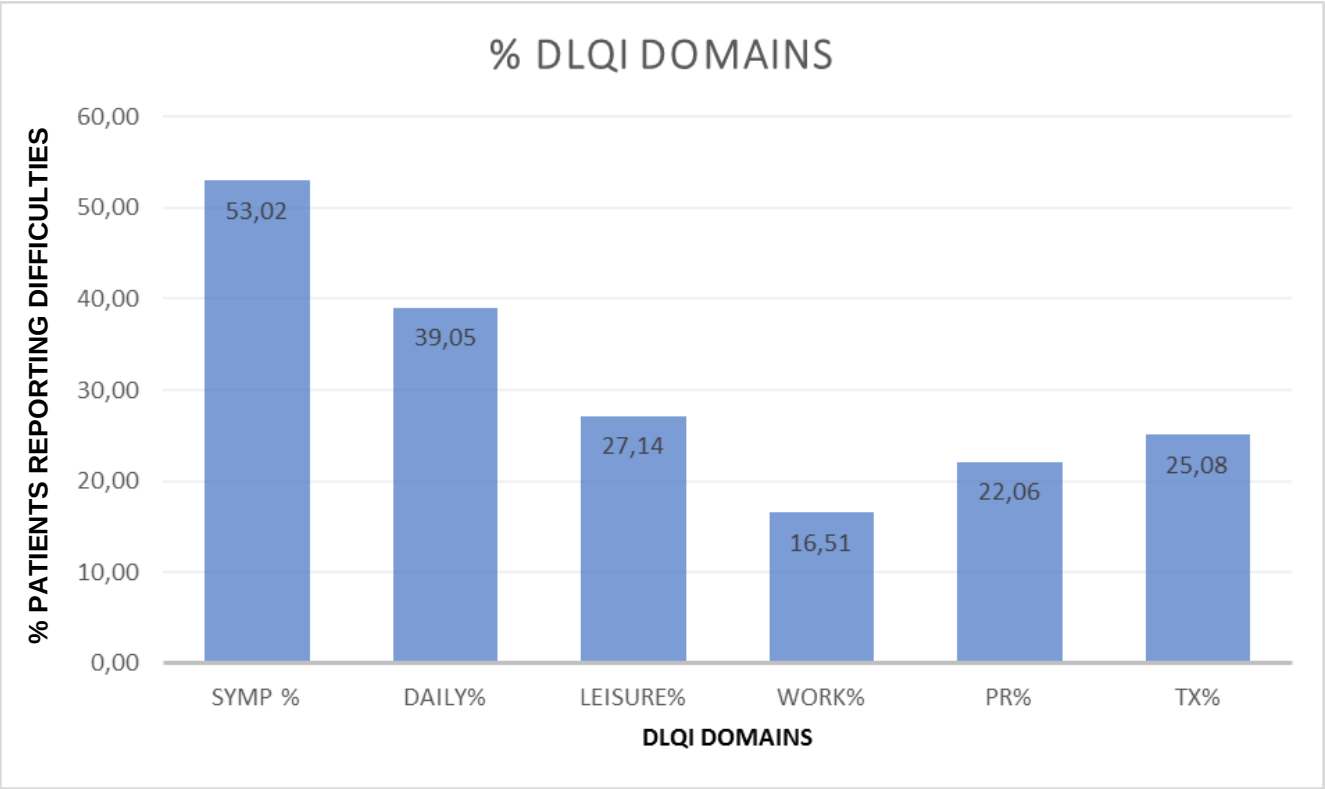

Figure 3.3 Dermatology life quality index scores by domains in 105 psoriasis patients (SYMP= symptoms and feelings, DAILY=daily activities, PR=personal relationships, TX=treatment)

3.4.2 Psoriasis disability index scores

In the case of the PDI scores, PsO had a large- very large effect on HRQoL in about half the patients (Table 3.4). The domains that were most affected were daily activities (42%) and treatment (24.4%) with almost equal effect on the other three domains of personal relationships, leisure and work (Fig. 3.4).

Table 3-4 Psoriasis disability index scores in 105 psoriasis patients

QoL (median PDI Score; IQR)	10;15
QoL Effect Grouped (PDI)	**n(%)**
None	6(5.71)
Little	23(21.90)
Moderate	22(20.95)
Large	24(22.86)
Very large	30(28.57)
Median % of maximum disability	42.2(33,3)

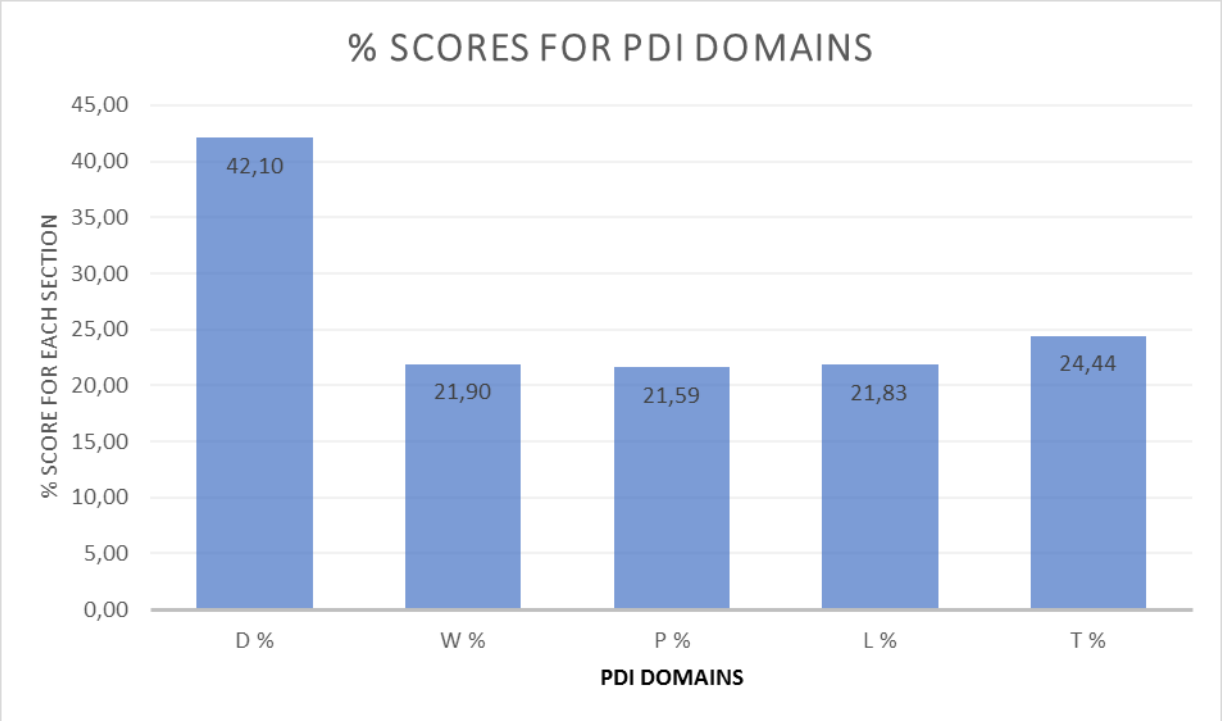

Figure 3.4 Psoriasis disability index scores by domains in 105 psoriasis patients

(D=daily activities, W=work, P=personal relationships, L=leisure, T=treatment)

3.5 Relationship between Psoriasis Area and Severity Index (PASI) and Health related quality of life (HRQoL) measures

DLQI

In the case of DLQI, patients with moderate to severe disease as defined by PASI >10, had significantly higher DLQI scores than those with mild disease.

Moderate-severe disease median DLQI (12) vs Mild disease median DLQI (6)

(p= 0,011)

PDI

Similarly, patients with a higher PASI scores had significantly higher PDI scores compared with those that had milder disease.

Moderate-severe disease median PDI (16) vs Mild disease median PDI (9) (p=0,002)

3.6 Predictors of health related quality of life in patients with psoriasis

Patients with moderate to severe skin disease, defined as a PASI >10, had worse scores for both the DLQI and PDI (Tables 3.5 and 3.6.). Moreover, patients with PsO affecting specifically the genital area, scored worse for the DLQI.

Table 3-5 Relationship of severity and area of psoriasis with Dermatology Life Quality Index

	Yes	**No**	**P-value**
median (25, 75)	**median (25, 75)**		
Moderate-severe disease (PASI>10)	12 (6;17)	6(3;13)	0,011
Facial Involvement	11.5 (5;19.5)	8(4;13)	NS
Limb Involvement	8(4;15)	7.5 (2;13)	NS
Nail Involvement	7.5 (4;15)	8(3;14)	NS
Genital Involvement	18.5 (12.5;22)	7 (4;14)	0,033

NS - not significant

Table 3-6 Relationship of severity and area of psoriasis with Psoriasis Disability Index

	Yes	**No**	**P-value**
median (25, 75)	**median (25, 75)**		
Moderate-severe disease (PASI>10)	16 (8;29)	9 (4;15)	0.002
Facial involvement	16 (5.5;29.5))	9 (4;16)	0.05
Limb involvement	10 (4;21)	8 (0;13)	NS
Nail involvement	10.5 (4.5;21)	9 (4;19)	NS
Genital involvement	18 (11;28.5)	10 (4;19)	NS

NS - not significant

Apart from severity of skin disease, younger age had a negative effect on both DLQI and PDI scores (Figure 3.5 & Figure 3.6). Marital status also impacted on the DLQI scores. Patients in a relationship (median DLQI= 15), those were single (median DLQI = 12) or and widowed (median DLQI= 11) had higher DLQI scores than those who were married or divorced (median DLQI= 6.5 and 4), respectively) (p=0.020).No such relationship was evident with respect to the PDI scores. In the case of the DLQI only, smokers scored worse than to non-smokers/ex-smokers (median(IQR)) of 11(6, 16) vs 6 (3, 13), respectively, p= 0.029) and there was a trend towards unemployed/retired patients doing worse than those who were employed (median (IQR) DLQI of 6.5 (2, 13) vs 9 (5, 15), respectively p=0,08).

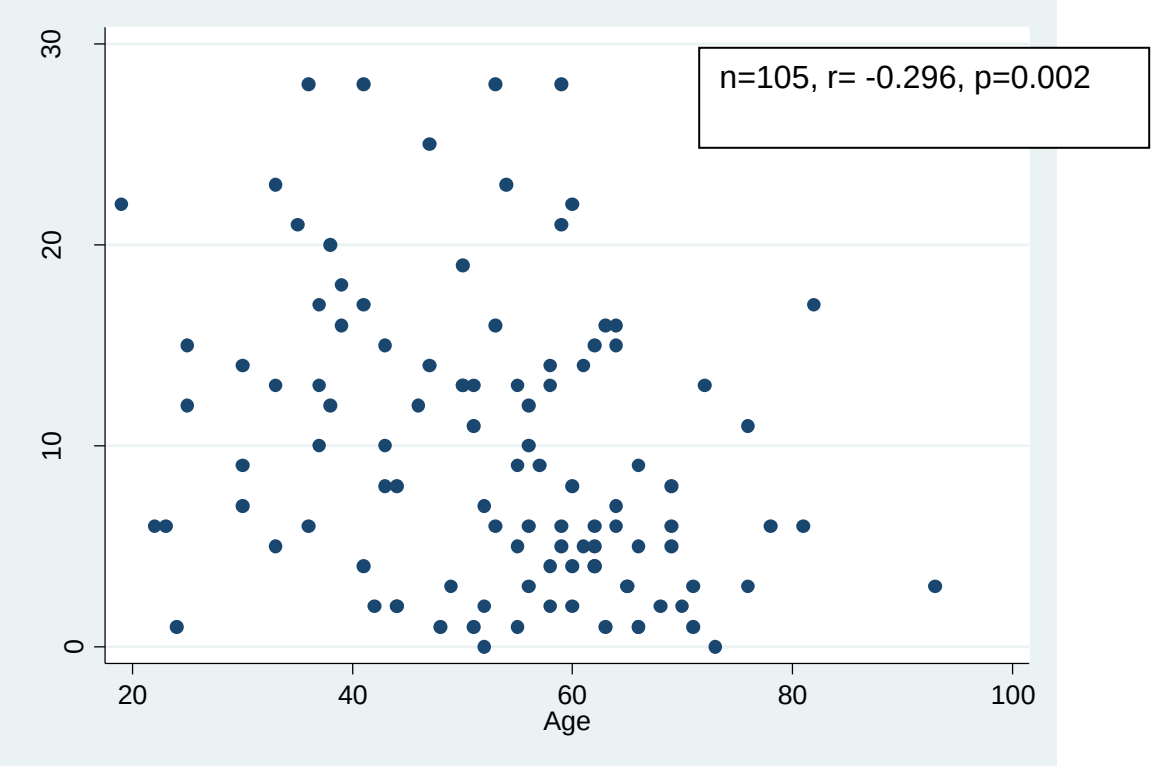

Figure 3.5 Two-way scatterplot showing relationship between the Dermatology Life Quality Index score and patient age in years (r=Pearson coefficient)

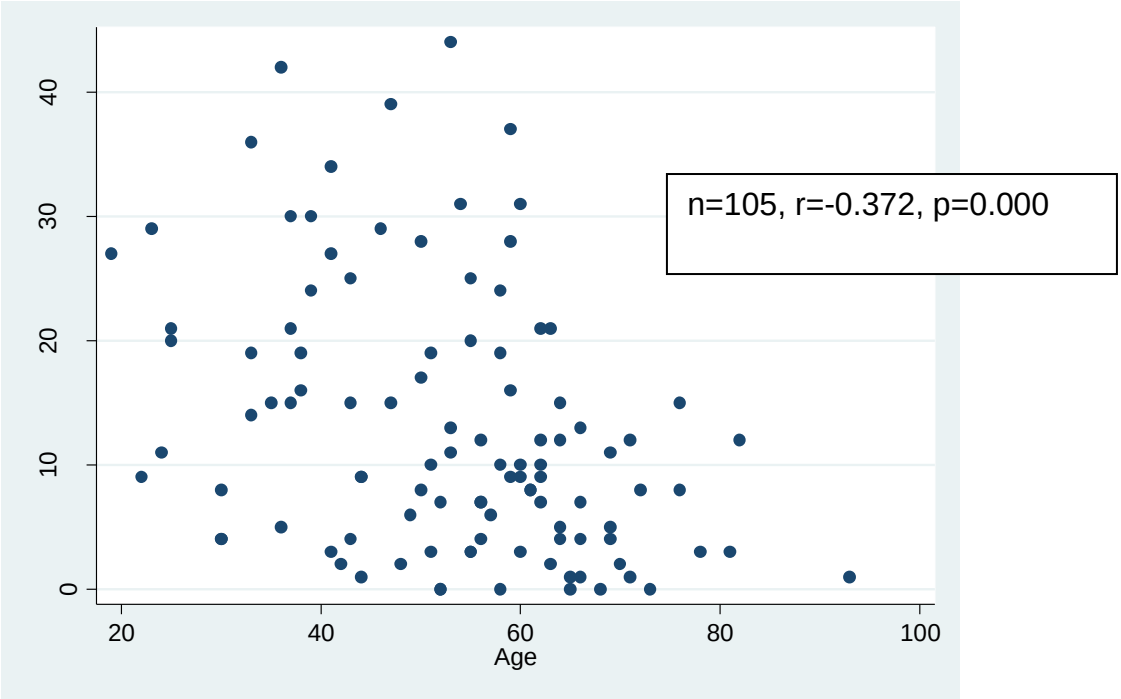

Figure 3.6 Two-way scatterplot showing relationship between the Psoriasis Disability Index score and patient age in years (r=Pearson coefficient)

3.7 Regression Analysis

The regression results showing the determinants for quality of life among psoriasis patients are shown below in Table 3-7and Table 3-8.

Table 3-7 Regression analysis of PDI score

PDIScore	Univariate		Multivariate	
	IRR	**P-value**	**IRR**	**P-value**
Sex (Males*)				
Females	0,967	0,531	0,798	0,002
Race (African*)				
Whites	0,831	0,092	0,905	0,488
Indian	0,974	0,083	0,985	0,894
Coloured	1,335	0,109	1,300	0,011
Age	0,979	0,000	0,955	0,000
Marital Status (Married*)				
Single	1,441	0,000	0,674	0,002
Divorced	0,644	0,000	0,771	0,046
Widow	1,31	0,000	1,415	0,000
In a relationship	1,717	0,000	0,838	0,158
Employment Status (Employed*)				
Unemployed	1,259	0,000	1,659	0,000
Smoking Status (Smoker*)				
Non-smoker	0,808	0,000	0,909	0,216
Ex-smoker	0,593	0,000	1,110	0,365
Face Involved	1,609	0,000	1,028	0,725
Limbs Involved	1,545	0,000	1,311	0,013
Duration	1,007	0,000	1,018	0,000
PASI>10	1,733	0,000	1,581	0,000
Diabetes Present	0,865	0,029	0,845	0,035
Hypertension Present	0,977	0,682	1,623	0,000
Dislipaedimia Present	0,945	0,343	0,970	0,679
Obesity Present	0,927	0,166	0,791	0,001
PSA Arthritis	1,196	0,002	1,309	0,000
Constant			46,753	0,000

Table 3-8 Regression analysis of DLQI score

DLQI Score	Univariate		Multivariate	
	IRR	**P-value**	**IRR**	**P-value**
Sex (Males*)				
Females	0,984	0,794	0,820	0,016
Race (African*)				
Whites	0,861	0,207	1,010	0,947
Indian	0,825	0,042	0,947	0,681
Coloured	1,112	0,244	1,151	0,215
Age	0,985	0,000	0,976	0,000
Marital Status (Married*)				
Single	1,398	0,000	0,972	0,845
Divorced	0,656	0,003	0,708	0,200
Widow	1,328	0,001	1,352	0,007
In a relationship	1,823	0,000	1,877	0,223
Employment Status (Employed*)				
Unemployed	1,259	0,000	1,499	0,000
Smoking Status (Smoker*)				
Non-smoker	0,782	0,000	0,887	0,163
Ex-smoker	0,518	0,000	0,803	0,106
Face Involved	1,307	0,000	0,998	0,725
Limbs Involved	1,280	0,015	1,160	0,013
Duration	1,000	0,877	1,007	0,016
PASI>10	1,500	0,000	1,382	0,000
Diabetes Present	0,937	0,385	0,932	0,434
Hypertension Present	1,021	0,749	1,329	0,001
Dislipaedimia Present	0,958	0,538	1,043	0,614
Obesity Present	0,976	0,699	0,861	0,075
PSA Arthritis	1,002	0,980	1,039	0,671
Constant			19,509	0,000

The incidence rate ratios of the univariate and multivariate models for PDI Score are presented first with the associated p-values. At univariate level the variables age, marital status, employment status smoking status, facial and limb involvement, duration of disease, surface area of disease as well as the co-morbidities of diabetes and PSA arthritis were significantly associated with quality of life among psoriasis patients. The multivariate analysis controlled for all other factors and revealed the determinants of quality of life among psoriasis patients based on PDI scores. Independent determinants of quality of life were sex, race, age, marital status, employment status, duration and surface area of disease, diabetes, hypertension, obesity and PSA arthritis status. In this full model the constant showed that if all variables had a value of zero, the PDI score would be approximately 47. Additionally, the full model revealed the following:

PDI Scores

Female patients had a 20% lower PDI score than males.

Being Mixed race had a 30% increased PDI score compared to African patients.

Each additional year of age had a 4% decrease in PDI scores. There is a 2% increase in PDI score for each additional year of disease duration.

To have a PASI > 10, increased PDI score by 58%.

The presence of having limbs involved increased the expected PDI score by 31%, as compared with not having the limbs involved.

The effect of being unemployed/retired was expected to increase PDI scores by 66%

The effect of being single or divorced was to decrease the PDI score by 33% and 23% respectively, while the effect of being widowed was to increase the PDI score by 42%, all compared to married patients.

The presence of diabetes or obesity decreased the expected PDI score by 15% and 21% respectively. The presence of hypertension and psoriatic arthritis increased the expected PDI score by 62% and 31% respectively.

DLQI Scores

Next the incidence rate ratios of the univariate and multivariate models for DLQI Score are presented with the associated p-values. Age, marital status, employment status smoking status, facial and limb involvement and surface area of disease were significantly associated with quality of life among psoriasis patients at the univariate level. The multivariate analysis controlled for all other factors and revealed the determinants of quality of life among psoriasis patients based on DLQI scores. Independent determinants of quality of life were sex, age, marital status, employment status, limb involvement, duration, surface area of disease as well as hypertension status. In this full model the constant showed that if all variables had a value of zero, the DLQI score would be approximately 20. The full model revealed the following:

DLQI scores

Race was found not to be a significant factor in determining DLQI scores when using regression analysis.

Female patients had a 18% lower DLQI score than male patients.

Each additional year of age was associated with an estimated 2% decrease in DLQI scores.

The state of unemployment/retirement was expected to increase the DLQI score by 50%.

The effect of a person being widowed increased the expected score by 35% compared to married counterparts.

Limb involvement increased DLQI by 16%.

Each additional year in disease duration was associated with an estimated 1% increase in DLQI scores.

Having a PASI > 10, resulted in an estimated 38% higher DLQI score.

The presence of hypertension increased the expected DLQI by some 33%.

In summary

Of the 100 patients in our study, plaque type psoriasis was found to be the most common type of psoriasis.

A lower than expected PASI score was recorded.

Patients with psoriasis were found to have an impaired QoL as assessed by both the DLQI and PDI instruments.

QoL scores were significantly influenced by disease severity as measured by the PASI score.

Additional factors influencing QoL scores were age, sex, duration of disease, unemployment status as well as having genital and limb involvement.

4 CHAPTER FOUR: DISCUSSION

In this cross-sectional study of urban based patients with psoriasis in a tertiary hospital complex in Johannesburg, South Africa we evaluated the impact of psoriasis on health-related quality of life, using the DLQI and PDI health-related quality of life measurement instruments. We will explore the demographics of our sample, and discuss the findings of our quality of life measures and the factors that were found to impact them.

In our setting by far the majority of patients attending state hospitals are of black African origin, however patients of Indian and mixed origin accounted for the majority, 70% of our study sample. The findings by Hartshorne in a survey in Johannesburg in 2000 had found the incidence of psoriasis to be higher in patients of Indian origin Psoriasis accounted for 9.6% after eczema (30.4%) and superficial fungal infections (11.8%) in patients of Indian descent. The commonest skin diseases in black patients were eczema (32.7%), acne (17,5%) and superficial fungal infections (5.7%)(Hartshorne, 2003).

As expected there was an almost equal distribution of males and females, and the average age of 53 years was not surprising.

Similar to studies elsewhere, plaque type psoriasis, was found to be the most common type, accounting for 98,1%, and a third of our patients had psoriatic arthropathy(Garcia-Diez et al., 2008).

The three main comorbidities found in our group of patients were hypertension, dyslipidaemia and diabetes mellitus at rates of 38,1%, 29,5%and 23,8% respectively. Studies have found an association of metabolic syndrome and its components in patients with psoriasis(Gisondi et al., 2007). In addition, there has been noted to be an increased risk of myocardial infarction in patients with psoriasis(Ludwig et al., 2007).
Notably only a small percentage of patients, 4,8% had associated HIV infection, much lower than in the general South African population. (Zuma et al., 2016) The low incidence of patients with associated HIV in our study may be co-incidental. However it could also suggest that the stigma of disclosing HIV status may still deter many patients from partaking in studies and making their status known. These patients may already feel embarrassed due to the visible nature of a skin condition such as psoriasis.

The median PASI score in our population was 5,5, comparable with PASI scores from developed countries. (de Korte et al., 2004).
Our small sample size and the fact that nearly 40% of patients were on some form of systemic agent, could account for this lower PASI score. Johannesburg is an urban city, with patients having access to a number of hospitals and healthcare providers, and these scores may not be a true reflection of PASI scores throughout a developing country like South Africa. In a study from Durban, the mean PASI of patients from urban areas was less (11.9) compared to that of rural patients (17.9), suggesting perhaps that patients from urban settings in South Africa have a lower PASI score than patients from rural areas, that have less access to healthcare resources(Hariram et al., 2011).

In spite of the majority of patients studied having mild disease as measured by PASI, in more than two thirds of patients, psoriasis had a moderate to severe effect on health-related quality of life as measured by DLQI and PDI. A higher PASI score indicating increasing severity of disease was significantly associated with higher DLQI and PDI disability scores. These findings are in keeping with studies from developed countries (Gelfand et al., 2004) (de Korte et al., 2004).

When looking at the DLQI scores in terms of effect on QoL, 30.5% of patients had scores equating to “a very large effect” on QoL and 10.5% had scores equating to “an extremely large effect” on QoL. Interestingly, the domains of DLQI that were most affected were those of “symptoms and feelings” in 53% and “daily activities” in 39% of patients. This shows that South African patients expressed experiencing symptoms such as itch and pain due to their PsO and reported feeling “embarrassed and self-conscious” because of their skin. The 2 questions pertaining to symptoms and feelings on the DLQI are not included in the PDI, and perhaps these 2 questions can be incorporated into a PsO-specific questionnaire like the PDI in the future. Jobanputra added 2 additional questions to the DLQI, pertaining to anxiety and depression. The additional questions on anxiety and depression were some of the most highly scored in their study. (Jobanputra and Bachmann, 2000)

The PDI scores showed that 28% of patients had PDI >18, reflecting a very large impairment in quality of life. The domains of PDI illustrated a higher percentage 42% for questions relating to Daily activities, and an almost equal/uniform distribution for questions relating to Work 21,9%, Personal relationships 21,5%, Leisure 21,83% and

Treatment 24,4%. The Daily activities section reflect on the impact of psoriasis interfering with an individual's ability to do house and garden work. It evaluates its influence on the frequency individuals having to change their clothes and on the limitations of type and colour of clothes worn. It also reflects problems they may experience when visiting a basic service such as a hairdresser. A large European study found that daily activities were adversely affected in patients with psoriasis, similarly the study done in Durban, South Africa on 69 patients with psoriasis, found that the greatest impairment in the PDI score was also in Daily activities(Hariram et al., 2011, Dubertret et al., 2006). When expressed as a percentage of maximum disability the median PDI percentage of maximum disability was 42,2% and mean of 28,7%. Finlay et al reported a median PDI of 38% of maximum disability score in a UK study(Finlay and Coles, 1995).

The question regarding treatment in the DLQI and PDI instruments asks to what extent has psoriasis treatment made your home messy or was it a problem being time consuming. In our setting perhaps another more appropriate question would be "To what extent has lack of treatment influenced your skin condition".

The systemic treatment of psoriasis can have severe side effects, phototherapy can be time consuming, and overall treatment and access to treatment costly to individuals. Knowing the degree of disability caused by psoriasis in terms of its impact on quality of life is important in making clinical decisions regarding treatment with potential side effects. We found 39% of patients were on some form of systemic treatment, with the most common systemic agent being methotrexate 26,7% followed by neotigason 9,5%. Methotrexate and neotigason are well established treatments for psoriasis(Cabello

Zurita et al., 2017). These treatments are also relatively cheaper compared to other available agents, which can account for their common use. Only 1 % of patients were on cyclosporine, which could be due to its high cost and short -term use. There were no patients that were on phototherapy at the time. This was due to the lack of availability of functioning phototherapy units in state hospitals in Johannesburg at the time our study was conducted.

The effect on QoL in patients with psoriasis may need to be evaluated more regularly and documented, to assist in motivating for adequate medications and equipment such as phototherapy machines. As with correct treatment QoL can be improved for patients.

Both the DLQI and PDI performed equally well and as in a number of other studies a significant correlation between DLQI and PDI have been demonstrated. The questions in these two instruments are very similar which can account for the close correlation. Our study was in keeping and found a positive correlation between these two measurement tools, with a correlation coefficient of 0,837(Aghaei et al., 2009). In future the use of only one of these tools may be sufficient making their use quicker and easier for clinicians.

A number of factors appeared to negatively impact on HRQoL in the present study. The significant factors included disease severity and younger age, which showed an increased effect on both the DLQI and PDI scores. In addition, the DLQI scores were also negatively influenced by marital status, male sex, unemployment, genital and limb involvement and smoking status.

Age correlated negatively with both DLQI and PDI. Younger patients had scores reflecting a greater effect on quality of life than older patients. This finding is consistent with that by Gelfand (Gelfand et al., 2004) and McKenna and Stern(McKenna and Stern, 1997). Emphasizing the idea that older patients have come to terms with their disease and have learnt coping skills in managing aspects of their health and lives. In contrast, younger patients often have added stressors that society places on appearance and may not yet have developed the necessary coping skills.

Patients who were married and divorced have better DLQI scores than those who were either widowed, single, or in a relationship. Previous work suggests that married individuals have the support of their spouses and stability, and older, married people have been found to have better QoL scores (Zachariae et al., 2002). Conversely, these findings suggest the unmarried groups, who are those widowed, single, or in a relationship have poorer QoL scores.

Genital involvement of PsO is not a topic that is often discussed with patients by the health care providers. It is often seen as disrespectful and socially inappropriate to discuss the genital area in certain cultures. In this study, patients with genital involvement had poorer DLQI scores. Genital involvement of PsO has been found to profoundly affect an individuals' quality of live and sexual health (Ryan et al., 2015, Meeuwis et al., 2011).

The percentage of patients that were employed was 40% compared to 60% unemployed/retired. The national unemployment rate in South Africa at the time was 25%. Regression analysis showed an increase in both DLQI and PDI scores in individuals who were in the unemployed/retired group. The economic burden of psoriasis has been documented in the USA and Europe. It is significant, with a study in Germany finding that patients with moderate to severe disease reporting an average annual cost of Euros 2866 per patient. Psoriasis has been associated with reduced work productivity (Pearce et al., 2006) and as well as increased time lost from work (Finlay) The study by Feldman et al found that patients with severe psoriasis had higher expenses as well as a lower quality of life in work. There was a higher number of patients with severe psoriasis associated with lower family income.

The cost of treatment to patients with psoriasis can be very expensive. The financial implications to psoriasis patients and relationship to socio-economic status in South Africa has not been studied. Furthermore, the financial burden of disease and its relation to quality of life has also not been explored. Therefore, a possible unemployment rate of 60% in this group of patients would be concerning.

There has been very little data published on Quality of Health in patients with skin diseases including psoriasis on the African continent.

In a Tanzanian study on adults with chronic skin diseases, quality of life was found to be reduced as assessed by DLQI in patients with psoriasis, eczema, vitiligo, Kaposi sarcoma and dermatitis cruris pustulosa et atrophicans. Factors that negatively influenced QoL in these patients included itch and pain, relapsing and unresponsive skin disease. (Etemesi, 2002)

In Egypt, in 100 patients with psoriasis quality of life was evaluated using the PDI instrument. They found that PDI scores were higher in those with severe disease. And that the highest PDI scores were those involving questions relating to work, treatment and frequency of bathing. (Zedan, 2002)

In the larger study done in Cape Town, South Africa patients with skin diseases were found to have similar levels of impairment as measured by DLQI to patients from Western countries. Interestingly higher levels of impairment in patients were found in those who were a younger age, unemployed and from an Afrikaans speaking background. (Jobanputra and Bachmann, 2000) The findings from our study that younger patients, those who were unemployed and male having poorer QoL scores, may be significant in the setting of developing countries. Younger patients are often living with single parents, grandparents or orphaned, and are at times even heading households. The extra burden of a chronic skin disease may be more significant for them.

Although quality of life instruments is developed and more widely used in developing countries in the West. There is a role for them in developing African countries. The large number of these tools in itself is challenging, as it does not allow comparison between patients from different countries and studies. The variability of scoring also precludes straightforward interpretation of their results. These tools also lack evaluating certain areas, such as psychological impairment.

Modification of these instruments rather than developing newer ones, such as the modified DLQI used in the Cape Town study may be a more appropriate tool to use. Greater consensus in the dermatological community on a more uniform, concise, easy to use tool such as a modified DLQI is needed, to make the use of QoL tools in clinical practice more common.

There are a number of limitations to the present study. Firstly, the relatively small sample size and secondly, the urban setting of our hospital may not reflect the true extent of impairment in HRQoL that may potentially be worse in patients from rural, resource poor areas in South Africa. Thirdly the use of another PsO severity scoring system other than the PASI, such as body surface area, or self -assessed severity score could have been included. Lastly the lack of a third QoL instrument such as the generic SF036 would allow comparison with other chronic medical diseases, but was not done due to patients' time constraints.

Summary and way forward

Notwithstanding the shortcomings, this study provides important new insights on of PsO on HRQoL in a developing country, such as South Africa, where healthcare funds and resources are limited. It highlights the need to allocate greater health resources, especially for patients with more severe disease and younger patients. In future, larger multicentre studies that include qualitative assessments, are needed in African countries to better understand illustrate the true impact of PsO on QoL of patients on the continent.

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5 APPENDICES

5.1 Appendix 1: DATA COLLECTION SHEET

Data Collection Sheet

Unique ID: Date:

Demographic Details:

1. Age: ___

2. Gender: Male ☐ Female ☐

3. Race: Black ☐ Coloured ☐ Indian ☐ White ☐ Other ____

4. Marital status: : Single ☐ Relationship /Cohabiting ☐ Married☐ widowed ☐

Divorced ☐

5. Employment status: Employed ☐ Unemployed ☐

6. Habits: Smoking ☐ Alcohol☐

Clinical Characteristics:

7. Age of onset ___

8. Duration of disease ___

9. Associated arthropathy yes / no

10. Family history yes/ no

11. Localization of disease:

Face ☐ Neck ☐ Breast ☐ Trunk ☐ Legs ☐

Feet ☐ Hands ☐ Arms ☐ Genitals ☐ Scalp ☐ Nails ☐

12. Type of PsO : Plaque ☐ Guttate ☐ Erythrodermic ☐

Pustular ☐ Inverse ☐

Comorbidities:

13. Diabetes☐

14. Hypertension☐

15. IHD☐

16. Dyslipidaemia☐

17. CVA☐

18. HIV☐

19. Other _____

Medication: _____ _____ _____

_____ _____ _____

Physical Examination:

20. Weight ____ **21.** Height ____**22.** BMI ____

23. Hip circumference ___ **24.** Waist circumference ____

25. Blood pressure ____

5.2 Appendix 2: PASI

PSORIASIS AREA AND SEVERITY INDEX (PASI) WORKSHEET

HOSPITAL NO.: .

PATIENT NAME: .

DATE OF VISIT: .

The Psoriasis Area and Severity Index (PASI) is a quantitative rating score for measuring the severity of psoriatic lesions based on area coverage and plaque appearance.

Plaque characteristic	Lesion score	Head	Upper Limbs	Trunk	Lower Limbs
Erythema	0 = None 1 = Slight 2 = Moderate 3 = Severe 4 = Very severe				
Induration/Thickness					
Scaling					
Add together each of the 3 scores for each body region to give 4 separate sums (A).					
Lesion Score Sum (A)					

Percentage area affected	Area score	Head	Upper Limbs	Trunk	Lower Limbs
Area Score (B) *Degree of involvement as a percentage for each body region affected (score each region with score between 0-6)*	0 = 0% 1 = 1% - 9% 2 = 10% - 29% 3 = 30% - 49% 4 = 50% - 69% 5 = 70% - 89% 6 = 90% - 100%				
Multiply Lesion Score Sum (A) by Area Score (B), for each body region, to give 4 individual subtotals (C).					
Subtotals (C)					
Multiply each of the Subtotals (C) by amount of body surface area represented by that region, i.e. x 0.1 for head, x 0.2 for upper body, x 0.3 for trunk, and x 0.4 for lower limbs.					
Body Surface Area		**x 0.1**	**x 0.2**	**x 0.3**	**x 0.4**
Totals (D)					
Add together each of the scores for each body region to give the final PASI Score.					

PASI Score = ☐

5.3 Appendix 3: DLQI

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

Please check you have answered EVERY question. Thank you.

5.4 Appendix 4: PDI

APPENDIX 3: PSORIASIS DISABILITY INDEX

study No: Date:
Score:

- **Thank you for your help in completing this questionnaire.**
- Please tick one box for every question.
- Every question relates to the **LAST FOUR WEEKS ONLY**.

All questions relate to the LAST FOUR WEEKS.

DAILY ACTIVITIES:

1. How much has your psoriasis interfered with you carrying out work around the house or garden?
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

2. How often have you worn different types or colours of clothes because of your psoriasis?
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

3. How much more have you had to change or wash your clothes?
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

4. How much of a problem has your psoriasis been at the hairdressers?
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

5. How much has your psoriasis resulted in you having to take more baths than usual?
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

- There are two different versions of questions 6, 7 and 8.
- If you are **at regular work or at school** please answer the first questions **6 - 8**.
- If you are **not at work or school** please answer the second questions **6 - 8**.

All questions relate to the LAST FOUR WEEKS.

WORK OR SCHOOL (if appropriate)

6. How much has your psoriasis made you lose time off work or school over the last four weeks?
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

7. How much has your psoriasis prevented you from doing things at work or school over the last four weeks?
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

8. Has you career been affected by your psoriasis? e.g. promotion refused, lost a job, asked to change a job.
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

IF NOT AT WORK OR SCHOOL: ALTERNATIVE QUESTIONS

6. How much has your psoriasis **stopped you** carrying out your normal daily activities over the last four weeks?
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

7. How much has your psoriasis **altered the way** in which you carry out your normal daily activities over the last four weeks?
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

8. Has your career been affected by your psoriasis? e.g promotion refused, lost a job, asked to change a job.
   Very much ❑ **A lot** ❑ **A little** ❑ **Not at all** ❑

All questions relate to the LAST FOUR WEEKS.

PERSONAL RELATIONSHIPS:

9. Has your psoriasis resulted in sexual difficulties over the last four weeks?

Very much ❑
A lot ❑
A little ❑
Not at all ❑

10. Has your psoriasis created problems with your partner or any of your close friends or relatives?

Very much ❑
A lot ❑
A little ❑
Not at all ❑

LEISURE:

11. How much has your psoriasis stopped you going out socially or to any special functions?

Very much ❑
A lot ❑
A little ❑
Not at all ❑

12. Is your psoriasis making it difficult for you to do any sport?

Very much ❑
A lot ❑
A little ❑
Not at all ❑

13. Have you been unable to use, criticised or stopped from using communal bathing or changing facilities?

Very much ❑
A lot ❑
A little ❑
Not at all ❑

14. Has your psoriasis resulted in you smoking or drinking alcohol more than you would do normally?

Very much ❑
A lot ❑
A little ❑
Not at all ❑

TREATMENT:

15. To what extent has your psoriasis or treatment made your home messy or untidy?

Very much ❑
A lot ❑
A little ❑
Not at all ❑

Please check that you have answered all the questions.

Thank you for your help.

5.5 Appendix 5: ETHICS APPROVAL

M140509

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M140509

NAME: (Principal Investigator)	Dr Mercedes Morrison
DEPARTMENT:	School of Clinical Medicine CM Johannesburg Academic Hospital
PROJECT TITLE:	Quality of Life in Patients with Psoriasis
DATE CONSIDERED:	30/05/2014
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof D Modi
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 09/07/2014

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**

Principal Investigator Signature M140509Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

5.6 Appendix 6: INFORMED CONSENT

I, the undersigned. Mr/Ms/Mrs.……

Hereby confirm that the procedure and the purpose of the study was explained to me by Dr…….. I furthermore confirm my understanding that my participation is voluntary and that I can withdraw my consent any time.

Patient's surname…… Signature _ Date:

Investigator's name…… Signature _ _ Date:

5.7 Appendix 7: INFORMATION DOCUMENT

Title: QUALITY OF LIFE IN PATIENTS WITH PSORIASIS

Greetings: Good day, My name is Mercedes Morrison, I am a medical doctor in the department of dermatology.

Introduction: I am doing a study involving patients with psoriasis. In particular on how psoriasis affects the lives of patients. In this study we want to learn what level of impact psoriasis has on the various aspects of an individuals' life.

Invitation to participate: We are inviting you to take part in our study entitled,
"Quality of Life in patients with Psoriasis". Other patients with psoriasis attending our outpatient departments will also be invited to participate.In the study we would like you to please complete 2 simple questionnaires. They contain 10, and 15 questions respectively. The questions are about how psoriasis influences your everyday life .The questions are very straightforward, and it will take you about 10-15 minutes to complete both.
We would also like to obtain your permission to get some information from your file such as your age, duration of psoriasis and other medical conditions. You are welcome to look at both questionnaires and the list of data we want to take out of your file, before you agree to take part in the study. We will examine you, check your blood pressure, weight, height and hip circumference. We will also examine your skin to see how severe your psoriasis is.

Risks: There is no risk involved in the study.

Benefits: The study will help us learn more about the impact of psoriasis on the lives of our patients. It will also provide us with more information regarding our patients with psoriasis.

Participation is voluntary: Your participation in our study is completely voluntary. You can refuse to participate or withdraw from the research at any stage. Your refusal to participate/or withdrawal will in no way compromise your care and treatment
received.

Ethics: Permission to do this study has been received from the Wits Human Research Ethics Committee, the CEO's of Charlotte Maxeke Academic Hospital, Chris Hani Baragwanath Academic Hospital and Helen Joseph Hospitals.

Confidentiality: All personal information will be coded and kept confidential.

Contact Details of Researcher: For further information regarding this study, queries and reporting of study related adverse events, you can contact:

Dr Mercedes Morrison on 072 033 8553
or alternatively
Dermatology department (011) 488-3644

Contact Details of REC administrator and chair: For reporting of any complaints or problems please contact:
Human Research Ethics Committee (Medical)Tel 717-1234\2700 fax 011 717 1265
email:anisa.keshav@wits.ac.za