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Original Article

## Quality of Life and Associated Factors among Patients Diagnosed with Pemphigus Vulgaris Attending Clinic at Kenyatta National Hospital

Leah Wangari Karanja<sup>1\*</sup>, Roopkamal K. Saini<sup>2</sup> & Beatrice Wangari Ndege<sup>1</sup>

- <sup>1</sup> Jomo Kenyatta University of Agriculture and Technology, P. O. Box 62000-00200, Nairobi, Kenya.
- <sup>2</sup> Kenyatta National Hospital, P. O. Box 20723-00202, Nairobi, Kenya.
- \*Author for Correspondence ORCID ID; https://orcid.org/0009-0000-7581-3303; Email: ashkareih@gmail.com

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#### **ABSTRACT**

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Keywords:

Pemphigus vulgaris, Quality of life, DLQI score, Autoimmune disorders, Itching.

Background: Pemphigus vulgaris (PV) is a rare autoimmune disorder that affects the skin and mucous membranes. Prevalence of PV ranged from 0.38 to 30 per 100,000 people, with more than 50% of these patients having a low quality of life. The visible nature of PV lesions can lead to emotional distress, affecting selfesteem and body image. PV patients may face social isolation due to misunderstandings about the disease's contagiousness. However, the quality of life of these patients has not been exhaustively investigated. Purpose of the study: To determine the quality of life and associated factors among patients diagnosed with pemphigus vulgaris attending the dermatology clinic at Kenyatta National Hospital. Methodology: This was an analytical cross-sectional study utilising quantitative and qualitative approaches conducted at Kenyatta National Hospital. A consecutive sampling technique was used to sample 76 PV patients attending the dermatology clinic. The quality of life was assessed using the Dermatology Life Quality Index (DLQI). A structured questionnaire including these validated tools and patient-specific information such as demographic and clinical characteristics, depression level and quality of life. Descriptive analysis was done where the mean DLQI score was calculated and scores were characterised using the DLQI validated scoring, which was summarised using frequencies and percentages. Student t-test and ANOVA were conducted to investigate differences in DLQI scores based on patient characteristics and presenting symptoms. Significance was assessed at a p-value less than 0.05. Performed using Stata version 17. Thematic analysis was performed, where themes and subthemes were obtained. Conducted using Dedoose v7.1.1. Results: The average age was 47.9±14.2 years, and 69.7% were female. Clinical characteristics revealed that 48.7% had the disease for between 2-5 years, and 31.6% had a family history of autoimmune disorders. Common symptoms included blisters (65.8%) and itching (42.1%). Strong social support was seen in 52.6% of the patients. The mean DLQI score for the 76 patients in this study was 13.0 (Standard Deviation [SD]  $\pm$  7.7), indicating a medium to high impact of the disease on their quality of life. Further, 26.3%, 34.2% and 22.4% had medium impact, high impact, and very high impact. Female patients, inpatients, social support, duration of disease, current medication, family history, as well as presenting with itching, were associated with a higher impact on their quality of life. There was also limited knowledge of disease and treatment experiences, and emotional coping was a key identified theme.

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Conclusions and recommendations: There is a significant impact of PV on patients' quality of life, particularly among females, those on active medication, and those with a family history of autoimmune disorders. Itching exacerbates symptoms, and limited knowledge about PV's autoimmune nature is prevalent. There is a need for patient education on PV's causes and management.

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#### INTRODUCTION

Quality of life (QOL) encompasses an individual's experience and perception of their well-being with respect to an underlying need in an individual's life. This takes into consideration cultural health and personal wellbeing (Sajedianfard et al., 2021). It is a complex idea that is influenced not only by one's physical health but also by a variety of nonmedical factors, such as one's personality, aspirations, expectations, social standing, marital status, and religious encounters. There are many dermatological disorders, the vast majority of provide a significant risk of mortality to patients but have the potential to have a significant negative impact on a patient's quality of life(Sebaratnam et al., 2012). One of these conditions includes pemphigus vulgaris (PV).

Bullae and painful erosions of the skin and mucous membranes are the clinical hallmarks of pemphigus, an autoimmune illness that is extremely uncommon but extremely severe. Pemphigus is caused by autoantibodies that are directed against desmosomes (Tamási et al., 2019). The epidermis of the two primary subtypes, vulgaris and foliaceus, can be

differentiated from one another according to the depth of the cleavage plane (Paradisi et al., 2009). Patients who have pemphigus foliaceus (PF) have scaly and crusty superficial erosions of the skin, but their mucous membranes are unaffected by the condition. PV blisters are distinguished by a loss of cell adhesion in the deep epidermis, which is located just above the basal layer. Additionally, PV blisters are linked to autoantibodies against desmoglein (anti-Dsg-3), which is a keratinocyte cell-surface adhesion protein. The PF blisters are more superficial and can be found immediately below the horny layer. These blisters have been linked to antiDsg-1&3. The incidence of the disease ranges from 0.75 to 5 cases per million people every year, with a significant amount of geographic diversity for both subtypes. Although pemphigus can appear at any age, the condition is most frequently identified in people in their forties through their sixties. In most populations, PF is significantly less prevalent than PV (Paradisi et al., 2009).

Pemphigus vulgaris is the commonly occurring form of the pemphigus group, although the incidence of PV varies across different geographic regions and ethnicity (Agolli et al., 2023) (Alpsoy

et al., 2015). In Germany, the cases of PV range 0.5 per million individuals (Bertram et al., 2009), and 0.8 per million in Finland (Kianfar et al., 2022). There is evidence that people of Ashkenazi Jewish and Mediterranean heritage are more likely to develop PV than other populations, which points to a genetic predisposition (Kridin & Schmidt, 2021; El Hadadi et al., 2022).

A recent report in Tehran established that 77% of patients with PV experienced anxiety and depression with more impaired quality of life (Ghodsi et al., 2012). Among Korean patients, it was identified that pemphigus vulgaris and pemphigus foliaceus significantly reduced the QOL of patients (Sung et al., 2015). The patient's age, the length of time they had the disease, the number of times they were hospitalized, the absence of secondary studies, the type of treatment they had, and their occupation were all factors that contributed to a lower quality of life (Azfar et al., 2021) (Tiwari et al., 2020). Due to the fact that pemphigus is one of the most common diseases that result in hospitalization in hospital skin wards, as well as the high pressure that this disease puts on patients, the rarity of studies about the impact that this disease has on the quality of life of patients, and the differences in the culture and quality of life between our society and other cultures, it is imperative that research be conducted into the effects that this disease has on patients.

There is limited data from the local context on PV and quality of life. A recent study at Kenyatta National Hospital by Wanyika et al. (2022) identified that almost half of the patients with PV common developed complications, with complications, including sepsis, herpes simplex, diabetes mellitus and hypertension (Wanyika et al., 2022). However, there is limited research on the quality of life and associated factors among patients with PV. Thus, the study sought to determine the quality of life and associated factors among patients diagnosed with pemphigus vulgaris attending the dermatology clinic at Kenyatta National Hospital.

#### METHODS AND MATERIALS

## **Research Design**

This study adopted a cross-sectional study design utilising both quantitative and qualitative approaches.

## **Study Setting**

The study was conducted at the Dermatology clinic at Kenyatta National Hospital. The Kenyatta National Hospital is the country's largest referral facility, boasting a bed capacity of 2,400 as well as about 6,000 staff members. Within Kenya's Nairobi County, in the country's higher hill region, is where you'll find the hospital. The KNH acts as a referral centre for complicated medical problems and specialist treatments on a national level. Patients are often referred to KNH from other healthcare facilities across the country. Kenyatta National Hospital is a comprehensive medical facility that provides a wide range of medical services, including specialised care in various departments such as surgery, internal medicine, paediatrics, obstetrics gynaecology, orthopaedics, and dermatology, among others. Dermatology clinic at KNH runs on Fridays between 8.00 am to 2.00 pm, with approximately five patients with pemphigus vulgaris attending the clinic in each session.

## **Study Population**

The study included adult patients diagnosed with PV attending the dermatology clinic at Kenyatta National Hospital. Adult patients 18 years and above with PV diagnosis attending clinic and agreed to participate in the study were recruited while iindividuals diagnosed with forms of pemphigus other than Pemphigus Vulgaris such as Pemphigus Foliaceus were excluded to maintain homogeneity in the study group, those with severe cognitive impairment or conditions that hinder their ability to understand and respond to studyrelated questions were excluded. Further, participants with other severe dermatological conditions or chronic illnesses that may significantly impact quality of life independently of Pemphigus Vulgaris were excluded.

### **Sample Size Determination**

The sample size was determined using Fischer's formula based on a previous study conducted in Hungary, which found that 27.3% of PV patients had good quality of life (Mitev et al., 2019). The confidence interval was considered at 95% and a 10% margin of error, giving a sample size of 76 patients with PV diagnosis attending the clinic at KNH dermatology clinic.

For the qualitative arm of the study, two focus group discussions were conducted. One of the groups included male patients, while the second focus group included female PV patients seeking care at KNH.

#### **Sampling Procedure**

Consecutive sampling was used for the quantitative arm. Recruitment was done consecutively until the sample size was attained. A purpose sampling technique was used to recruit participants for the focus group discussions.

#### **Research Instruments**

For the quantitative arm, a structured questionnaire was used to collect data. Quality of life was assessed using the Dermatology Life Quality Index (DLQI) questionnaire. For the qualitative arm, a focus group discussion guide was used to collect data.

#### **Recruitment and Data Collection Procedure**

Recruitment of the study participants was done by the principal investigator with the help of research assistants. The research assistants were trained beforehand on filling out the data collection tool and obtaining informed consent. The researcher approached patients at each respective study area, explained the purpose of the study, and administered consent. Those who met the inclusion criteria were recruited to the study. Recruitment was done while patients waited in line before seeing a doctor. On each clinic day, the files of patients attending the clinic were retrieved from the records department and taken to the clinic. Thus, the researcher targeted only patients with PV, considering that other patients with

different dermatological conditions were also seeking care in the same clinic.

Once the patients who met the inclusion criteria consented and were recruited, the principal investigator, with the help of research assistants, administered the questionnaire. Participants were required to provide their demographic and clinical characteristics. Following this, the Dermatology Life Quality Index (DLQI) was administered to assess the quality of life. Data collection was done consecutively until the sample size was attained.

For the qualitative arm of the study, those who agreed were included in the two groups, with each of the groups having seven participants. The Pi, who also served as the moderator, conducted the discussions in a serene environment within the clinic. The discussions were recorded, which allowed for verbatim transcription.

#### **Dermatology Life Quality Index (DLQI)**

The Dermatology Life Quality Index (DLQI) is a widely used questionnaire that assesses the impact of skin disease on a person's quality of life. It was developed to measure the impact of various dermatological conditions, including Pemphigus Vulgaris, on daily functioning and well-being. The DLQI is a self-administered questionnaire that provides a numerical score, reflecting the impact of skin disease on a person's life (Liluashvili & Kituashvili, 2019).

The DLQI consists of ten questions covering different aspects of life, and respondents rate the impact of their skin disease over the past week on each item. The responses are given on a scale from 0 to 3, with 0 indicating no impairment, 1 indicating a small degree of impairment, 2 indicating a moderate degree of impairment, and 3 indicating a very large degree of impairment. The scores from each question are then summed to give a total DLQI score, with higher scores indicating a greater impact on quality of life (Wu et al., 2018).

The DLQI provides a valuable quantitative measure of the impact of skin diseases on quality of life, allowing healthcare professionals to assess

the effectiveness of treatments and interventions from the patient's perspective. Lower DLQI scores indicate better quality of life, while higher scores suggest a more significant impact on daily functioning and well-being. It is a useful tool in both clinical practice and research studies focusing on dermatological conditions.

Table 1: Classification of Patents Based on DLQI Questionnaire Index

Group	Questionnaire score	Disease impact on quality of life
1	1 - 0	No impact
2	5 - 2	Little impact
3	10 – 6	Medium impact
4	20 - 11	High impact
5	30 - 21	Very high impact

## Validity and Reliability

A pre-test was conducted at the Kenyatta National Hospital dermatology clinic. The pre-test emphasised ensuring that the selected research instrument contained all the necessary questions to help attain better outcomes in improving research validity. To enhance reliability, an expert dermatologist reviewed the study data collection instrument in relation to the study objectives. An expert statistician was also contacted to review the data collection tool.

#### **Data Management and Analysis**

Data was collected using structured a questionnaire and stored in a lockable drawer accessible to the researcher. Data entry was done on a daily basis using EpiData version 3.1 to ensure a high level of completeness and exclude any questionnaires with incomplete information. The database was then uploaded to Google Drive to prevent any unintentional loss and was updated as data entry progressed throughout the data collection process. The hard copy questionnaires were stored for a period of five years, after which they were discarded.

Descriptive analysis was performed to determine the quality of life, where the mean DLQI score was calculated and scores characterised using the DLQI validated scoring, which was summarised using frequencies and percentages. Student t-test and ANOVA were conducted to investigate differences in DLQI scores based on patient characteristics and presenting symptoms.

Significance was assessed at a p-value less than 0.05.

Audio files from the focus group discussions were transcribed verbatim by a professional transcriber, and the researcher reviewed the transcripts alongside the audio files to enhance the trustworthiness and accuracy of the data. The audio files were also uploaded to Google Drive to control data loss. Thematic analysis was performed using Dedoose v7.1.1.

#### **Ethical Consideration**

Ethical approval was obtained from KNH-UoN ERC (Reference Number: **P801/10/2023** 

### **RESULTS**

A total of 76 patients with PV participated in the study, while two focus group discussions of seven participants each were conducted, including male and female patients.

## Characteristics of Patients Diagnosed with Pemphigus Vulgaris Attending Dermatology Clinic at Kenyatta National Hospital.

The average age was 47.9(Standard deviation [SD]±14.2) years. The majority of patients were aged between 41 and 60 years, accounting for 37 (48.7%). Most of the patients, 53(69.7%), were female. In terms of educational background, 29(38.2%) of the patients had completed primary education, while 28 (36.8%) had attained secondary education. The majority of patients were married, 49 patients (64.5%). The duration of PV diagnosis varied among patients, with 37 (48.7%) of the patients having the disease

duration of between 2 to 5 years ago. Most patients (82.9%) indicating that they were newly patients reported no prior history of PV, with 63 diagnosed, as shown in Table 2.

Table 2: Characteristics of Patients Diagnosed with Pemphigus Vulgaris Attending Dermatology

Clinic at Kenyatta National Hospital.

Characteristics	Frequency	Percent
Age (Mean, SD) years	47.9±14.2	
≤40 years	23	30.3
41 - 60 years	37	48.7
More than 60 years	16	21.1
Gender		
Male	23	30.3
Female	53	69.7
Highest level of education		
No formal education	5	6.6
Primary level	29	38.2
Secondary	28	36.8
Tertiary	14	18.4
Marital status		
Single	27	35.5
Married	49	64.5
Religion		
Christian	70	92.1
Muslim	6	7.9
Duration of disease		
Less than or equal to 2 years	29	38.2
2 - 5 years	37	48.7
More than 5 years	10	13.2
History of PV		
No	63	82.9
Yes	13	17.1
Current treatment		
Steroids	76	100.0
Currently on any PV medication		
No	28	36.8
Yes	48	63.2
Family history of autoimmune disorders		
No	52	68.4
Yes	24	31.6

## Primary Symptoms Experienced by Patients Diagnosed with Pemphigus Vulgaris Attending Dermatology Clinic at Kenyatta National Hospital

The primary symptoms experienced by patients diagnosed with pemphigus vulgaris (PV) at Kenyatta National Hospital were predominantly skin blisters, which were reported by 50 patients (65.8%). Additionally, itching was reported by 32 patients (42.1%), which can exacerbate discomfort and lead to further irritation of the

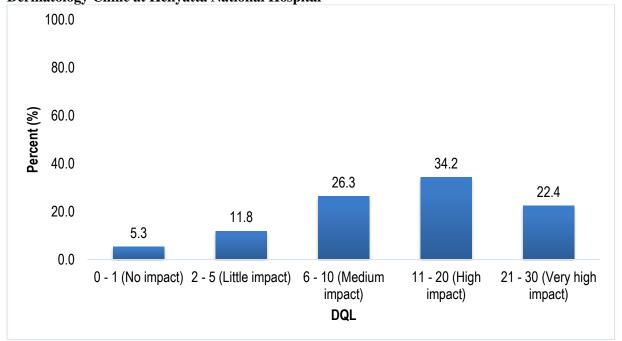
affected areas. Oral lesions were experienced by 23 patients (30.3%), while pain was less commonly reported by 9 patients (11.8%).

## The Quality of Life of Patients Diagnosed with Pemphigus Vulgaris Attending Dermatology Clinic at Kenyatta National Hospital

The mean DLQI score for the 76 patients in this study was 13.0 (Standard Deviation [SD]  $\pm$  7.7), indicating a moderate to high impact of the disease on their quality of life. The findings

further, 26 patients (34.2%) experienced high impact, and 17 patients (22.4%) reported very high impact, as shown in Figure 1.

Figure 1: The Quality of Life of Patients Diagnosed with Pemphigus Vulgaris Attending Dermatology Clinic at Kenyatta National Hospital



The Factors Associated with Quality of Life among Patients Diagnosed with Pemphigus Vulgaris Attending Dermatology Clinic at Kenyatta National Hospital.

The findings showed that females reported a mean DLQI score, which was higher than males,  $16.0\pm6.5$  vs  $6.0\pm5.3$ , p<0.001. Muslim patients had a much higher mean DLQI score of  $21.2\pm4.6$ , compared to Christian patients who had a mean of  $12.1\pm7.4$ , p =0.005. The length of time since diagnosis significantly affected QoL. Patients diagnosed for 2 years or less had a higher mean DLQI score of  $16.2\pm8.1$  compared to those diagnosed for 2-5 years ( $11.6\pm7.3$ ) and more than 5 years ( $8.6\pm4.0$ ), with p = 0.007. Patients who had received prior treatment for PV had a significantly higher mean DLQI score of

19.2±9.1, compared to those who had not received treatment (11.0±6.1), p<0.001. Patients currently taking medication for PV reported a higher mean DLQI score of  $16.1\pm7.5$ , compared to those not on treatment (7.64 $\pm$ 4.5). The p-value (<0.001) suggests that active treatment for PV might correlate with a higher perception of disease impact, possibly due to the side effects or challenges associated with ongoing medication. Patients with a family history of autoimmune disorders reported a significantly higher mean DLQI score of 19.7±6.2, compared to those with no such family history  $(9.9\pm6.2)$ , p<0.001. Patients experiencing itching had a significantly higher mean DLQI score of 16.2±8.4, compared to those without itching (10.7 $\pm$ 6.3), p =0.002

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Table 3: The Factors Associated with Quality of Life among Patients Diagnosed with Pemphigus

Vulgaris Attending Dermatology Clinic at Kenyatta National Hospital.

Characteristics	DLQI (Mean, SD)	F/t statistic	P value
Age			
≤40 years	13.1±8.1	0.165	0.848
41 - 60 years	13.3±8.0		
More than 60 years	12±6.6		
Gender			
Male	6.0±5.3	42.738	< 0.001
Female	16.0±6.5		
Highest level of education			
No formal education	15.6±4.7	0.229	0.876
Primary level	13.0±7.4		
Secondary	12.5±8.8		
Tertiary	12.9±7.1		
Marital status			
Single	13.4±7.1		
Married	12.8±8.1		
Religion			
Christian	12.1±7.4	8.559	0.005
Muslim	21.2±4.6		
Duration disease			
Less than or equal to 2 years	16.2±8.1	5.396	0.007
2 - 5 years	11.6±7.3		
More than 5 years	8.6±4.0		
History of PV			
No	13.4±7.5	1.033	0.313
Yes	11.0±8.5		
Have any previous treatments for pemphigus vulgaris			
No	11.0±6.1	19.387	< 0.001
Yes	19.22±9.1		
Currently on any PV medication			
No	7.64±4.5	29.353	< 0.001
Yes	16.1±7.5		
Family history of autoimmune disorders	1011=710		
No	9.9±6.2	41.381	< 0.001
Yes	19.7±6.2	.11001	10.001
Blisters	1717=012		
No	12.2±6.2	0.366	0.547
Yes	13.4±8.4	0.500	0.0 17
Pain	13.120.1		
No	12.8±7.5	0.37	0.545
Yes	14.4±9.3	0.57	0.5 15
Itching	14.4±2.5		
No	10.7±6.3	10.688	0.002
Yes	16.2±8.4	10.088	0.002
Oral lesions	10.4±0.4		
No No	12.7±7.1	0.288	0.593
		0.200	0.333
Yes	13.7±9.1		

## Exploring Knowledge and Perception of Pemphigus Vulgaris among Patients Attending the Dermatology Clinic at Kenyatta National Hospital

The findings were grouped into six key themes based on the patients' responses to focus group discussion questions. Each theme highlights specific challenges, insights, and coping strategies.

Theme	Subtheme	Comments
Theme 1: Limited Knowledge and Awareness of Pemphigus Vulgaris (PV)	Unfamiliarity Before Diagnosis	"I had never heard of pemphigus vulgaris until the doctor told me." (FGD 1, Male aged 44 years)
	Misconceptions About Causes	"Maybe it comes from bad water or witchcraft; I'm not sure." (FGD 2, Female aged 34 years)
	Difficulty Describing the Disease	"I just know it causes wounds on the skin, but I don't really understand why." (FGD 1, Male aged 32 years)
Theme 2: Understanding of Symptoms and Diagnosis	Recognition Through Physical Symptoms	"I noticed blisters that wouldn't heal, and that's when I knew something was wrong." (FGD 2, Female aged 39 years)
	Role of Healthcare Providers in Diagnosis	"The doctor said it's a problem with my skin fighting itself, but I still don't get it fully." (FGD 2, Female aged 31 years)
	Lack of Awareness About Complications	"I don't know if it can get worse. I just take my medicine." (FGD 1, Male aged 40 years)
Theme 3: Treatment Experiences and Challenges	Experiences With Medication	"I was given tablets and creams, but the side effects made me weak." (FGD 2, Female aged 30 years)
	Limited Understanding of Treatment Risks	"No one really told me about side effects. I found out when my body started swelling." (FGD 1, Male aged 54 years)
Theme 4: Sources of Information	Reliance on Healthcare Workers	"I only trust what the hospital people tell me. I don't check online." (FGD 2, Female aged 30 years)
	Difficulty Accessing Reliable Information	"It's hard to find anything about PV around here. Most people don't even know it exists." (FGD 1, Male aged 37 years)
Theme 5: Emotional Coping and Support Systems	Psychological Struggles	"Sometimes I feel isolated because people think my wounds are contagious." (FGD 1, Male aged 41 years)
	Support from Family and Faith	"My family and prayers keep me going through this illness." (FGD 2, Female aged 29 years)
Theme 6: Future Concerns and Information Needs	Desire for More Information	"I want to know if this disease can be cured completely."
	Concerns About Long-Term Management	"Will I have to take medicine for the rest of my life?" (FGD 2, Female aged 36 years)

## **DISCUSSION**

The mean DLQI score in this study was 13.0 (SD  $\pm$  7.7), indicating a moderate to high impact of pemphigus vulgaris (PV) on the patients' quality

of life. This finding is consistent with the study in Iran, which also reported a similar moderate to high impact, with a DLQI score of 11.0 (Ghodsi et al., 2020). Both studies used the Dermatology Life Quality Index (DLQI) tool, which is designed to assess the impact of dermatological conditions on the quality of life. The DLQI tool is widely used and considered a valid measure for evaluating how conditions like PV affect patients' physical, social, and emotional well-being.

Similarly, Layegh et al. (2013) conducted a crosssectional study in Iran among PV patients and used the DLQI questionnaire to assess quality of life. Their study found that 39.7% of patients had a poor quality of life, which highlights the significant burden that PV imposes individuals, affecting various aspects of their lives, such as daily functioning and social interactions (Pouran et al., 2013). This result aligns with the current study, further reinforcing the moderate to high negative impact that PV has on quality of life, especially in terms of physical appearance, skin lesions, and associated symptoms like itching, which can be distressing. The similarities in findings across these studies emphasise the reliability of the DLQI tool in assessing the quality of life in PV patients. The consistent use of a cross-sectional study design in these studies allows for direct comparison and enhances the generalizability of the findings. These studies collectively suggest that PV significantly disrupts patients' quality of life, underscoring the need for better management strategies, including improved patient education, psychosocial support, and targeted treatments to alleviate the disease's impact.

Our study found that several factors, including gender (female), religion, duration of disease, previous PV treatment, current PV medication, family history of autoimmune disorders, and itching symptom, were significantly associated with high DLQI scores, indicating a higher impact of PV on patients' quality of life. These findings are consistent with those from a study conducted in Iran by Sarvin et al. (2021), which revealed that gender, disease duration, and family history were significantly associated with poor quality of life

among PV patients. The influence of these factors on quality of life reflects the multifaceted nature of the disease, as both biological and environmental factors contribute to the burden of PV. Similarly, the study by Ghodsi et al. (2020) found that the length of disease was significantly associated with poor quality of life. The longer the duration of PV, the more it affected patients' day-to-day functioning, which aligns with our findings that duration of disease was linked to higher DLQI scores. Chronic diseases like PV, which are long-lasting and require continuous management, can result in cumulative physical and emotional distress, making it harder for patients to adapt and maintain a satisfactory quality of life over time.

In our study, female gender was found to have a significant association with higher DLQI scores, which is consistent with the findings in the studies by Sarvin et al. (2021) and Ghodsi et al. (2012). Women may experience more significant psychosocial stress due to visible skin lesions and the social stigma that often accompanies dermatological conditions. This is particularly pronounced in low-resource settings, where cultural and societal perceptions of beauty and health may increase the emotional toll of living with PV. The itching symptom, another key finding in our study, has long been recognised as a major factor affecting the quality of life in PV patients, as it can cause significant discomfort, sleep disturbances, and further psychological distress.

The present study showed there were significant gaps in patients' knowledge of pemphigus vulgaris (PV), especially regarding its causes, symptoms, and long-term management. Like the study by Nasimi et al. (2019) in Tehran, we found that poor illness perception among PV patients is largely due to limited awareness and a lack of adequate information about the disease. This gap in understanding leads to heightened emotional distress, a finding consistent with Bettolini et al. (2024) in Italy, who noted that the psychological burden of PV, particularly the stigma associated with visible lesions and the chronic nature of the disease, contributed to further complications such as sexual dysfunction and relationship stress. Our

study, conducted in a different setting, similarly identified family support and faith as crucial coping mechanisms for managing the emotional challenges of PV. While Bettolini et al.'s study was based in Europe, the psychological impact of PV linked to visible symptoms and chronicity is relevant across different cultural contexts, including ours. Patients with visible symptoms of PV seeking care are likely to share similar emotional experiences, reinforcing the importance of addressing both the physical and psychological aspects of the disease.

### **Study Limitations**

This was a single-centre study in an urban setting; hence, the findings might not be generalisable to represent the Kenyan context, including the rural setup.

## CONCLUSION AND RECOMMENDATIONS

The study showed a high impact of PV on the daily functioning of the patients, with reported high (34.2%) or very high (22.4%) impacts on their quality of life, indicating that PV disrupts their personal, social, and professional lives. Females and those on active medication or with a family history of autoimmune disorders reported worse QoL outcomes. Itching was a key symptom that further deteriorated QoL for many patients. In addition, the knowledge and perception of PV among patients was limited. Misconceptions about the causes of PV, such as linking it to bad water or witchcraft, and difficulty describing the disease beyond its physical symptoms, reflect a critical gap in understanding the autoimmune nature of the condition. Thus, there is a need for enhanced patient education on the pathophysiology and long-term management of PV, ensuring that patients understand the autoimmune nature of the disease and its treatment options. In addition, it is fundamental to improve communication regarding treatment risks and side effects to help patients better manage their condition and adhere to prescribed therapies.

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#### **Conflict of Interest**

The authors did not have any conflicts of interest to declare

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