

## ASSESSING THE IMPACT OF AUTOIMMUNE BULLOUS DISORDERS ON QUALITY OF LIFE: A SNAPSHOT SURVEY

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### Abstract

#### Objectives:

To evaluate the quality of life (QoL) in patients with autoimmune bullous disorders (ABDs).

#### Study design and setting:

A cross-sectional survey was conducted at the Pak Emirates Military Hospital, Rawalpindi,

#### Methodology:

A total of 190 patients aged 18–70 years with clinically and histologically confirmed ABDs were recruited using consecutive sampling. Demographic and clinical data were obtained through structured interviews and medical records. QoL was assessed using the Dermatology Life Quality Index (DLQI) questionnaire. A p-value of  $\leq 0.05$  was considered statistically significant for all analyses.

#### Results:

The mean age of participants was  $45.3 \pm 13.2$  years, with 54% males and 46% females. Pemphigus vulgaris (51%) was the most common diagnosis, followed by bullous pemphigoid (32%) and pemphigus foliaceus (18%). Prednisolone (39%) and azathioprine (33%) were the most frequently prescribed medications. Comorbidities included hypertension (25%), diabetes (21%), and hyperlipidemia (12%). Regression analysis revealed that older age ( $p = 0.018$ ), longer disease duration ( $p = 0.002$ ), presence of comorbidities ( $p = 0.011$ ), and hospitalization history ( $p = 0.028$ ) were significant predictors of higher DLQI scores. Gender and educational status showed no significant association.

#### Conclusions:

ABDs substantially impair patients' QoL, with older age, prolonged disease, comorbidities, and hospitalization contributing significantly. Routine QoL assessments should be integrated into clinical care to ensure holistic, patient-centered management.

#### Keywords:

Autoimmune bullous diseases; Quality of life; Questionnaires; Skin diseases, blistering

### Introduction

Autoimmune bullous disorders (ABDs) comprise a rare yet clinically significant group of chronic dermatological conditions that profoundly affect patients' physical, psychological, and social well-being.<sup>1</sup> These diseases are characterized by the presence of circulating autoantibodies that target structural components of the skin and mucous membranes, leading to blistering, erosions, and, in many cases, long-term morbidity. The most prevalent forms of autoimmune blistering diseases (ABDs) are pemphigus vulgaris (PV), bullous pemphigoid (BP), mucous membrane pemphigoid (MMP), and epidermolysis bullosa acquisita (EBA).<sup>2</sup> These diseases can be considered rare in comparison to the number of dermatoses present; however, they have dire ramifications and consequences given the chronic, relapsing course of the disease and an overall impact on quality of life (QoL).

The global prevalence of ABDs is reliant on geographic areas, with rates affected by genetic, environmental, and socioeconomic factors. Pemphigus vulgaris, for example, is reported with increased frequency in the Mediterranean countries, the Middle East, and South Asia, as environmental triggers such as high ultraviolet (UV) exposure may be a contributing factor in these areas.<sup>3</sup> As an example, bullous pemphigoid tends to affect the aging populations across the globe, and the incidence rates are steadily rising in areas with aging populations. These epidemiologic patterns present the notion that ABDs are a rare yet increasing concern for public health.<sup>4</sup>

ABDs are clinically characterized by more than just visible lesions.<sup>5</sup> Painful lesions, mucosal involvement, and recurrent flares greatly impacted the patient's ability to eat, speak, or perform usual activities.<sup>6</sup> Moreover, both corticosteroids and immunosuppressants, when utilized as treatment, create their own challenges such as increasing the risk of infection, adding osteoporosis and diabetes, and carrying cardiovascular risks. Patients thus face a dual burden of physical sequela from their ABDs and morbidity associated with treatment.<sup>7</sup>

Additionally, while often overlooked, psychological and social consequences are equally concerning. Patients experience increased anxiety, depression, low self-esteem, and social withdrawal (particularly if lesions are visible involving the face, scalp, and/or oral cavity).<sup>8</sup> The unpredictable relapsing but remitting nature of these diseases adds uncertainty, but also the feeling of loss of control, and increasing mental anguish. Social outcomes include social stigma and isolation, as well as limited productivity at work, amplifying the multifaceted nature of ABDs in their lives.

Within the past decade, researchers have recognized these hidden dimensions with increasing frequency. Recent studies have highlighted that QoL impairment from ABDs is often equivalent, if not greater, than that experienced in other chronic dermatological conditions, such as psoriasis or atopic dermatitis. However, standard clinical assessments, primarily measuring lesion counts, antibody titers, or severity scores, do not traditionally measure these psychosocial dimensions.<sup>9-11</sup>

To fill this gap, disease-specific QoL instruments have been developed, most notably, the Autoimmune Bullous Disease Quality of Life (ABQOL) questionnaire and its complementary scale, the Treatment of Autoimmune Bullous Disease Quality of Life (TABQOL) questionnaire. Both of these instruments are specifically tailored to assess the impact of ABDs on patients' lives, including various effects such as functional limitations, side effects of treatment, and emotional difficulties. These instruments have been validated in multiple languages and cultures, attesting to their versatility and relevance across different cultures.

The present study is motivated in part by the need to fill an existing gap in research through a comprehensive assessment of patient QoL in ABDs. The use of validated QoL instruments, which assess both clinical outcomes and psychosocial domains, will contribute to a multi-dimensional understanding

of the impact of ABDs on quality of life. It is hoped the outcomes will help develop strategies that lead to more effective, patient-centered care and inform wider health care policy that addresses the complex needs of ABD patients on the continuum of care. The present study aimed to determine the mean quality of life (QOL) scores in individuals diagnosed with autoimmune bullous disorders.

### Methodology

The study was designed as a cross-sectional survey and was conducted at the indoor and outpatient departments of dermatology at Pak Emirates Military Hospital, Rawalpindi. The study was carried out from 1st April 2025 to 31st November 2025. Ethical approval was obtained from the Ethical Review Committee (ERC) of Pak Emirates Military Hospital (Approval No: A/28/ERC/25/2025, dated 1st May 2025).

The sample size was calculated using the WHO sample size calculator, considering a 95% confidence interval, a population mean  $\pm$  standard deviation of  $14 \pm 7$ , and an absolute precision of 1, which resulted in a calculated sample size of 190 participants.<sup>12</sup>

Non-probability consecutive sampling technique was employed to recruit the participants. Patients of both genders, aged between 18 and 70 years, who had clinically and histologically confirmed autoimmune bullous disorders and presented with skin and/or mucosal lesions such as blisters, erosions, or ulcerations were included in the study. Patients who had incomplete clinical or histopathological records or those with cognitive impairments were excluded from the study.

A total of 190 patients who met the inclusion criteria were consecutively recruited from both the inpatient and outpatient dermatology departments of Pak Emirates Military Hospital, Rawalpindi. Before data collection, all participants were provided with a thorough explanation of the study objectives, procedures, and their rights, including the right to withdraw at any time. Informed verbal consent was obtained from each participant before enrollment.

The principal investigator conducted structured face-to-face interviews with each participant in a private and comfortable setting to ensure confidentiality and encourage honest responses. Demographic details, including age, gender, marital status, education level, occupation, and socioeconomic status, were collected. Clinical information, such as type of autoimmune bullous disorder, duration of disease, presence of mucosal or cutaneous lesions, comorbidities, history of hospitalization, and current medication use, was obtained from both patient interviews and verified through medical records.

Following the collection of baseline demographic and clinical data, participants were administered a validated Dermatology Life Quality Index (DLQI) questionnaire to assess the impact of their condition on quality of life.<sup>13</sup> The DLQI questionnaire consists of ten items covering six domains: symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment. Each item was read aloud to participants who required assistance, and responses were recorded by the investigator.

The DLQI has been previously validated, showing a Cronbach's alpha value of 0.834, indicating high internal consistency. Data were collected systematically to minimize errors, with double-checking of each questionnaire for completeness before the participant left the session. Participants who were unable to answer any items due to cognitive or language barriers were excluded to maintain data integrity. All collected data were anonymized and coded to maintain confidentiality and were stored securely for subsequent statistical analysis.

Data were analyzed using SPSS version 23.0. Quantitative variables, including age and DLQI scores, were presented as mean  $\pm$  standard deviation for normally distributed data and as median and interquartile range for non-normally distributed data. Qualitative variables, such as gender, marital

status, education level, type of autoimmune bullous disorder, comorbidities, hospitalization history, and medication use, were presented as frequencies and percentages. The Kolmogorov-Smirnov test was applied to assess the normality of the collected data. Potential confounders, including age, gender, comorbidities, disease duration, hospitalization history, and educational status, were adjusted using linear regression analysis. A p-value of  $\leq 0.05$  was considered statistically significant for all analyses.

### Results

The study included 190 participants with a mean age of  $45.3 \pm 13.2$  years. Slightly more than half of the participants were male (54%), while 46% were female. Regarding marital status, the majority were married (67%), followed by single participants (21%), with smaller proportions being divorced (6%) or widowed (5%). In terms of educational status, most participants had completed secondary education (40%), while 21% had primary education, 24% were graduates, 10% had postgraduate qualifications, and 10% were illiterate. (Table 1)

**Table 1. Demographic Characteristics of Participants (n = 190)**

Variable	Category	n (%)
Age (years)	Mean $\pm$ SD	45.3 $\pm$ 13.2
Gender	Male	102 (53.7)
	Female	88 (46.3)
Marital Status	Single	40 (21.1)
	Married	128 (67.4)
	Divorced	12 (6.3)
	Widowed	10 (5.3)
Education	Illiterate	18 (9.5)
	Primary	40 (21.1)
	Secondary	76 (40.0)
	Graduate	46 (24.2)
	Postgraduate	10 (5.3)

Among the participants, half were diagnosed with Pemphigus Vulgaris (51%), followed by Bullous Pemphigoid (32%) and Pemphigus Foliaceous (18%). Regarding disease severity, 38% had active, recurrent disease, 26% had active new-onset disease, 23% were in partial remission, and 13% were in complete remission. The most commonly used medications were Prednisolone (39%) and Azathioprine (33%), followed by Cellcept (16%), Rituximab (10%), and other therapies (3%). Comorbidities were present in a proportion of participants, with hypertension affecting 25%, diabetes 21%, hyperlipidemia 12%, ischemic heart disease 6%, stroke 3%, and other conditions 5%. In terms of hospitalization status, 58% of participants were treated as outpatients, while 42% required hospitalization. (Table 2)

**Table 2. Clinical Characteristics of Participants (n = 190)**

Variable	Category	n (%)
Diagnosed Disorder	Pemphigus Vulgaris	96 (50.5)
	Pemphigus Foliaceous	34 (17.9)
	Bullous Pemphigoid	60 (31.6)
Disease Severity	Active, new-onset	50 (26.3)
	Active, recurrent	72 (37.9)

	<b>Partial remission</b>	44 (23.2)
	<b>Complete remission</b>	24 (12.6)
<b>Drug History</b>	<b>Azathioprine</b>	62 (32.6)
	<b>Prednisolone</b>	74 (38.9)
	<b>Cellcept (Mycophenolate)</b>	30 (15.8)
	<b>Rituximab</b>	18 (9.5)
	<b>Others</b>	6 (3.2)
<b>Comorbidities</b>	<b>Diabetes</b>	40 (21.1)
	<b>Hypertension</b>	48 (25.3)
	<b>Hyperlipidemia</b>	22 (11.6)
	<b>IHD</b>	12 (6.3)
	<b>Stroke</b>	6 (3.2)
	<b>Others</b>	10 (5.3)
<b>Hospitalization Status</b>	<b>Hospitalized</b>	80 (42.1)
	<b>Outpatient</b>	110 (57.9)

Linear regression analysis was performed to assess the impact of potential confounders on total DLQI scores, adjusting for age, gender, disease duration, comorbidities, hospitalization history, and educational level. The analysis identified several significant predictors of higher DLQI scores. Increasing age was associated with higher DLQI scores ( $p = 0.018$ ), as was longer disease duration ( $p = 0.002$ ). Participants with comorbidities also had significantly higher DLQI scores compared to those without ( $p = 0.011$ ). Additionally, a history of hospitalization was linked to higher DLQI scores ( $p = 0.028$ ). Gender and educational level were not significantly associated with DLQI scores in this analysis. These findings indicate that older age, prolonged disease, comorbid conditions, and hospitalization contribute to poorer quality of life in patients with autoimmune bullous disorders. (Table 3)

**Table 3. Linear Regression Analysis: Adjusted Effects of Potential Confounders on Total DLQI Score (n = 190)**

Variable	B (Unstandardized)	SE	Beta (Standardized)	t	p-value
Age	0.12	0.05	0.18	2.40	0.018*
Gender (Male vs Female)	1.05	0.92	0.07	1.14	0.256
Disease Duration (years)	0.25	0.08	0.21	3.13	0.002*
Comorbidities (Yes vs No)	2.18	0.85	0.15	2.57	0.011*
Hospitalization History (Yes/No)	1.92	0.87	0.14	2.21	0.028*
Educational Level	-0.75	0.42	-0.10	-1.79	0.075

*Significant predictors of higher total DLQI scores: Age, disease duration, presence of comorbidities, and hospitalization history ( $p \leq 0.05$ ). Linear regression analysis adjusted for all listed potential confounders.*

## Discussion

This cross-sectional snapshot of 190 patients with autoimmune bullous disorders (ABDs) at Pak Emirates Military Hospital confirms that ABDs impose a substantial burden on patients' lives and identifies older age, longer disease duration, presence of comorbidities, and prior hospitalization as independent predictors of worse Dermatology Life Quality Index (DLQI) scores. In our cohort ( $n = 190$ ) pemphigus vulgaris was the commonest diagnosis ( $\approx 51\%$ ) followed by bullous pemphigoid and pemphigus foliaceus. After adjustment for multiple confounders, higher DLQI scores were significantly associated with increasing age ( $p = 0.018$ ), longer disease duration ( $p = 0.002$ ), presence of comorbidities ( $p = 0.011$ ), and hospitalization history ( $p = 0.028$ ). Gender and education were not significant predictors. These results are broadly consistent with recent work while also providing some locally relevant contrasts.

Multiple recent studies report that pemphigus patients often report greater QoL impairment than some other ABDs, particularly when mucosal involvement or active disease is present. An Indian cross-sectional study and several multicenter reports have shown higher DLQI or disease-specific QoL impairment in pemphigus compared with bullous pemphigoid in many samples, particularly among treatment-naïve or active cases. For example, a tertiary-center Indian series observed a higher mean DLQI in pemphigus than in bullous pemphigoid and emphasized that active disease correlated with worse QoL.<sup>11, 14</sup> In the present study, where pemphigus vulgaris comprised half the sample, it fits this pattern: because pemphigus tends to be more mucocutaneous and chronic, it plausibly drives much of the QoL burden observed in mixed ABD cohorts. This aligns with reviews that show disease type and flare state are key determinants of patient-reported outcomes.<sup>15, 16</sup>

The present study found that increasing age was associated with worse DLQI. This is concordant with some, but not all, reports. A multicenter observational study and population analyses have noted that bullous pemphigoid, which predominates in older adults, can be associated with substantial functional decline and poorer health-related QoL, often because older patients carry more comorbidities and frailty, so age effects may be mediated through comorbidity and hospitalization.<sup>15, 17</sup>

However, other smaller studies (including single-center pemphigus cohorts) have not always observed a simple linear effect of chronological age on DLQI; in some samples, younger, socially active patients reported high psychosocial impact despite less medical comorbidity. This heterogeneity suggests that age effects may be context-dependent (disease mix, social roles, support systems). Our finding of an independent age effect after adjustment indicates that in our setting, older age adds QoL burden beyond comorbidity alone, which may reflect regional factors (care access, social support, or sequelae of delayed diagnosis).<sup>18, 19</sup>

Longer disease duration predicted worse DLQI in our analysis. Several recent studies echo this relationship: chronicity is repeatedly linked to cumulative functional impairment, treatment side-effects, and psychological wear-and-tear. For example, observational cohorts and registry analyses have reported that persistent disease activity or multiple relapses correlate with higher DLQI or disease-specific QoL indices. These studies emphasize that cumulative disease burden, and not only current activity, drives reduced QoL, supporting our finding.<sup>9, 20</sup>

The present study found that comorbidities and prior hospitalization independently predicted higher DLQI. This is consistent with literature showing that comorbid chronic diseases (diabetes, hypertension, cardiovascular disease) and episodes requiring inpatient care amplify functional limitations, psychological distress, and out-of-pocket costs, all factors that worsen QoL scores in skin disease populations. Studies from Iran and India have specifically reported worse DLQI among ABD patients with coexisting systemic disease or those requiring hospital admissions for disease control, matching our observations.<sup>11, 21</sup>

Although our descriptive data showed prednisolone and azathioprine as the most used agents and rituximab used in a minority (10%), we did not model treatment type as a main predictor. Several recent studies have documented that effective disease control, especially with steroid-sparing and targeted therapies such as rituximab, produces meaningful QoL gains over weeks to months. Rituximab cohorts and real-world registries report clinically important DLQI improvements following B-cell targeted therapy, particularly in patients with refractory pemphigus. This suggests that treatment access (and treatment-related remission rates) are important mediators of QoL; in settings where advanced therapies are less available or delayed, chronicity and hospitalization may carry larger QoL penalties.<sup>22</sup>

Several studies highlighted psychosocial factors (illness perception, social support, depression/anxiety) as strong correlates of QoL, sometimes stronger than demographic variables. Segal et al. (2021) and other single-center studies found that perceived illness control, social support, and psychiatric symptoms had sizeable associations with QoL. Our dataset did not include detailed psychometric measures beyond DLQI, which limits comparison; nonetheless, the independent effects of hospitalization and chronicity in our model likely capture some of this psychosocial distress. Future work should integrate validated measures of depression, anxiety, and social support to more fully explain QoL variance.<sup>23, 24</sup>

Regional reports using DLQI have reported mean DLQI values and similar patterns of impairment, often with higher scores in pemphigus and in newly diagnosed or untreated patients. An earlier Pakistani study using the Urdu DLQI found substantial QoL impairment among pemphigus patients, supporting the external validity of our findings in this geographic and cultural context. Our study, with a larger sample and multivariable adjustment, adds weight to these earlier local observations.<sup>12, 14</sup>

Strengths of our study include a relatively large single-center sample, use of a validated QoL instrument (DLQI), and adjusted regression analyses. Compared with many small single-center studies in the literature, our sample size allowed multivariable modeling of demographic and clinical predictors. Limitations mirror those noted across the literature: cross-sectional design, single-center recruitment, use of DLQI rather than ABD-specific instruments, and lack of formal psychiatric screening or detailed socioeconomic metrics. A variety of new reviews state the need to integrate general dermatology QoL measures with disease-specific and mental-health scales to comprehensively assess them; further investigations will need a multimodal approach.

The findings of this study have several important clinical implications for autoimmune bullous disorder (ABDs) therapy. To begin with, there is one of the most important age-related conditions that is underscored by the high correlation between older age and Dermatology Life Quality Index (DLQI) scores, that is, the sensitivity of age-related care. Frailty, limited mobility, polypharmacy, and social covariance may also be other factors that complicate the living with ABDs in older people, which further add to the impacts of ABDs on the quality of life. A holistic approach where geriatric principles are considered should be taken by clinicians in the management of bullous dermatoses in the elderly. This

may include increasing the frequency of monitoring patients, reducing hospital stays, and coming up with supportive care in order to sustain independence and psychological health.

Second, the observation that longer disease duration is a predictor of poorer quality of life (QoL) without considering the items of the DLQI indicates the need to control the disease early and continuously. Chronicity not only subjects patients to the impact of the disease on acting or functioning, but also the long-term toxicity of corticosteroids and immunosuppressants. Clinicians should thus incorporate treatment plans that aim at achieving long-term remission, at the same time considering the minimal possible cost of side effects. Premature use of steroid-sparing agents/biologics when such as rituximab, can reduce chronic morbidity and enhance quality of life.

The comorbidities and hospitalization affect the QoL worsening once again, supporting the necessity of multidisciplinary care. ABD patients are often characterized by cardiovascular disease, diabetes, or other chronic medical issues that make the management of the disease difficult. A more efficient care model can be based on the coordination of the dermatologists, internists, psychiatrists, and nutritionists in order to support the overall health problems of the patients. Moreover, due to the close relationship between hospitalization and impairment during QoL, the clinicians ought to utilize the outpatient care model whenever possible. Improving the services of day-care infusion and tele-dermatology follow-up can be useful in decreasing the number of inpatient admissions and their resultant impact on the social and work life of patients. Lastly, the current research gives additional support to why QoL assessments should be implemented in the dermatology practice.

The DLQI and the disease-specific ABQOL will provide our patients with a voice that might otherwise be lacking in the clinic, where significant areas of their lived experience are usually not covered within clinical assessment. The frequent use of these procedures will assist in determining those patients who are suffering psychological distress, experiencing social isolation or treatment fatigue, and an avenue is created to make earlier referrals to mental health care and patient support groups. Practice-QoL assessment intervention in disparate resource settings, including Pakistan, will be essential in promoting more culturally-sensitive, patient-centered, and equitable health care.

### Conclusion

The study in the paper provides a general overview of the significant impact of autoimmune bullous diseases on the quality of life of patients. ABDs will erode emotional well-being, social interaction, and life contentment, more than just skin blisters and erosion. In our study, we showed that most of the change in affect quality of life was due to older age, longer duration of the disease, comorbidity, and hospitalization, whereas such demographic factors as gender and education were not contributors. This proves that ABDs are a greater burden than transcends the skin alone. It also contributes to the debate on care delivery, in which clinically effective care and patient-centered and holistically conscious care are needed.

Regular evaluation of the quality of life allows clinicians to reveal other aspects of disease burden, determine the kind of interventions to provide in line with patient needs, and offer psychosocial assistance. It is particularly applied in resource-limited environments, where effective management of a disease and supportive care can prove beneficial in physical distress as well as the psychosocial burden. Finally, such a competent approach to enhance the lives of patients with ABDs is the necessity to shift the focus of disease treatment to the individuals, as chronic medical conditions, like ABDs, are in the field of medical, psychological, and social issues. This study gives a push to a novel framework,

presenting the evidence to guide clinicians, policymakers, and researchers in applying interventional strategies that improve the health-related quality of life of patients with autoimmune bullous diseases.

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