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Effect of Educational Guide on Knowledge and Quality of Life for Pemphigus Vulgaris Patients

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Abstract

Background: Pemphigus vulgaris (PV) is a chronic autoimmune disease characterized by painful and debilitating blistering of the skin and mucous membranes, which significantly disrupts patients' physical, emotional, and social well-being. Despite studies demonstrating that people with PV have a markedly lower quality of life (QOL), and despite existing interventions focusing on disease management and symptom control, there remains a notable research gap in systematically evaluating how a structured, patient-centered guide can improve the overall QOL of affected individuals. **This study aimed to** assess the effect of educational guide on knowledge and the quality of life for pemphigus vulgaris patients. **Methods:** This quasi-experimental study employed a purposive sample of 60 patients, equally divided between study and control groups. **Data collection** two tools were used: Tool 1 structured interview questionnaire sheet comprised two parts patients' demographic, medical data, and patients' knowledge related to disease and lifestyle activities. Tool 2 Autoimmune Bullous Disease Quality of Life Questionnaire (ABQOL). **Results:** Post-intervention assessment revealed that nearly two-thirds (66.7%) of the study group demonstrated a good level of knowledge, compared to one-fifth (20%) of the control group. Moreover, the study group showed substantial improvement in autoimmune bullous skin disorder quality of life scores, with the proportion of patients showing mild impact increasing from 6.6% pre-intervention to 56.7% post-intervention. **Conclusions:** The implementation of the nursing educational guide sessions effectively improved patients' knowledge and quality of life. **Recommendations:** Future research should include longitudinal studies to assess the sustainability of QOL improvements over time.

Keywords: Autoimmune Bullous Disease, Educational Guide, Lifestyle, Pemphigus Vulgaris, Quality of Life.

Introduction

Pemphigus vulgaris is considered one of chronic, fetal, and disabling disease that affects the patient's physical and psychological status. It is an autoimmune and severe mucocutaneous blistering disease with unknown cause. This disease is characterized by circulating autoantibodies that affect the skin and mucous membranes of the nose, mouth, throat, and genital organs. The blisters are painful, fragile, and easy to rupture leaving the skin area hazardous for infection **(Ingold., et al., 2024)**.

Pemphigus vulgaris triggered by some risk factors such as viral infections, certain medications, thermal burns, emotional stress, diet, ultraviolet rays, ionizing radiation therapy, pesticides, and allergens **(Babu et al., 2019)**. Its onset typically occurs between ages 40 and 60, affecting both genders equally. It is most frequently associated with other diseases like Parkinson's disease, rheumatoid arthritis, dementia, cardiovascular disease, epilepsy, and Myasthenia Gravis. It is associated with many different life threating complications such as septicemia, pneumonia, and cardiovascular disease **(Moro et al., 2023)**.

Pemphigus vulgaris disease has resulted in mucosal and skin lesions with a high recurrence rate that requires long-term hospitalization for chronic immunosuppressive therapies with its associated side effects. On other hand no known cure for those patients, but there is a symptomatic treatment. Consequently, all these events have a negative impression on patients' physical and emotional health, social functioning, and relative well-being, **(Di Lernia, et al., 2020)**. Therefore, the health-related quality of those patients can be negatively affected by this disease.

The acantholysis, dissociation of keratinocytes and disfigurement of the skin result from pemphigus vulgaris leads the patients are always alone. **(Zhang, et al., 2023)**. It has a suppressive impact on sexual relationships, lower chance of marrying, and married people divorce as their marital needs are not met, due to genital erosions and a lack of knowledge about the disease **(Maione, et al., 2024)**. Additionally, patients with pemphigus vulgaris are more vulnerable to psychological disorders such as depression, suicidal ideations, anxiety, neglected grooming, eating, drinking disorders, and sleep disturbance. All these factors affecting on quality of life and necessitate psychological support, psychotherapy, rehabilitation, and education on how to cope with this chronic condition to control symptoms and prevent the complications **(Matthews, and Ali. 2022)**.

Education and guidance considered the gold stone for patients with pemphigus vulgaris for symptomatic control, overcome the adverse effects of the disease, promote coping mechanisms with the disease and improve physical, emotional, and social aspects of health-related quality of care **(Calabria et al., 2021)**. Nurses play a vital role in guidance process for the patient with pemphigus vulgaris by promoting patient comfort, implementing targeted nursing interventions, allow verbalize concerns, teaching patients about the disease process, and complications, assisting patients to participate in their usual activities, encouraging patients' medication adherence and suggesting lifestyle modifications **(Raciti et al., 2021)**.

Significance of the study

Pemphigus vulgaris is autoimmune disease characterized by painful and debilitating blistering of the skin and mucous membranes that significantly disrupts patients' physical, emotional, and social well-being. The severity of its symptoms often leads to limitations in daily activities, social isolation, and psychological distress, magnifying the disease's overall burden **(Kowalewska et al., 2020).** Pemphigus vulgaris exhibits a global prevalence, with its incidence potentially influenced by ethnic background and geographical distribution. The documented frequency ranges from 0.1 to 0.5 cases per 100,000 individuals annually. Nonetheless, elevated rates have been observed among specific ethnic groups. The average onset typically occurring between the ages of 40 and 60 years. The prevalence rate of PV appears to be relatively equivalent between males and females **(Ingold et al., 2024).** Also there remains limited research on the efficacy of specifically designed guides for PV patients. Therefore, this study carried out to evaluates how educational guides impact patients' outcomes across multiple dimensions: disease knowledge, self-management skills, resilience, coping strategies, and overall quality of life.

Aim of the study

This study aimed to assess the effect of an educational guide on the knowledge and quality of life for pemphigus vulgaris patients.

Research hypotheses:

H1: Pemphigus vulgaris patients' knowledge will improve among study group than control group after receiving educational guide sessions.

H2: Pemphigus vulgaris patients' quality of life will improve among study group than control group after receiving educational guide sessions.

Methods:

Design:

A quasi-experimental design was implemented using pre- and post-test assessments of both study and control groups.

Setting:

The study was conducted at the Dermatology Department of Mansoura University Hospital.

Sample Size Calculation:

Sample size was calculated using G*Power 3.19.7 software. Parameters included: independent t-test analysis, 95% confidence interval, type I error (α) of 0.05, power (1-β) of 86%, effect size (d) of 0.8, two-tailed test, and allocation ratio (N2/N1) of 1.

Subjects:

Purposive sample of sixty patients admitted to the dermatology department and equally divided into two equal groups:

- Control group (n=30): patients who receiving routine hospital care
- Study group (n=30): patients who receiving care as designed by researcher (educational guide sessions).

Inclusion Criteria

- Confirmed diagnosis of pemphigus Vulgaris.
- Adults' patient of both genders aged 20 -60 years.
- Able to read, understand, and respond to study materials (e.g., educational guide and quality of life questionnaires). For illiterate patients, the ability to respond with aid.
- Willingness to participate in the study.

Exclusion Criteria

- Other skin disorders.
- Mental or cognitive impairment.

Tools:

Data collection utilized two tools based on a comprehensive literature review.

Tool I: Structured Interview Questionnaire

This tool was developed by researchers based on recent literature review, which includes the following two parts:

Part (1): Patients' demographic characteristic and medical data: demographic characteristic address personal data such as age, gender, marital status, educational level, occupation, and residence. Medical data includes duration of illness, family history, and comorbidities **(Sajedianfard, 2021)**.

Part (2): Patients' knowledge related to disease and lifestyle activities: it is used to assess patients' knowledge related to disease and its different activities related lifestyle for control and study group. It includes 9 main questions that covered 46 sub choices related to “disease’ such as definition, types, causes, risk factors, symptoms, diagnosis, treatment, and complications”; Knowledge related different lifestyle activities as following (diet allowance, care of mouth lesions, skin care, mouth & teeth care, eye care, medical consultation, and other activities **(Joly et al., 2020).**

Scoring system: one-score was given for "correct answer or yes question" & zero for "incorrect answer or no question. The total knowledge score was scored as following: < 50.0% for poor knowledge, 50.0 - < 75.0% for fair knowledge and ≥ 75.0% for good knowledge.

Tool II: Autoimmune Bullous Disease Quality of Life Questionnaire (ABQOL). This tool adopted from **Ghareh et al., (2023)** to assess quality of life activities affected by pemphigus vulgaris, it consisted of 20-question survey, and each question was cheeked according to respondent response as all the time, sometimes, occasionally, and never as a pre and posttest for study and control group.

Scoring system: "All the time" = three-point, "Sometimes" = two-point, "Occasionally" = one-point, and "Never" = 0 point. The responses to each item were counted, with ABQOL maximum score =60 and a minimum score =0. Increased scores are associated with lower life quality. The following categories were assigned to the scale's total score:

- Good: from 0 to < 20
- Fair: from 20 to < 40
- Poor: from 40 to 60

Fieldwork

An official letter from Mansoura's Faculty of Nursing given to the appropriate authorities in the selected setting for obtaining permission.

Ethical considerations:

The researchers obtained approval from the Research Ethics Committee at the Faculty of Nursing, Mansoura University (**No.P.0501, 30-7-2023**). Informed consent obtained from study participants, who informed about the purpose of the study and assured that their identities and responses to the questionnaire would be confidential; answering was voluntary, and participation (or not) would have no effect on their current or future condition.

Validity of the tools: The tools were developed by the researchers after reviewing related literature. They were tested for content validity by a panel of six experts from the fields of medicine and nursing. The necessary modifications were made based on their feedback.

Reliability: The knowledge assessment sheet and ABQOL questionnaire were tested for reliability using Cronbach's alpha coefficient with reliability scores of 0.85 and 0.88 respectively.

A pilot study was conducted with 6 patients (10% of the sample) prior to data collection to assess the tools' relevance, feasibility, applicability, reliability, and clarity, as well as to determine the time required to collect data from each participant. Based on the pilot study results, the tools were modified accordingly. These patients were not included in the main study.

Procedures:

The framework of the study was carried out from August 2023 to September 2024 according to three phases as the following:

a.Assessment phase:

- All participants (study & control groups) were interviewed individually to collect the necessary data using all the study tools.

b.Implementation phase:

- This phase started by implementing the educational guide for the study group only throughout the researchers. The educational guide implemented in form of four sessions as following:

- *First session*: consisted of knowledge about pemphigus vulgaris; definition, types, causes, and risk factors.

- *Second session*: consisted of manifestations, diagnostic evaluations, treatments, and complications.

- *Third session*: This session consisted of measures to improve QOL and how to deal with daily life activities. It covers wound care, oral care, dietary adjustments, infection prevention, and lifestyle modifications.

- *Fourth session*: consisted of a summary of the main points to remember of how to deal with flaring symptoms and the importance of medical follow-up.

- The educational session carried out in the morning shift. Each session was lasts 35 minutes. Each patient was interviewed individually.

- The instructional media used are power point presentation, videos, and colored handout.

- A colored booklet was given to the study group to help them in reviewing and understanding educational content.

- Control group exposed to hospital routine care. After finishing the data collection of posttests, the researchers distributed a colored booklet to the participants in the control group.

c. Evaluation phase:

Study and control group was evaluated as following:

- Immediately after implementing educational guide sessions as a posttest using tool one part 2 for evaluating knowledge.

- After three months following the completion of the educational guide sessions, utilizing tools two to assess the impact on patients' QOL.

- The control group had routine care at the mentioned department. This routine care emphasis on managing symptoms by medicine without focusing on enhance activities of daily living.

Data Analysis:

After data collection, the data was coded and entered into SPSS (version 27; IBM Corp). Error checks followed data entry. Analysis involved calculating frequencies and percentages for categorical data and means and standard deviations for continuous data. Inferential statistics included the chi-square and Fisher's exact tests for comparing non-normally distributed categorical variables. The Mann-Whitney U test was used to compare the means of two groups for non-normally distributed continuous variables. Statistical significance was defined as $P \leq 0.05$, with $P < 0.01$ considered highly significant.

Results

Table (1): Presents a comparison of demographic and medical data between the study and control groups. Males constituted the majority in both groups, representing 70% of the study group and 73.3% of the control group. The mean age was 35.20 ± 12.04 years for the study group and 37.93 ± 11.84 years for the control group. Marital status was similarly distributed, with married individuals including over half the sample in both groups (73.3%). Additionally, the study and control group were employed (70% & 76.7%) respectively. About education, the most frequently observed level in both groups was secondary school (33.3%). Most participants lived in rural areas (80% in the study group and 73.3% in the control group). Finally, there was no statistically significant difference between study and control group in their demographic characteristics. Also, it displays a comparison of medical data between the study and control groups about disease’s duration, 50% of the study group reported having the illness for 1-2 years whereas, the majority (70%) of the control group experienced the illness for less than one year. The family history of the disease was present in a similar proportion of participants in both groups (46.7% in the study group and 43.3% in the control group). Bullous Comorbidity profiles were comparable between the two groups, with 10% in both study and control groups have hypertension followed by of diabetes and cardiac disease. This indicating a general absence of major comorbidities within the study population. Finally, there is no statistically significant differences between the groups across all medical variables ($p > 0.05$ for all comparisons).

Table (2): Delineates the levels of knowledge regarding pemphigus vulgaris patients in both the study and control groups pre and post intervention. It demonstrates that a significant proportion of the control group has inadequate knowledge in contrast to the minimal percentage observed within the study group following the intervention (56.7% & 3.3%). In a contrasting manner, nearly two-thirds of the study group exhibit a good level of knowledge post-intervention, as opposed to one-fifth of the control group (66.7% & 20%). Ultimately, the intervention proved to be exceptionally effective in enhancing the knowledge levels of patients in the study group when compared to those in the control group, as substantiated by the statistically significant chi-square value (60.41) and p-value (<0.001). There were no statistically significant differences between study and control groups' knowledge in pre-intervention chi-square value (0.24) and p-value (0.885).

Table (3): Set out the ABQOL data for both the study and control groups pre and post intervention, which included educational sessions and guides. It shows a significantly improved quality of life for the pemphigus vulgaris study group. The study group showed an increase in mild Autoimmune Bullous Skin Disorder Quality of Life (ABQoL) scores (from 6.6% in pre-intervention to 56.7% post-intervention), while the control group saw minimal change. Severe ABQoL impairment in the study group substantially decreased (from 20% in pre-intervention to 10% post-intervention), while it worsened in the control group (from 16.7% to 33.3%), a statistically significant difference (p<0.001). The post-intervention difference in total mean ABQoL scores between groups was also highly significant (U=114.0, p<0.001), confirming the positive impact of the intervention on the study group's QoL.

Figure (1): Shows correlation between knowledge scores and quality of life scores for control group post intervention regarding Pemphigus Vulgaris. There is a non-significant, negative, mild correlation between total knowledge score and total quality of life score (rs = - 0.302, p > 0.05).

Figure (2): Shows correlation between knowledge scores and quality of life scores regarding pemphigus vulgaris for study group post intervention. There is a significant, negative and moderate correlation between total knowledge score and total quality of life score (rs = - 0.559, p < 0.05), this means that increasing knowledge score is correlated with decreasing quality of life scores. "Lower scores of quality of life on ABQOL scale refers to better quality of life".

Table (1): Frequency distribution of studied groups according to demographic and medical data.

Items	**Study group (n=30)**		**Control group (n=30)**		**X^2**	**P-Value**
	N	**%**	**N**	**%**		
Gender					2.17	0.161
Male	21	70	22	73.3		
Female	9	30	8	26.7		
Age					24.39	0.358
20-<30 years	9	30	6	20		
30- <40 years	11	36.7	9	30		
40-<50 years	5	16.7	8	26.7		
50-60 years	5	16.7	7	23.3		
M±SD	**35.20 ± 12.04**		**37.93 ± 11.84**			
Marital status					3.96	0.410
Single	7	23.3	6	20		
Married	22	73.3	22	73.3		
Widowed	1	3.3	2	6.7		
Occupation					0.76	0.343
Employed	21	70	23	76.7		
Not employed	9	30	7	23.3		
Level of education					5.18	0.819
Read and write	14	46.7	10	33.3		
Secondary	10	33.3	10	33.3		
University	6	20	10	33.3		
Residence					2.72	0.126
Urban	6	20	8	26.7		
Rural	24	80	22	73.3		
Duration of Illness (in years)						
< one year	8	26.7	21	70.0	3.87	0.276
1< 2	15	50.0	7	23.3		
2 or more	7	23.3	2	6.6		
Co-morbidities						
Diabetes Mellitus	2	6.7	3	10	0.75	0.667
Hypertension	3	10	3	10		
Cardiac disease	1	3.3	2	6.7		
Family History						
Yes	14	46.7	13	43.3	0.07	0.795
No	16	53.3	17	56.7		

Table (2) Levels of total knowledge among study and control groups in pre and post intervention regarding Pemphigus Vulgaris.

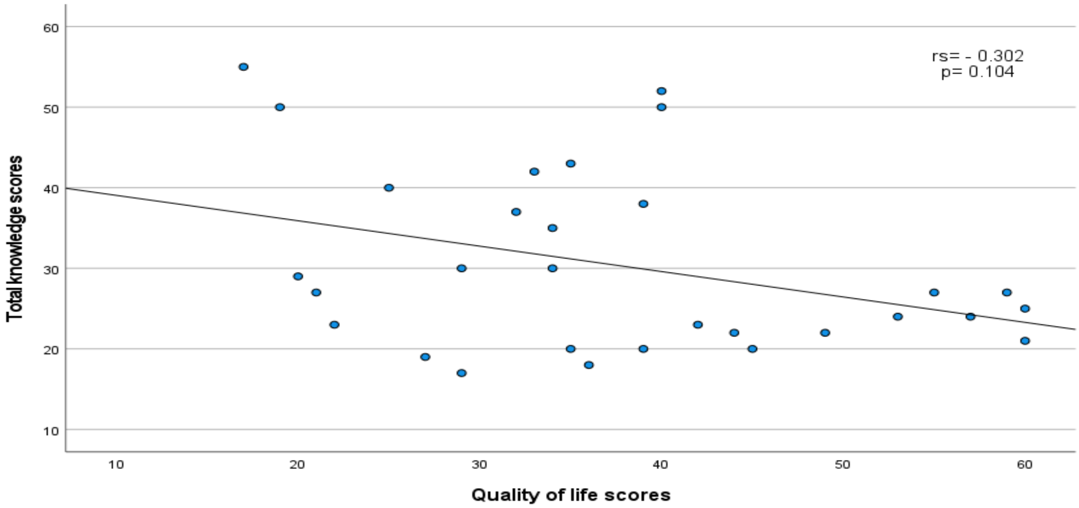
Level of knowledge	**Pre-intervention**				**χ^2**	**P-Value**	**Post-intervention**				**χ^2**	**P-Value**
	Control group (n = 30)		**Study group (n = 30)**				**Control group (n = 30)**		**Study group (n = 30)**			
	No	**%**	**No**	**%**			**No**	**%**	**No**	**%**		
Poor	21	70	22	73.3	0.24	0.885	17	56.7	1	3.3	60.41	<0.001*
Fair	6	20	5	16.7			7	23.3	9	30.0		
Good	3	10	3	10			6	20.0	20	66.7		

P value (*) significant at (P<0.05)

Table (3) Comparison of Quality of Life (QoL) between study and control groups pre- post-intervention regarding Pemphigus Vulgaris.

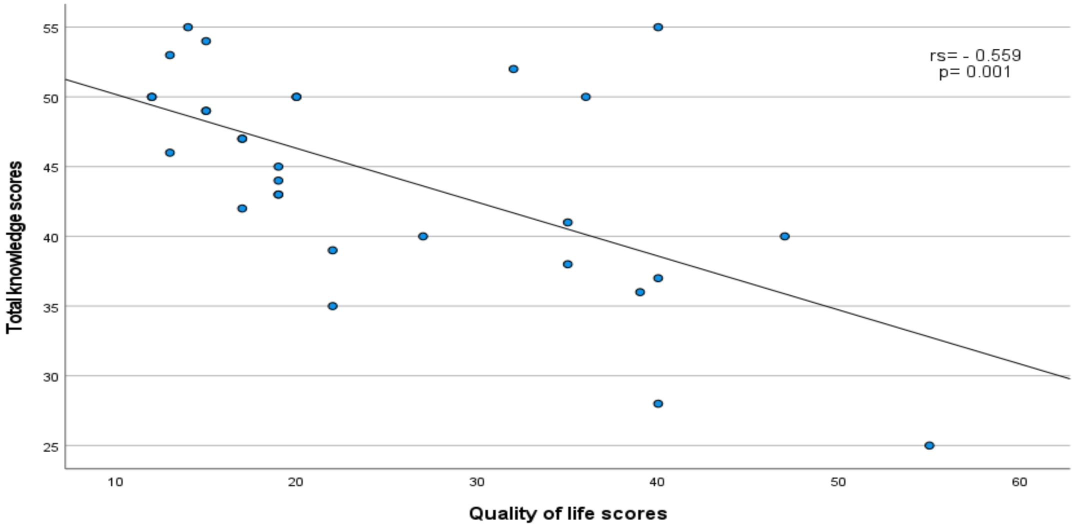
ABQOL	**Study (n = 30)**		**Control (n = 30)**		**Test of Sig**	**p**
	No.	**%**	**No.**	**%**		
Pre Good	2	6.6	2	6.6	χ^2= 0.168	MCp= 1.000
Fair	22	73.3	23	76.7		
Poor	6	20	5	16.7		
Total Score (Mean ± SD.)	**16.97 ± 3.99**		**16.69 ± 3.83**		**U=573.50**	**0.646**
Post Good	17	56.7	2	6.7	χ^2= 31.305*	MCp<0.001*
Fair	10	33.3	18	60		
Poor:	3	10	10	33.3		
Total Score (Mean ± SD.)	**9.11 ± 3.33**		**16.06 ± 3.88**		**U=114.0**	**<0.001***

ABQOL: Autoimmune Bullous Skin Disorder Quality of Life; χ^2: chi-squared test; **U:** Man-Whitney U Test; MCp: Multiple Comparison Procedure. **P value** (*) significant at (P<0.05)



rs for spearman correlation test

Figure (1) Correlation between knowledge and quality of life for the control group post intervention regarding Pemphigus Vulgaris (N=30).



rs for spearman correlation test

Figure (2) Correlation between knowledge and quality of life for the study group post intervention regarding Pemphigus Vulgaris (N=30).

Discussion

Pemphigus vulgaris is a severe autoimmune disease-causing blister on the skin and mucous membranes. It significantly affects quality of life, particularly mental well-being, due to pain, lesions, and treatment side effects. Disease severity correlates with quality of life; worse cases often mean poorer quality of life. Early diagnosis and proper treatment, along with addressing the psychological and social issues for patients with Pemphigus vulgaris, are crucial for improving quality of life **(Segal et al., 2021).**

Pemphigus vulgaris patients participated in this quasi-experimental study, forming a study group and a control group, each with 30 individuals. The study found no statistically significant differences between the groups' demographic and medical variables at the outset. This baseline comparability demonstrates group homogeneity and successful randomization, bolstering the validity of any outcome differences observed after the intervention involving guides and educational sessions.

This study, which hypothesized that an educational guide would improve the knowledge and quality of life for patients with pemphigus vulgaris in the study group compared to control one in empowering self-management and potentially improving health outcomes. Additionally, the post-intervention difference between study and control groups in total mean ABQoL scores was also highly significant that confirming the educational sessions and guide had a positive impact on the study group's QoL. Also, there was a non-significant, negative, and mild correlation between total knowledge score and total quality of life score among the control group. Whereas a significant, negative, and moderate correlation between total knowledge score and total quality of life score was showed among the study group post intervention. This means that increasing knowledge score is correlated with decreasing quality of life scores. "Lower scores of quality of life on ABQOL scale refers to better quality of life".

Our study results supported by (**Dawood et al., 2024)** showed a statistically significant improvement in mean scores after the application of a nursing care protocol. The agreement between the two studies may be because both studies were applied to Egyptian patients with the same Quasi-experimental study design, but without control group as in our study. Moreover, this finding is consistent with the work of (**Fournier et al., 2023)**, which highlights the need for strong support networks to positively influence the lives of patients with severe conditions. These protocols are valuable because they offer essential information and guidance for appropriate care.

Additionally, research by **(Nikhitha et al., 2024)** indicated that pemphigus vulgaris negatively affects a dermatology life quality index, while support group education can improve patient life quality. Furthermore, (**Kowalewska et al., 2020**) found that patients with skin conditions often exhibit negative attitudes and struggle with disease management, and that their quality of life depends on the specific skin disease.

Likewise, this finding aligns with the growing body of research emphasizing the importance of patient education and support in managing chronic skin conditions and their impact on QoL. Since, the debilitating nature of PV, characterized by painful blisters and erosions, significantly impacts patients' physical and emotional well-being **(Popescu et al., 2024).**

Similarly, daily activities are often disrupted, and the chronic nature of the disease can lead to long-term psychological distress. Previous research consistently demonstrates the negative impact of Pemphigus vulgaris on various aspects of quality of life, including physical functioning, social interactions, and emotional well-being (**Riopelle & Lake., 2022**).

Similarly, the study of **Zhang., Lin., Feng., Ou., & Gong, (2023)** highlighted non-pharmacological interventions can effectively support psoriasis patients in adapting to skin changes and improving their quality of life. These interventions include patient education, cognitive behavioral therapy, peer support programs, and motivational interviewing. These methods can empower patients to better manage their condition and improve overall well-being.

The current study showed that, post-intervention analysis revealed significantly greater knowledge improvement in the study group compared to controls. Whereas Pre-intervention knowledge levels showed no significant difference between groups. Similarly, in their 2019 prospective controlled pilot study entitled "Analyzing the value of an educational program for psoriasis patients," **Bubak et al**. randomized 24 psoriasis patients to an intervention group and 29 to a control group. The investigators concluded that participation in the educational program demonstrated significantly greater gains in disease-specific knowledge and self-management skills among psoriasis patients. These findings suggest that structured educational interventions may confer beneficial effects on long-term psoriasis management.

The present study's educational guide likely empowered patients with crucial knowledge and self-management skills, facilitating the observed improvements in their quality of life. This underscores the potential of well-designed educational resources to improve patient outcomes and work in conjunction with standard treatment approaches.

Limitations of the study:

Despite the encouraging results of this study, it's important to acknowledge that the limited sample size (60 patients) may restrict the generalizability of its findings.

Furthermore, the study's short-term follow-up period does not provide information about the long-term effects of the educational guide. Despite these limitations, the study provides valuable insights into the benefits of educational interventions for patients with pemphigus vulgaris.

Conclusion:

The educational nursing guide were effective in improving knowledge and quality of life for patients with pemphigus vulgaris.

Recommendations:

- Future research is needed with larger and more diverse samples to generalize the results.
- Incorporate educational nursing guideline on pemphigus vulgaris patients’ care to improve their QoL at Dermatology Department of Mansoura University Hospital.

- Longitudinal studies are needed to assess the sustainability of quality-of-life improvements over time.

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