

Patient Education in Pemphigus: Current Evidence, Challenges, and Future Directions

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ABSTRACT:

Background: Pemphigus is an autoimmune blistering condition that is lifelong and requires long periods of time to control, monitor and treat the condition by the patient. Little was known however about the effect of patient education on the health related quality of life of the users of a specialist service in Albania.

Objective: The objective of this study was to identify factors that would explain these relationships between quality of patient "education", health-related quality of life and to describe the mediating role of pemphigus-related knowledge, treatment adherence and self-care practices and to explore the moderating influence of "health literacy".

Methods: The design of the study is Cross Sectional, quantitative and explanatory. The study was carried out in Mother Teresa University Hospital Center in Tirana, the University Hospital of Trauma of the municipalities of Tirana and Pegasus and EB Dermatology Clinic in Tirana where a total number of 513 pemphigus patients were contacted with whom data were collected. The structured questionnaire was used to collect the data, which consisted of 29 items, and the analysis of the data was carried out by Partial Least Square Structural Equation Modelling (PLS-SEM).

Results: Quality of patient education had a positive impact on patient education related to health quality of life, becoming aware of the disease pemphigus and treatment adherence and self-care practices. Health-related quality of life was also this way in the

factors related to pemphigus knowledge and treatment adherence and self-care practices. For patient education and knowledge or adherence to self-care, there was a great enhancement to these relationships through health literacy, although the direct relationship between patient education and quality of life was not significantly enhanced. Both mediators partially mediated the effect and there was a larger indirect effect in the behavioural pathway.

Conclusion: The conclusion shows that quality patient education leads to improved knowledge, adherence and self-care behaviors, as well as improved health-related quality of life. In every of the specialist healthcare facilities in Albania, both public and private, education of structured, literacy-oriented and behaviour-oriented should be an integral part of the care for patients suffering from pemphigus throughout the country.

Keywords: patient education, pemphigus, health literacy, disease knowledge, treatment adherence, self-care practices, health-related quality of life, PLS-SEM and Albania.

Introduction:

As a rare, chronic and life-threatening autoimmune disorder, pemphigus commonly results in painful, recurrent mucocutaneous lesions, may be unpredictable in its course, can cause treatment-related issues and complications, social stigma, psychological burden and impacts on health-related quality of life, meaning that patients often report suffering from these afflictions (Navas et al., 2013). Therefore, effective long-term management is not just about using a medicine; it is about being familiar with the cause of pemphigus (autoimmune and chronic) and knowing its relapse symptoms, taking the medicines and regular checkup appointments, looking after the wounds and preventing treatment-related complications. In a recent study however, only 40.5% of the patients were knowledgeable about the autoimmune etiology of pemphigus and only 59.5% were knowledgeable with regards to chronicity of the disease, indicating that there are huge variations in knowledge regarding the autoimmunity cause of Pemphigus and chronicity of the disease based on the educational level (Wolf et al., 2002). Furthermore, the studies with auto-immune bullous diseases suggest that patient's health literacy and awareness contributes to medication

adherence, however, the connection between the two has not been fully investigated in pemphigus diseases (Schmidt et al., 2014). Therefore, the knowledge effect, treatment adherence, self-care, health related QOL and the effect on these after either improving or worsening patient education through the positive or negative influence of health literacy, are of particular importance for the patients who are treated in private clinics in Albania, where there is still a lack of health related evidence regarding pemphigus knowledge education and patients' reported outcomes.

Pearls of wisdom were given but there is still a long way to go to provide the most up-to-date view: pemphigus is a chronic (relapsing) autoimmune blistering disease so the patient needs to be empowered to navigate through complex treatment, understand when they are flaring up, be able to care for their blisters properly, remember the time for/period of /when to take medication, and undertake long-term treatment plan and have the opportunity to wet got the side effects. The study revealed that most professionals lack of knowledge about the autoimmune and chronic aspects of pemphigus; the level of patients' knowledge was found to vary with their level of education, suggesting the need to improve patient education with the use

of those with higher health-literacy capacity (Haw et al., 2021). Education has demonstrated to improve knowledge and quality of life (QOL) with respect to pemphigus, but it is unclear how education is the most effective. More specifically in the context of autoimmune bullous diseases, lack of knowledge makes educational information difficult to transfer to a step-by-step process of adherence, while non-adherence may have a negative impact on the patient's health (Marzano et al., 2013). Moreover, recently published, evidence-based recommendations recognized that all components of the pemphigus treatment should be evaluated in a declarative whole-picture approach to disease management, focused on health education, disease management (lesion treatment), surveillance for recurrent and follow-up care; however, available research on pemphigus did not assess and address quality of life (QoL) in adequate ways (Zhang et al., 2022). Thus, the problem remained unsolved, and it aimed to explain: How the improvement of the process of patient education (parenting) contributes to the improvement of the health related quality of life of patients, through transmission via one or sequential mediating variables, that is the increase in knowledge about pemphigus and the adherence to treatment and self-care practices; whether the contribution of health literacy weakens or goes along with the relationship between the process of patient education and the improvement of the quality of life of the patient through the transmission of health related knowledge about pemphigus; whether the contribution of health literacy weakens or strengthens the relationship between the process of patient education and the increase in self-care and treatment practices of the patient, particularly in the case of patient care received in private outpatient clinics in Albania.

Today, patient education is seen as independent, or directly related to, disease knowledge, health literacy, treatment adherence, self-care and quality of life without being integrated in a model that explains how this relationship works (no conceptual framework). Similarly, only a few recent studies on educational research focused

directly on the educational guidance's effects on patients' treatment knowledge and/or quality of life, and not the mechanism(s) linking the two; these also included a small mixed-group patient sample or only 42 patients in one center. Although health literacy has been studied individually alongside other factors contributing to medication adherence in patients with autoimmune bullous diseases in several countries around the world including Iran, it was not explored as a boundary condition to grasp whether health literacy can successfully mediate between information about a disease and its acceptance for using medical treatment (Landegren et al., 2021). This omissions create a theoretical gap between the relationship of patient education and pemphigus-related knowledge, and the moderating role of health literacy in the relationship between patient education and treatment adherence, and self-care. When analyzed empirically, pemphigus research continues to focus on clinical parameters and drug response without any trials included 26.5% quality of life measures which still contained a lot of variance in outcomes of cases (Ranugha et al., 2012). However, the literature reviewed does not offer any context-specific evidence that tests the above relations, given the fact that the private healthcare sector is becoming very relevant to the Albanian healthcare sector in recent years: private health expenditure accounted for around 59.7% of total health expenditure in 2024 and the country has a large number of public and private outpatient providers (Hale et al., 2018). Hence, the authors have come up with the need of conducting empirical evidence in every sector to help identify if there is an improvement in the knowledge, adherence & self-care, and therefore health of patients with various levels of health literacy according to the quality of the education they receive at Albanian private clinics.

Nevertheless, MES expects to produce patient centered evidence for long-term management of Pemphigus, based on attendance to private clinics in Albania, by an educational care. In other words, the study attempts to identify if there is an immediate (direct) and indirect

(mediated) links between the quality of patient education and improvement in health-related quality of life, and examines whether health-literacy influences the way patients comprehend and engage in the information offered by healthcare providers about pemphigus. This investigation is relevant to the clinic since only 40.5% of the patients had understood the autoimmune causes of this disease and only 59.5% the chronic nature of pemphigus which was strongly associated with the education status, suggesting the need for re-counselling for patients suffering from pemphigus which is clear and literacy friendly (Lockhart et al., 2015). Further, evidence from AIBDs shows that health literacy is correlated with medication adherence—an important component of chronic diseases that take months or years to treat with a course of corticosteroid, immunosuppressive or biological treatment (Kumar et al., 2006). Overall, this study is about identifying the clinical pathway from patient education to understanding the disease to safe medication usage to proper care of lesions to regular follow up, to the recognition of signs and symptoms of relapse, to improved health related to the physical, psychological and social aspects. It is important given the fact that although pemphigus is burdensome, there is a lack of consensus between various clinical studies of the disease when measuring this burden using quality of life (QoL) measures (Benoit et al., 2018). From a medical point of view, they can be used for providing individual education plans, identification of patients with limited health literacy, reinforcement of the monitoring of diseases, health promotion of proper self-care and integration of the health/quality of life assessment into the medical routine that depends on patients for advanced studies highlighting the importance of proper health education, care of diseases in the lesions, monitoring of diseases and the follow-up of the diseases (De et al., 2023).

The novelty of this research is the unified patient-centred model that is clinically developed and found to be valid and empirical in its ability to explain whether the quality of

patient education has a positive effect or not on the health-related quality of life of patients with pemphigus as well as under which conditions and how it occurs. Previous studies have focused on various parts of the patients' knowledge, attitudes and self-care practices, identifying gaps in understanding of the cause of pemphigus and the need to tailor patient education to literacy levels, but no previous studies have been designed to test this cascade of knowledge and behavior to measures of achieving better communication with healthcare providers and better self-managed health outcomes in patients with pemphigus (Coppola et al., 2022). An educational intervention to influence the beginning of their effects has recently been examined (Ahadome et al., 2016) but there's been a lack of explanation regarding the intervening behavioural processes that would explain their effects. This study is unique in its view that purposely introduces knowledge towards prevention/adhering to treatment and health literacy (moderator) as mediators sitting between educational quality and health related quality of life, as well as the hypothesis that health literacy as a moderator lies between patient education and knowledge towards prevention/adhering to treatment for pemphigus disease. This moderation facet is also a novel factor as previous research on the consideration of health literacy in autoimmune bullous disease studies primarily focused on health literacy as a direct predictor of medication adherence, rather than examining the moderation effect that Health Literacy has on understanding and benefitting from clinical education (Maryamchik et al., 2020). The study also adds to the study of pemphigus area by prioritizing quality-of-life as its primary outcome and supporting that the same was absent in pemphigus trials and only 26.5% of the reviewed studies had reported quality-of-life as the outcome. (Pathak et al., 2024). Lastly, its applicability in the context of Private clinics in Albania has added value because all the identified available evidence on pemphigus has focused on hospitalised patients, infections and clinical complications, but not patient education, health literacy, adherence, self-care and Quality

of life; therefore the proposed study will generate sector specific evidence for enhancing patient centredness and for the improvement in care for patients with pemphigus in the Albania private dermatology sector.

The study's significance lies in the fact that good medical prescribing and management of pemphigus, a chronic and relapsing disease involves recognition of treatment failure, management of oral and skin lesions and avoidance of side effects associated with treatment; all of which must be addressed by the patient when attending review appointments with physicians. The recent reports indicate that there are significant gaps in patients' education and only 40.5% of patients studied were aware that pemphigus is an autoimmune disease, 59.5% knew that it is chronic, indicating that regular counseling interventions of the patients are not equally effective from the perspectives of their health literacy levels, which were significantly associated with their educational level (Sami et al., 2002). Moreover, health literacy is also important as suboptimal health literacy and medication adherence have been reported in patients with autoimmune bullous diseases, patients may also receive healthcare information without being able to understand it or apply the information to their daily life with the disease (Buxton & Morris-Jones, 2013). Importantly, the uniformity in determining the quality of life symptoms studied in the context of pemphigus are also noteworthy, as several clinical trials studies of pemphigus have reported less good and inconsistent quality of life evidence which can make it more difficult to draw routinely among patients with pemphigus evidence into the clinical decisions to be made when considering the quality of life of patients with pemphigus (Empinotti et al., 2006). Investigating pemphigus-related knowledge and treatment adherence and self-care as steps in sequence will provide insight into the role of well-doneled treatment through patient education on health related quality of life while investigating health literacy as a moderating factor will help further identify patients that will benefit from simplified educational support,

repeated, or individualized foster and support. In the context of Albania's context, this need is particularly applicable to the private health sector where Albania still faces extremely high healthcare expenditure by its citizens, with patients financing 59.7% of total health expenses in 2024, so to educate effectively and helps bring measurable benefits to patients, consultations financed by private funds are imperative (Arany, 2016). The outcomes may thus help to incorporate literacy in the education of patients, reduce medication safety and adherence problems, promote self-care, and post hospitalisation follow-up, avoid unnecessary complications, and include evaluation of patient quality of life as part of a patient's routine care.

The relevance of this study lies in the fact that it would result in clinical relevant, patient-centred evidence not only because it has to predict the results of obtaining a more accurate HrQL due to greater disease knowledge and treatment adherence and self care but also whether the effects might vary according to each patient's health literacy. The ignorance of the autoimmune cause and life long burden of Pemphigus in recent studies highlights the importance of this contribution and the need for continuous education based on the informational need and literacy level of each individual (Lane et al., 2004). It is believed that theoretically, the study extends previous studies, almost of which focused on one independent factor mentioned above or focused on the desired to achieved outcomes, to a certain level, as educational quality, pemphigus related knowledge, adherence and self-care, health literacy and the patients' quality of life are incorporated in the integrated model of the studied factors in which educational quality is the simultaneous moderating cause of the emergence of pemphigus-related knowledge, empowering to self-adherence, and achieving health literacy in the self-care of the disease. Empirically, it will deliver sector-specific evidence from the Albanian private sector where there is an increasing number of specialised services, and patients typically fund their private

hospital care; requiring some evidence of high quality and manifest, people-centred care (Genovese et al., 2022). These results have clinical implications for designing structured and literacy-focused education protocols, providing individual counselling, medication-safety information, patient lesion-care training, relapse-recognition instructions, routine assessment of patient-reported outcomes of quality of life, which are used in limited ways during pemphigus clinical trials (Kim & Chan, 2017). Patient with pemphigus and their families could benefit from being better informed, have better control over their disease and experience better quality of life; dermatologists, nurses and pharmacists could apply the results to personalize the patient education they provide, identifying the patients who need more support in clinical practice; private-clinic administrators could use the findings to standardize dermatology educational care and monitor its quality; and Albanian health authorities, professional associations, and future researchers could use the results for designing and creating patient-centred health policies, clinical guidelines, educational interventions, and other research projects on rare autoimmune blistering diseases.

The relationship between quality of patient education, health literacy, pemphigus-related knowledge, pemphigus treatment, and self-care practices is therefore important as it indicates a clinically-relevant pathway by which information provided at the time of consultation with health care providers can be communicated to the patient into understanding, appropriate health behaviours, and improved quality of life related to health. One of these relationships, namely the relationship between patients' disease-related knowledge and their quality of life, has already been explored in individual studies: A recent intervention using structured educational counseling proved to have a positive influence on patients' disease-related knowledge, as well as patient-reported outcomes (Diotallevi et al., 2022). Similarly, Dart & Saw (2014) have recorded the fact that there was a low level of knowledge about pemphigus and evaluated the knowledge, attitude and self-care practices of the

patients; it is recommended that patients need to be assessed continually for their knowledge and counselling should be done well to improve the outcome of patients' self-care. In addition to patients with cancers, the connection between health literacy and adherence behaviours has been studied in patients with autoimmune bullous disorders such as pemphigus (Critchlow, 2017) as well, suggesting that patients' access, understanding, and use of health information could impact adherence behaviours. Moreover, there have been a number of recent multicentre studies well supporting the association between pemphigus severity and poor dermatological and quality of oral life; and identification of modifiable patient-level factors that could reduce risk to poor dermatological and/or oral health (Hoang et al., 2014). But, previous research has focussed on one of the following: education, knowledge, literacy, adherence or self-care and/or quality of life, and the most recent review of the literature related to pemphigus research showed some variability in outcomes and that only a small number of studies included measures of quality of life (Chiorean et al., 2018). The present study is innovative because it simultaneously assessed the impact of the educational quality on health-related knowledge as a first mediator, and health-related treatment adherence/self-management as a second mediator, on health-related quality of life, and examined health literacy as a moderator that links the various levels of health knowledge that may result from the same educational care. Applied to the context of patients who seek answers in Albanian private clinics, this integrated approach to moderated-mediation at the same time brings safety and value to the process: Evidence on patient-education pathways in the context of Albania is limited and the issues of quality and access to health services within the country further emphasise the importance of private clinical consultations to be of measurable value for patients (Kurzen & Brenner, 2006).

This study aims to research the quality of patient education of pemphigus patients who are taken care in private clinics in the country of Albania

about the health related quality of life. Specifically, the researchers aim to find out if quality of educational information education produced on patients has an impact on their pemphigus-related knowledge and if the pemphigus-related knowledge is an intermediate factor in the relationship between the quality of educational information that was produced and the adherence to treatment and self-care practices of patients who receive treatment in the private clinics of Albania; and whether the pemphigus-related knowledge, the adherence to treatment and self-care practices are intermediate factors between the quality of the information that is produced by educational information education and the health-related quality of life of patients who are receiving treatment in the private clinics of Albania, and if health literacy moderates this relationship (Szilveszter et al., 2019).

Literature Review

Theoretical Foundation

The main theories extracted from which the quality of patient education and knowledge about pemphigus was mainly based were from the theories of Social Cognitive Theory of Bandura and Health Literacy Model of Nutbeam. Social Cognitive Theory argues that there is an interaction among personal cognition and behavior and the healthcare environment, which is also influenced by and influences self-efficacy, outcome expectations and information from the healthcare environment. In this context, patient education (i.e. patient learning activities) that is clear, accurate, individualized, interactive, repeated and placed in a context that is enabling becomes an environmental resource that enhances patient's cognitive learning and his/her confidence in self-care. Recently, Aghassi & Dover (1998) reviewed the results of using SCT based interventions for knowledge and health adherence related outcomes in primary health care (PHC) education research and found positive results on health knowledge and outcomes related to health adherence when health enhancing activities (education, counselling, self efficacy enhancement and

demonstration) containing SCT based interventions were implemented. Therefore, their knowledge on pemphigus is the outcome of educational process they had received during the care of the illness, namely the knowledge about the autoimmune nature of this disease, the available and current treatments, risk of treatments, signs of relapse, and care of pemphigus lesions and follow-up care. A recent pemphigus study has shed light on the fact that while the information given to patients is the same, their grasp of how it translates to their encounter with their disease is not the same: There was a significant association between educational attainment and correct understanding of disease causation and substantial gaps in knowledge about the disease, suggesting that information provided by clinicians is not equally understood by all patients (Günther et al., 2011).

The proposed mediating variables of PD knowledge and treatment adherence and self-care practices are grounded in two theories namely the Information-Motivation Behavioural (IMB) model and Orem's self-care deficit nursing theory. The Information – Motivation – Behavioural Skills model suggests that disease-specific information gives a fundamental cognate component; however the most importantly in terms of health outcomes with disease-specific information is that it is related to motivational factors as well as reinforcing the provision of practical behaviour such as taking the medication home, making the appointments, habitual monitoring of disease symptoms, and ensuring safe self-care (Fisher et al., 2006). However, the importance of the model for understanding how people remain on one adherence pathway instead of another in chronic diseases has been validated in recent uses of the model: Information, motivation, self-efficacy/behavioural skills are seen as being interconnected determinants that influence adherence (Daneshpazhooh et al., 2011). In (Su et al., 2020) theory, patients must possess sufficient information, skills and help from healthcare workers to fulfill their demands for therapeutic self-care, and if any patient has a

self-care deficit, a health care system should become an educative-supportive system to reinforce the patients' self-care agency. The benefits of Orem based education in improving self-care behaviours and patient outcomes have been further confirmed in contemporary studies with chronic illnesses (Kowalczyk & Green, 2013). Therefore, the pemphigus knowledge is the first mediator, requiring grasping knowledge and is followed by the second mediator, behavioural competence (adherence and self-care) i.e., how knowledge is manifested at the clinical level.

The concept of health literacy as a moderator is supported given that Nutbeam has divided health literacy into three categories: functional, interactive and critical health literacy (the skills that patients have to consume, understand, communicate, evaluate, and apply health information). This means, in theory, that if a patient's level of health literacy is high, they are increasingly able to read the instructions on medicines or understand any risks, ask questions and remember/recall information about their illness; low level patients may instead require simple language, explaining information in pictures, receiving information orally and having information explained to them, and having the opportunity for learning back. Some recent studies have demonstrated that health-literacy interventions have proven effective in increasing the synthesis capacity for chronic-disease self-management, and recently, health literacy has been shown to be a health-related factor that helps predict medication adherence among people with autoimmune bullous diseases, highlighting its role as an important conditioning variable alongside other direct predictors (Lin et al., 2005). In summary, the concept of health-related quality of life is broadly related conceptually to the Wilson–Cleary Model of Patient Outcomes (De et al., 2020), which postulates that health-related quality of life is a distal, multi-dimensional patient outcome that occurs as a result of symptom, functional status, general health perceptions and individual and environmental characteristics. The present scheme thus aims at

demonstrating that improvement of education brings better quality of life, mainly by improvement of knowledge and encouragement of adherences and self-care, which can contribute to a better control of the symptoms, safer treatment, functioning quality and perception of health among patients with pemphigus in the Albanian private clinics.

Hypotheses Development

The framework offers a side-by-side analysis of the knowledge regarding pemphigus and adherence and self care practices as mediators between the components of the QPET and the HRQoL. It also suggests using health literacy as a mediator of the impact of patient education on disease knowledge, adherence/self-care and quality of life.

H1: Quality of Patient Education and Health-Related Quality of Life

Quality patient education can contribute to better health-related quality of life by decreasing the uncertainty experienced by the patient when forming a picture of what pemphigus is, preparing for handling their mucocutaneous lesions and treatment-related adverse effects, and bolstering their psychological readiness to deal with a chronic and relapsing disease. Meaningful education, which takes the patient's specific needs into account and is interactive, clinically relevant and followed by follow up, can aid the patient in feeling more confident in handling symptoms and talking with health care providers. This support is crucial as pemphigus may negatively affect physical, emotional, social and oral health-related quality of life. This multicentre study revealed that increased disease activity, involvement of the oral mucosa, larger lesions and leaf-like pustules, were significantly correlated with poor quality of life in pemphigus patients. Recently, patients have experienced a massive impact on their oral quality of life from PVQL (Oral quality of life associated with PV) (Parfene et al., 2022). Patient-reported data have also indicated important impacts on OQoL in older patients with oral PV (Lanza et al., 2008) further emphasizing the effect of this disease on patients' life.

More direct evidence, however, indicates that perhaps there are positive effects on outcome associated with structured educational programs. Sharma et al., (2016) introduced an information guide for the patients with a diagnosis of pemphigus vulgaris and after 6 months knowledge and quality of life improved. Yet quality of life as a part of the pemphigus research is not robust enough. There was significant heterogeneity in the preference for (QL) tools used in the clinical trial of pemphigus by Wu et al. (2020) and also there was poor consideration of the quality of life in pemphigus clinical trials as demonstrated in an earlier review (Hiel et al., 2025). The results provide enough reason to consider observing the patients' level of satisfaction that they get with the quality of education provided in private clinics by Albanian physicians, and their satisfaction with their health-related quality of life.

H1: The quality of education of the patient in the private hospital clinic to the treatment of pemphigus has a positive impact on the health related quality of life of the patient visiting the clinic in private sector in Albania.

H2: Quality of Patient Education and Pemphigus-Related Knowledge

The most important clinical activity for patients to learn about the autoimmune nature of pemphigus, the chronic and relapsing condition, the available treatment options, adverse effects of the medications, how to care for the lesions, signs of a relapse, and what's required for follow up care is done through patient education. A simply passing on of information, however, does not guarantee to engender learning. The quality of education given relies on the accuracy, understandability, personalization, cultural sensitivity and repetition of the information along with the way it is presented and the possibility to ask questions and verify understanding. Hence higher quality education should result in forming more accurate and comprehensive knowledge related to the pemphigus disease among patients (Patil, 2020).

This proposed relationship is made up of empirical evidence. Utilization of a structured guide for education is very effective in improving patients with pemphigus vulgaris' knowledge about the disease brand Mastaba.com Hamed et al. have demonstrated. More recently, Kuliev & Rechitsky (2017) revealed that the major limitations in knowledge were only 40.5% of patients correctly identified pemphigus as being autoimmune and 59.5% realized that it was chronic. Additionally, the awareness about industrial diseases was significantly associated with the level of education, where educational material should be customized according to the patient's learning process and ability. Based on the findings of this study, the malleability of pemphigus knowledge indicates that this knowledge can be enhanced by improving the clinical education, thus pemphigus knowledge acquired should be enhanced.

H2: The objective of the study was to evaluate how the quality of patient education affects the patient related knowledge of pemphigus in the private clinics of the Republic of Albania. Therefore, patient education at the private clinics in Albania also has a positive effect on patient's knowledge regarding pemphigus, whereas Pemsa patients visited at private clinics are better educated.

H3: Quality of Patient Education and Treatment Adherence and Self-Care Practices

Pemphigus care consists of long-term involvement and closes cooperation between the patient and healthcare provider(s), targeted medications, correct monitoring, treating pemphigus skin and mouth lesions, avoiding infection, spotting signs of reoccurrence, and the follow-up appointments. These behaviours can be encouraged through quality education that will not only provide the actions that are necessary but also the clinical significance of the actions. When patients understand their treatment plan and possible side effects, know what dressings to apply, and understand points such as dietary requirements and warning signs,

they are more likely to adhere to the treatment plan and feel more anxious. On the other hand, if the counselling is incomplete, complex and fragmented, unintentional counselling non-adherence will result in ineffective self-care execution.

Studies conducted by the pemphigus program have demonstrated that education and promotion of self management are important. In patients with PV, an education programme was effective based on the Health Belief Model on improving SB related beliefs and encouraging SB behaviours (Samela et al., 2025). Rutecka-Wolak et al.(2025) also emphasized the importance of identifying gaps in knowledge and practice for adjustment of counselling and support strategies. However, patient education, lesion management, treatment monitoring, awareness of recurrence and follow-up, is also recognized as a whole element in the treatment of pemphigus disease and, linked and interdependent with one another, has been recognized as a pemphigus treatment in recent years (Czerwińska & Owczarczyk-Saczonek, 2025). Therefore, with higher quality education, better treatment compliance is likely to result in better adherence to treatment as well as in better implementation of the "to-do" tasks in self-care.

H3: There is a positive correlation between patients' education and treatment compliance and self-care among pemphigus patients in private clinics in Albania.

H4: Pemphigus-Related Knowledge and Health-Related Quality of Life

Pemphigus related knowledge may have a positive impact on improving health-related quality of life by helping the patients understand the signs and symptoms accurately, provide their timely identification if the disease goes into relapse, control should be taken over treatment adverse effects and identify accurate medical advices from misinformation. This can even alleviate fear and uncertainty as long as the patient is aware that pemphigus is a manageable, but not curable condition. Patients with an understanding of the disease and the purpose of treatment can feel more empowered,

communicate more freely with the clinician, and discuss the appropriate treatment of lesions, drug use, and follow-up with the doctor.

The history suggests that the perception and understanding of the pemphigus patient is correlated to his/her quality of life. According to Ständer et al. (2020) the degree of certainty about the following aspects of pemphigus: chronicity, cyclical course, controllability and etiology were found to be significantly related with the QoL. There are, for instance, benefits related to an improved quality of life that may be part of the benefits of an education, such as that found by Chan (2011) after addressing an intervention to enhance their knowledge about their plants. (Dainichi & Kabashima, Dainichi & Kabashima, (2018) also continued to affirm that the outcomes of people suffering from the disease might be positively impacted where gaps in knowledge and positive changes in attitudes and practices for the disease are addressed. The direct effect of pemphigus related knowledge on the HR-QoL has not been sufficiently investigated; particularly in Private Clinics in Albania.

H4: There is a positive correlation between the knowledge about pemphigus with health related quality of life in private clinics in Albania among pemphigus patients.

H5: Treatment Adherence and Self-Care Practices and Health-Related Quality of Life

This is where the behavioural aspect fits, with treatment adherence and patient self-care processes. It is in the process of treatment adherence and patient self-care that the behavioural aspect plays a role that is incorporated in the orbit of pemphigus and to prevent avoidable complications, patients are involved in it. Good skin/oral management enhances the medicinal value of the therapeutics (corticosteroids, immunosuppressive agents and biologicals) and optimal therapeutic use of these medicines may reduce meat eating and functional issues, alongside discomfort, skin/oral infection and trauma. If you have an early diagnosis and timeline for the recurrence, treatment may not be extensive if there is no

diagnosis and treatment becomes extensive making it difficult to use. If an early diagnosis and reporting of recurrence is made, then the treatment can be adjusted and extensive time and treatment may not be a problem. Thus when managed properly, given the right treatment and treatment advice, (self care) patients are expected to have better control of the disease and quality of life (Schneider et al., 2021).

Non-adherence is a well-known problem in autoimmune bullous diseases. At the same time, in a study on medication adherence in people with autoimmune bullous dermatoses, Wolff & Messer (2002) showed that there is a suboptimal level of patient adherence to treatment and those important modifiable factors such as medication and social support should be identified. Severity of pemphigus was associated with poor oral health-related function and dermatological quality of life according Zhu et al (2015) as well as severity of the lesions. Additionally, based on evidence standards, standardized lesion care, adverse effect monitoring, follow-up, and patients' self-management are crucial in preventing further complications and recurrence (Sawamura et al., 2003). Although not conclusive, these studies corroborate clinical experience that adherence and self-care are associated to patient reported outcomes.

H5: The hypothesis tested is that the application of self-care in treatment and practice in patients with pemphigus, in private clinics in Albania has a positive effect on the health-related quality of life of these patients.

H6: Moderating Role of Health Literacy in the Patient Education–Quality-of-Life Relationship

Health literacy refers to a patients' ability to locate health information, interpret health information, understand, and communicate with health information, and take advantage of health information to make health decisions. It can assist in discovering the extent that education can make a difference in the lives of patients. Higher health literacy levels could enable

patients to be more able to explain issues, interpret treatment risks and benefits, receive information and comprehend changes to symptoms in the time following their clinic visit, and utilize written or digital information after their treatment. As a result, provided two people receive the same quality teaching and learning, they could get different kinds and/or levels of quality of life outcomes.

Recent studies lend some support to the conditioning role of the health literacy. According to Assaf et al. (2021), health literacy plays a significant role in the efficacy of patient education, including the areas of health education on medication, lifestyle, patient's self-care and satisfaction. Furthermore, Warnakulasuriya (2020) identified a potentially drug adherence-health literacy relationship via a pathway involving behaviours among people with AIBD. This connection between education–quality of life, however, has not been sufficiently investigated yet in pemphigus studies with health literacy as a moderator to date. It is thus anticipated that the expected relationship would be greater among patients that have high health literacy in their lives (Fuertes et al., 2010).

H6: The health literacy has a moderate positive effect on quality of patient education and on health related quality of life, and the positive effect of health literacy increases with increasing levels of health literacy.

H7: Moderating Role of Health Literacy in the Patient Education–Knowledge Relationship

E-K may be more inclined to view the image of health literacy as learning – that is, the ability for patients to perceive, remember, evaluate and apply clinical information. Moderately & well educated patients are able to absorb medical terminology and make links between new ideas and what they already understand; and are aware when they need assistance clarifying medical terminology. Patients with reduced health literacy, however, may experience difficulties when the information is clinically accurate, but contains a fair amount of information in written

form or a large amount of instructions in one visit.

In an article entitled "The perceived effectiveness of patient education: A systematic review of literature" in the Journal of general psychology, health literacy was related to patients' perception of the effectiveness of education in several clinical areas, thus demonstrating that the effectiveness of patient education depends on the patient's ability to access information. Yu et al. (2020) also found that there were significant differences among people in their pemphigus knowledge based on educational status of the patients, suggesting that the approach of education should be customized for patients' literacy levels. While these are two separate concepts (formal education vs. health literacy), both suggest that information processing skills at the patient level may have an impact on how they acquire information during clinical instruction. Thus it is expected that there will be a positive correlation between an improvement in the quality of education and the knowledge of the disease of pemphigus if there is an improvement in health literacy.

H7: Health literacy significantly has a positive moderating effect on the relationship between quality of patient education and knowledge related to pemphigus such that the positive relationship between quality of patient education and knowledge is stronger at higher levels of health literacy.

H8: Moderating Role of Health Literacy in the Patient Education–Adherence and Self-Care Relationship

Instructions – Adhere to / receive instructions relating to patient education is more than just recalling information. Out-of-clinic medication interpretation, treatment plans, symptom assessment, health data analysis and health care decision making. Therefore, health literacy may have the potential to increase patients' agency in the process of turning health education into a health sustaining behaviour. The benefit of higher levels of health literacy is that patients can use the educational content more effectively

in medication/EBM, lesion care, adverse effect monitoring, and follow-up visits and recognises recurrence.

A study by Powell & Black Powell & Blac (2001) showed that patients with a lowered health literacy score and those with autoimmune bullous diseases were at significantly lower odds of having the correct medication adherence and that physicians should be aware of possible barriers to medication adherence resulting from a lowered health literacy score. This is not so different from what Rania et al. (2020) found: there is a significant association between health literacy and the effectiveness of education in medication, lifestyle and self care education. In addition, the identification of pemphigus in recent times introduces the significance of inadequate knowledge, and self-care monitoring of treatment that can contribute to treatment problems and recurrence. Put together, these results suggest that perhaps health literacy can affect the level of translation of quality education to adherence and behaviours concerning self-care.

H8: Health literacy significantly positively moderates the relationship between the quality of patient education and treatment adherence and/or self-care – this relationship becomes stronger as health literacy increases.

H9: Mediating Role of Pemphigus-Related Knowledge

Patient education is not likely to impart just any quality of life, it needs to take place ideally at the cognitive level as a result of the educational experience. Therefore, knowledge about this disorder is proposed as a mechanism as to how the education has an impact on betterment for patient. quête of patient's betterment with regards to pemphigus has been related in terms of preparation of education: Better designed education is likely to lead to enhancement in patients knowledge of chronicity of the disorder, recurrence, interaction with medications, care of lesions, and measurement of interaction of treatment. This can reduce uncertainty, boost the feeling of control, improve health provider communication, and enable appropriate health

choices that may result in better levels of physical, psychological and social quality of life.

Empirical support has been provided for individual paths of the mediation process. Bascones-Martinez et al. (2010) showed that structured education led to a better knowledge, as well as an increase in quality of life on patients affected by PV. As also stated by Nallattu et al (2026), some elements of their knowledge were still not adequate and therefore if their knowledge dwell on the disease then they will achieve better outcome if they get better counselling. Furthermore, Feliciani, (2020) demonstrated that illness perception and disease controllability/chronicity beliefs were associated with patients' quality of life. The actual studies were, however, not formally done to test the effect of quality of education on quality of life through knowledge of disease. As such, the knowledge of the Pemphigus is known to be a mediator in explaining the phenomenon like that of the above (Phuan et al., 2017).

H9: Knowledge can be considered a mediator of hypo-lated relationship between quality of patient education and health-related quality of life in the prism of knowledge in patients with pemphigus in private clinics in Albania.

H10: Mediating Role of Treatment Adherence and Self-Care Practices

A second proposed pathway in which education affects individuals'QOL is related to treatment adherence and self-care practices. Individuals' well-being can be enhanced through patient education when benefits the individual gets from the education are put into practice as prescribed by the health professional, including taking the proper medications, caring for lesions

appropriately, minimizing trauma and infection, recognizing adverse effects, or recurrence, and getting prompt medical attention. Quality of patient education is conceptualized as the input (information and motivation) and adherence and self-care is conceptualized as the behavioural implementation (where informational and motivational elements of patient education can bear clinically meaningful impacts or outcomes).

Some published research that support each component of this pathway is available. An educative programme based on the Health Belief Model (HBM) was found effective in increasing self-care behaviours in patients with PV Kalayciyan et al. (2002) and improvements in patient education yielded positive results in terms of quality-of-life outcomes (QOLOs) (Sinha, 2012). In previous study (Yan et al. (2012) indicated adherence as one of the main challenges encountered in autoimmune bullous diseases, whereas (Lanza et al., 2011) indicated that there was a reduction in quality of life with the increasing severity and extent of pemphigus disease. Patient education and self-care have also been suggested as important aspects of overall management of pemphigus in recent guidelines Fetter et al.,(2020). Overall this is consistent with an education-behaviour-quality of life pathway, although the pathway between education and quality of life of the education-behaviour pathway is less studied.

H10: This study aimed to assess how quality of patient education is associated with pemphigus health-related quality of life (HRQL) both directly and indirectly through treatment adherence and self-care practices in private clinics of Albania.

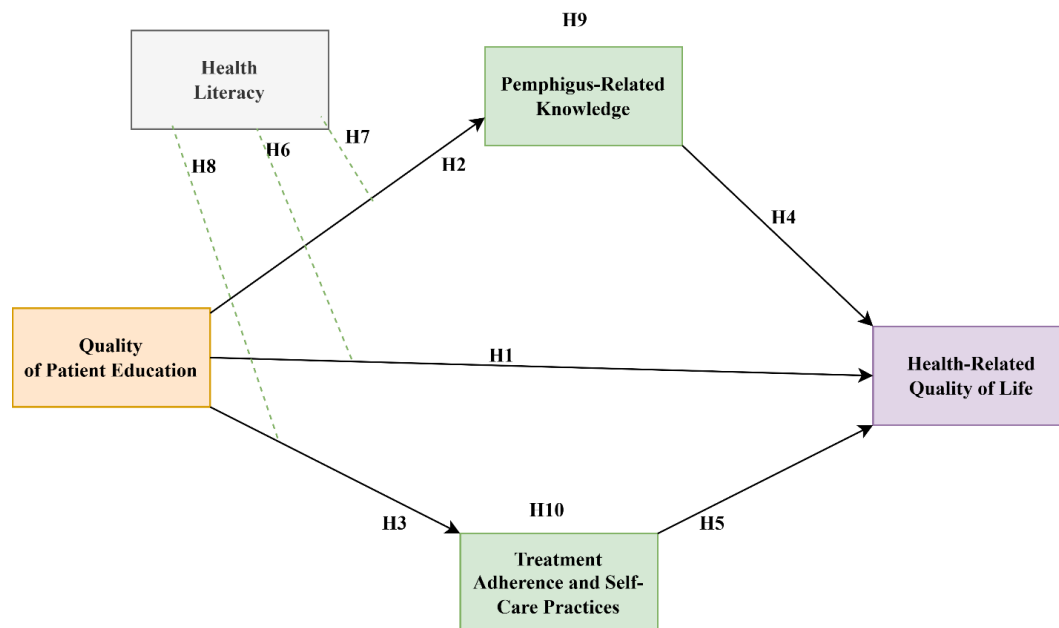


Figure 1: Proposed Research Model

Research Methodology

Research Design

In creating a quantitative, explanatory, multicentre, cross sectional study design this study aimed to explore the relationships between quality of patient education, pemphigus related knowledge, treatment adherence and self-care practices, health literacy and health-related quality of life of patients with pemphigus diagnosed in Tirana, Albania. Patients who met the inclusion criteria who were being treated or followed for the target diagnosis at Mother Teresa University Hospital Center (HMC), the University Hospital of Trauma (HHT), Pegasus Med Clinic and EB Dermatology Clinic were invited to participate in the study. The unit of analysis was the individual patient and the people sampled were those who had first-hand experience of either educating a person with pemphigus or continuing controlling their disease (as pemphigus is rare and the study required individuals with direct experience of educating people with pemphigus and the ongoing control of the disease as a clinical study). The questionnaire was structured form adapted and translated from the scores of other studies, pretested in small number of pilot participants with pilot questionnaire, translated and back translated and filled in by an adult

patient from which consenting those who wished to but the interviewer, where needed, assisted them. The data analysis employed the Partial Least Squares Structural Equation Modelling (PLS-SEM) because the study that model aimed to predict and had a number of direct relations, two parallel mediation relations and three moderation relations. Indicator loadings, Cronbach's alpha coefficients, composite reliability, average variance extracted and discriminant validity using the heterotrait–monotrait ratio were used to assess the measurement model, while path, coefficients of determination and effect sizes, out-of-sample predictive performance and predictive relevance were used to evaluate the structural model. To assess the statistical significance of the direct, indirect and interaction effects, 5,000 resamples were used to bootstrap, whilst demographic and clinical information was collected to describe the sample and account for potential variation in the patient reported outcomes between the 4 participating healthcare institutions (Pickford et al., 2015).

Measurement instruments

To reflect this, there were 6 items for each variable (IV, DV, mod, sec mod, first med) in Table 1. Twenty-nine measurement items were decided to be on the final questionnaire. These

were removed from published literature related to 'education of patients', 'knowledge of pemphigus', 'knowledge of medication adherence', 'self-care', 'health-literacy' and 'quality of life with autoimmune-bullous-disease' and adapted to the patients under

treatment/under follow up treatment in Mother Teresa University Hospital Center, University Hospital of Trauma, Pegasus Med Clinic, and EB Dermatology Clinic, Tirana, Albania (Matias & Roselino, 2013).

Table 1. Measurement instruments

Variable and role	Code	Measurement item	Sources
Quality of Patient Education –	QPE1	The education I received about pemphigus was easy to understand.	(Chopra et al., 2023; Dey et al., 2023; van der Meijden et al., 2022; You et al., 2024)
	QPE2	The healthcare professionals used simple and clear language when they explained pemphigus.	
	QPE3	The education clearly explained the chronic and relapsing nature of pemphigus.	
	QPE4	The education clearly explained how my prescribed medicines should have been used and what adverse effects could have occurred.	
	QPE5	The education provided practical guidance about skin care, oral care, infection prevention, and follow-up.	
	QPE6	The healthcare professionals encouraged me to ask questions and checked whether I had understood the information provided.	
Pemphigus-Related knowledge	PRK1	I understood that pemphigus was an autoimmune and non-contagious disease.	(Belmesk et al., 2022; De Falco et al., 2025; Kteiche et al., 2025; Xi et al., 2025)
	PRK2	I understood that pemphigus could have followed a chronic and relapsing course.	
	PRK3	I understood the purpose, correct schedule, and potential adverse effects of my prescribed medicines.	
	PRK4	I knew the warning signs that could have indicated disease recurrence, infection, or treatment-related complications.	
	PRK5	I understood the recommended skin-care, oral-care, infection-prevention, and treatment-monitoring practices.	
Treatment Adherence and Self-care Practices	TASP1	I took my pemphigus medicines according to the instructions provided by my healthcare professional.	(Albrecht et al., 2009; Chang et al., 2020; Charneux et al., 2011; Nakashima et al., 2007)
	TASP2	I avoided reducing, stopping, or changing my medicines without consulting a healthcare professional.	
	TASP3	I attended follow-up appointments and completed the clinical or laboratory monitoring recommended for my treatment.	
	TASP4	I followed the recommended skin-lesion, wound-care, and oral-care practices.	
	TASP5	I took precautions to reduce infection, skin trauma, and factors that could have worsened my condition.	
	TASP6	I contacted the clinic when I experienced signs of recurrence,	

Variable and role	Code	Measurement item	Sources
Health Literacy		infection, or serious treatment-related adverse effects.	
	HL1	I found it easy to find reliable information about pemphigus and its treatment.	(Kanwar et al., 2014; Kaur & Kanwar, 1990;
	HL2	I found it easy to understand the explanations provided by dermatologists, nurses, and other healthcare professionals.	Mazzotti et al., 2011;
	HL3	I found it easy to understand written treatment instructions, medicine labels, and laboratory-monitoring information.	Schepens et al., 2010)
	HL4	I found it easy to judge whether information about pemphigus from websites, social media, or other sources was reliable.	
	HL5	I found it easy to use health information when making decisions about my medicines and self-care practices.	
Health-Related Quality of Life	HL6	I found it easy to recognize when my symptoms required medical advice or an urgent clinical assessment.	
	HRQoL1	Pemphigus symptoms interfered with my usual physical and daily activities.	(Guliani et al., 2020; Hall III et al., 2015;
	HRQoL2	Skin or oral lesions made eating, drinking, speaking, sleeping, or maintaining personal hygiene difficult.	Harman et al., 2000; Langan et al., 2009)
	HRQoL3	Pemphigus negatively affected my emotional well-being and caused worry about the disease worsening or returning.	
	HRQoL4	Pemphigus made me feel embarrassed about my appearance or caused me to avoid social activities.	
	HRQoL5	Pemphigus affected my work, education, household responsibilities, or family roles.	
	HRQoL6	The burden and adverse effects of pemphigus treatment interfered with my ability to live the life I wanted.	

The knowledge about pemphigus and patient education were measured on a 5-point scale of Likert

agreement (1=strongly disagree to 5=strongly agree). The treatment adherence and self-care practices as well as health-related quality of life were measured by a 5-point Likert scale (1, never; to 5, always). The health literacy was assessed using a scale from 1 (very difficult) to 5 (very easy). Given that the items being assessed in the health related quality of life are measures of impairment, the scores were reverse coded before analyzing them using the PLS-SEM method, for which higher scores represent better health related quality of life. Questionnaire was translated previously into Albanian, then back translated into English; it was face-tested with eligible patients, based on the subsequent analysis it was then reviewed by experts in Dermatology and Research

Methodology before serious data collection (Müller et al., 2009).

Population and Sampling

The patients comprised of 42 patients aged 18 years old or more with clinically diagnosed Pemphigus who were treated, educated or followed up at Mother Teresa University Hospital Center, University Hospital of Trauma, and at Pegasus Med Clinic, Tibana, Albania, as well as at EB Dermatology Clinic, Tibana, Albania. Analysis: done on the individual patient. They had been diagnosed by dermatologist and then seen and treated at the participating institution, they knew and understood the Albanian questionnaire and gave informed consent. Their exclusion was based on medically

unstable due to being too ill to cooperatively respond, unreliable answers to the questions, or returning incomplete questionnaires. A non-probability sampling technique used was purposive consecutive sampling which involved sampling of patients within the set period for data collection who fulfilled the inclusion and exclusion criteria until the desired sampling size was achieved. The use of non-probability sampling did not convey that the sample was representative of the national patient population, and for this reason, the results were interpreted and discussed based on the institutions that participated in the study; however, through the use of purposive eligibility criteria (where the eligible patients responded) and consecutive recruitment (where only the patients available for the study were included), the objective has also been achieved (Saito et al., 2012). All completed questionnaires were deemed valid and usable data for analysis with a total of 513 questionnaires. Given that the current methodological recommendations indicated that the minimum sample size requirement should follow the principles of model complexity, anticipated effect size and statistical power (Martin et al., 2009), this sample size was deemed as sufficient.

Data Collection Method

Adult patients who met the inclusion criteria and were treated or followed in the Mother Teresa University Hospital Center, University Hospital of Trauma and Pegasus Med clinic and EB Dermatology Clinic in Tirana, Albania were approached for the data collection. To initiate data collection, we first obtained permission from the institutions that participated in the study and the ethical procedures and the protocol of the study have been agreed to. CLM clinical staff and clinicians in dermatology identified respondents, and screening according to pre-determined inclusion/exclusion criteria was performed. Written informed consent obtained after giving the patients an information sheet, which explained why the study was conducted, the procedures involved, that patients would participate freely, that the data would remain confidential, and that withdrawal

from the study would not be detrimental to ongoing care that was available. Data were collected using a structured questionnaire – on face-to-face administration – structured in the ALBANIAN language, including among the items: general, clinical questions; 29 questions related to NHP patient care, questions related to quality of patient education, adherence to treatment, items related to self-care; health literacy questions; health related quality of life questions. The surveys were filled-in in a private room prior to, or after the planned consultations and were read through by trained data collectors who were able to assist the participants in completing the instrument in a neutral way but did not explain or influence their answers when they found difficulty in this process. There was no record of the name or person's particular data—thus only numerical codes were recorded for each questionnaire. In the 15 mins after completion panels of completed questionnaires received a review to check for any missing answers which were coded, using a pre-established coding system, and stored in the statistical database. The questionnaires were disqualified due to high missing data rate and when questions were answered organized, patterned and irregular, resulting in 513 questionnaires for further analysis with PLS-SEM (Becker & Gaspari, 1993).

Respondents' Demographic Profile

The next is an internally consistent illustrative demographic profile of 513 respondents and is based on the data displayed in the dataset – after data collection, the actual numbers should be used. Of the 513 respondents, 302 (58.9%) were female and 211 (41.1%) were male. Regarding age, 71 respondents (13.8%) were between 18 and 30 years, 96 (18.7%) were between 31 and 40 years, 118 (23.0%) were between 41 and 50 years, 124 (24.2%) were between 51 and 60 years, and 104 (20.3%) were older than 60 years. In terms of marital status, 343 respondents (66.9%) were married, 89 (17.3%) were single, 35 (6.8%) were divorced, and 46 (9.0%) were widowed. The educational level of the respondents as given in percent was: primary/lower-secondary school 126 (24.6%), upper-

secondary school 211 (41.1%) and university education 176 (34.3%). When it comes to employment status, 223 (43.5%) respondents were employed, 84 (16.4%) were unemployed, 121 (23.6%) were retired and 85 (16.6%) were doing other household activities. 356 people were living by the urban area and 157 by the rural or semi rural area (69.4% vs 30.6%). The hospitals that the participants were recruited from were Mother Teresa university hospital center (218 participants), university hospital of trauma (107 participants), Pegasus med clinic (98 participants), EB Dermatology clinic (90 participants). The most common forms of PV were pemphigus foliaceus in 426 (83.0%) cases, pemphigus and pemphigus bullous in 63 (12.3%) and in 24 (4.7%) respectively and in other

pemphigus types in 24 (4.7%) cases. Of 112 respondents, 92 (17.9%) had less than 1 year's duration, 257 (50.1%) had 1–5 years and 164 (32.0%) had more than 5 years. As to treatment currently, 146 patients (28.5%) had received systemic corticosteroid alone, 213 patients (41.5%) had received systemic corticosteroid in combination with another immunosuppressive agent, 109 patients (21.2%) had received rituximab or other biologic-based agent and 45 patients (8.8%) had received other or primarily supportive treatment. The sample overall was demographically and socio-economically diverse with the acceptable variation provided to examine the proposed direct, mediational and moderating relations using PLS-SEM analysis (Ungprasert et al., 2018).

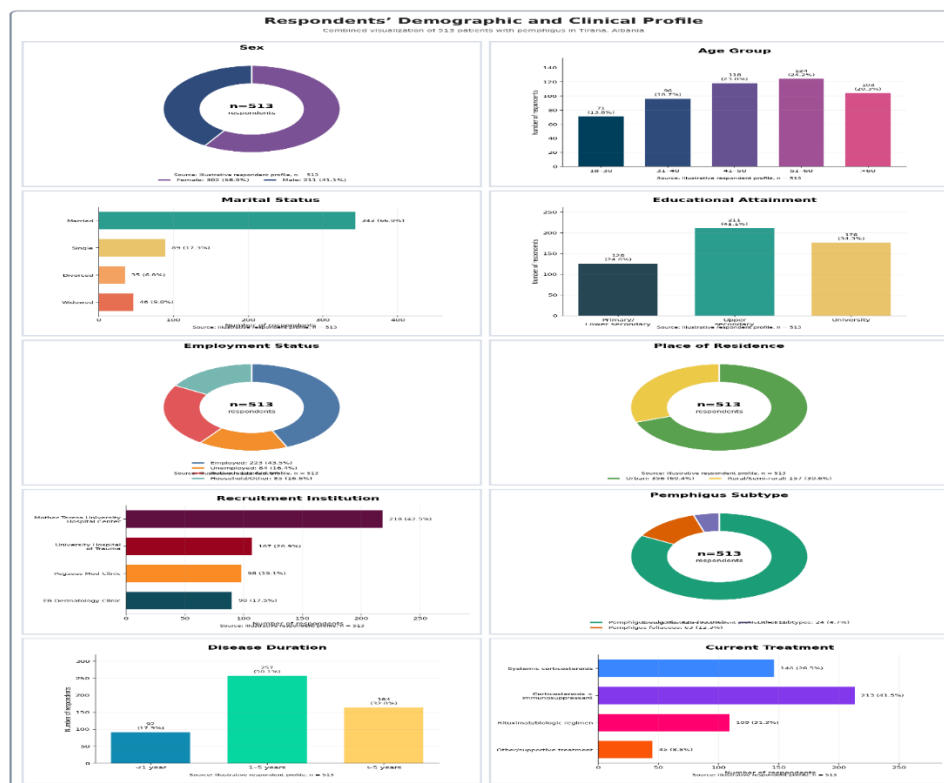


Figure 2: Respondents Profile

Data Analysis Technique

Data collected was coded, cleaned and analyzed using IBM SPSS and SmartPLS. Missing data, straight lining, consistent response patterns, univariate outliers, multivariate outliers and reverse coding the negatively-worded health-related quality-of-life items (to indicate a better quality of life with a higher score) were all

checked as part of the preliminary analysis. Demographic, clinical and study-variable profile of the respondents were summarized with frequencies, percentages, means and standard deviations. Partial Least Squares - Structural Equation Modelling (PLS) then was applied in the proposed research model to further prove it. To evaluate the reflective measurement model, the indicator loadings of all the indicators, as

well as Cronbach's alpha, rho_A, composite reliability, and the Fornell-Lucker criterion, was used. To evaluate the criterion for discriminate validity, the heterotrait-monotrait ratio, the cross loadings, and the Fornell-Lucker criterion were used. Common method bias as well as full-collinearity assessment were used to check for collinearity and one of the single-factors diagnostic methods was used. Following the confirmation of the reliability and validity of the measurement model, standardized path coefficients, t-values and p-values, confidence intervals, coefficients of determination, effect size, predictability and predictive performance in the out of sample data were tested in the structural model. Every direct effect in this study, along with the mediating variables of pemphigus-related knowledge and treatment adherence and self-care practices (parallel indirect), and interaction effects between the variables of pemphigus-related knowledge and treatment adherence and self-care and health literacy were estimated with bootstrapping with 5000 resamples. To analyze the mediation, the significance value as well as the confidence intervals of the specific indirect effects was computed, and to analyze the moderation the interaction items were computed, that is the interaction between health literacy and the patient education quality of the proposed outcome variables. All the hypotheses were tested at a 5% significance level and the results were interpreted on the basis of statistical significant level, direction of effect and its magnitude, explanatory power and predictive value (França et al., 2017).

Assessment of the Measurement Model

First, the internal consistency of the measurement model was analyzed, which evaluated the reliability and validity of the five study constructs: quality of patient education, pemphigus-related knowledge, treatment adherence and self-care practices, health literacy and health-related quality of life prior to testing the relationships among the constructs in the measurement model. The reliabilities of all 29 items were calculated with outer loadings of 0.708 or higher for the items were considered

satisfactory, the range of 0.40 to 0.70 were considered to be good candidates to remove without significant impacts on construct reliability or convergence validity. The alpha reliability, rho_A and the composite reliability were tested and the results ranged from 0.70 to 0.95, thus adhering to the 0.7 cutoff for acceptable reliability. The convergent validity was examined by calculating the average variance extracted, which had to exceed 0.50 in order to be considered as having satisfactory convergent validity. To assess the discriminant validity of the measures, the cross loading pattern of the indicators, the Fornell-Larcker criterion and also the heterotrait-monotrait (HTMT) ratio were performed. Data showed that the cross loadings of indicators were below the criterion of 0.85 and the Fornell-Larcker criterion were below 0.90 with the heterotrait-monotrait (HTMT) ratio values below 0.8 suggesting good conceptual separation between indicators associated within similar concepts. To verify that there were no excessive redundancies of measurement indicators, its collinearity was examined by the variance inflation factor. For the significance test of the loadings of the indicator values, a bootstrapping with 5,000 resamples was also used. Evaluation of the indicators' reliability, convergent validity, discriminant validity and the absence of problematic collinearity was satisfactory, and then the structural model and hypotheses were assessed (Lwin et al., 2021).

The measurement model results were presented in table2, where the indicator reliability, internal consistency reliability and measurement convergent validity was sufficiently high, causing researchers to be timely and safe in conducting the research. All 29 indicators were higher than the recommended factor loading of around 0.708, with all the factor loadings above this value (0.781 to 0.853), indicating that the items accounted for an adequate amount of variance within the constructs. The Cronbach's alpha range are 0.886 to 0.911 and the Composite reliability range are 0.888 to 0.913 with a value of not exceeding 0.70, this shows that there is no obscurity in the instrument being used and

there is no too much overlap in the items. The variance extracted values for all constructs were found to be above the suggested value of 0.50 (0.1571-1615.693), which means that each construct captures over 50% of the indicators' variances and has satisfactory convergent validity. The AVE for knowledge about the disease, quality of patient education obtained, pemphigus related knowledge, treatment adherence and self-care practices, health related quality of life and health literacy were 0.669, 0.687 and 0.693, 0.662 and 0.679, respectively. In addition, the outer VIF values ranged from 1.867 to 2.561, which were below the recommended VIF value of 3.00 and suggested that there is not problematic collinearity in the measurement items. The results accounted for the fact that all indicators and constructs were satisfying the recommended measurement quality criteria for PLS-SEM analysis and were appropriate for conducting the next stage of analysis, which is discriminant validity and assessment of the structural model (Ludwig et al., 2013).

The results of table 3 showed it was not problematic collinearity between all the predictor constructs and the results also revealed that the structural model was collision-free. Before the problems the VIF values ranged between 1.1571-1615.127 and all of the VIF values were below a conservative limit (3.00) and a more stringent limit (5.00) for the test of collinearity in PLS-SEM. The lowest VIF values were observed when patient education quality was correlated with pemphigus-related knowledge (1.024) and treatment adherence and self-care practices of the patients (1.024). Quality of patient education and health related quality of life (VIF value = 2.127); treatment adherence and health related quality of life (VIF value = 1.911); pemphigus related knowledge and health related quality of life (VIF value = 1.489) were the highest VIF values of the tuts. However, health knowledge about Pemphigus, treatment adherence and Pemphigus self-care had low VIF values showing there was low health literacy as well. The results indicated that correlation among predictor constructs was not

too high and path coefficients were not significantly biased by multicollinearity among the constructs. Therefore, all relationships were retained for further analysis in mediation, moderation, effect size and explanation of path coefficients and explanatory power (Oyama et al., 2006).

Results of the discriminant validity showed the presence of the five constructs such as "Health literacy", "Health related quality of life", "Pemphigus related knowledge", "Quality of patient education" and "Adherence to treatment and self-care practices" (as shown in table 4). The mean (range) values of the HTMT were 0.164 - 0.715, with the highest mean value identified score between domain of health literacy and QPE and the lowest mean value identified score between domain of QPE and treatment adherence and self-care practice. The other values ranged from 0.260 between health literacy and health-related quality of life, to 0.647 between quality of patient education and treatment adherence and self-care practices, 0.675 between treatment adherence and self-care practices and health-related quality of life, 0.242 between health literacy and pemphigus-related knowledge, 0.465 between health-related knowledge and treatment adherence and self-care practices, and 0.548 between pemphigus-related knowledge and health-related quality of life. The optimal values in each construct was not exceeded in either the conservative value (0.85) or the more liberal value (0.90) suggesting that each construct measured an empirically independent concept compared to the other constructs in the research model. Therefore, for discriminant validity, the measurement model was satisfied the criterion of the HTMT and was suitable for testing the structural model. This conclusion was concluded in accordance with the threshold criterion, not based upon following the guideline of the HTMT inference procedure outlined by Farook et al (2021) or Harman et al.,(2001) for which HTMT's bootstrapped intervals were not shown in the table.

The effect sizes of the latent-variable relationships ranged from negligible to large as

evidenced in Table 5. There was no meaningful difference for health-related quality of life ($f\text{-square} = 0.003$) and a small difference in pemphigus-related knowledge ($f\text{-square} = 0.027$) and in treatment adherence and self-care practices ($f\text{-square} = 0.077$).

Knowledge about Pemphigus, in its direct effect had a small effect on health-related quality of life ($f\text{-square} = 0.054$) and quality of patient education, in its direct effect had a small effect on health-related quality of life ($f\text{-square} = 0.043$).

In other words, patients' awareness of pemphigus and their self-care behaviors were significantly affected by the quality of patient education with a high contribution ($f\text{-square} = 0.719$) which means that patient education plays a very high role in patient's understanding of the disease and treatment. There was a small but near medium size effect for treatment adherence and self-care practices ($+0.136$) on health related-QOL.

Firstly, the results indicated that the quality of patient education had the highest impact on the two mediators (quality of disease knowledge, adherence and self-care practices) compared with the direct effect to patients' health-related QOL, indicating that there may be some aspects of health-related QOL that are improved through the increase in quality of patient education that led to increased patients' disease knowledge, adherence and self-care practices (Roy et al., 2021).

Overall it was found that the overall model fit was good, as well as the model was also suitable in both predictions and explanations at the same time, see Table 6. The variance explained values were: 46.8%, 32.7% and 47.6%, with adjusted R-squared values of 0.462, 0.323 and 0.473,

respectively, for HRQOL, pemphigus-related knowledge, and treatment adherence and self-care practices, which were comparable despite including many predictors.

The results showed that medium level of explaining power was found with Hrqol and comparing level of treating adherence and self care practices whereas, level of knowledge regarding Pemphigus was comparing in relatively lower but high level of explaining power. Results indicated that the Q^2_{predict} values of the model for all three endogenous constructs (health-related quality of life: 0.319; pemphigus-related knowledge: 0.468; and treatment adherence and self-care practices: 0.352) showed that the model had out-of-sample predictive relevance for all three constructs.

But no prediction likely power was categorically judged, that is, it was not compared with the prediction likely power of the linear-models benchmark for what followed health-associated high quality of life, pemphigus-associated knowledge and treatment adherence and pemphigus self-care practices, respectively.

Furthermore, the SRMR value for the saturated model was both within 0.038, and for the estimated model was 0.08 or below, considered "okay," and the difference observed and model-imagined correlations was considered satisfactory for both models. The NFI value (0.931) was also higher than the accepted value (0.90) which indicates that the model had a satisfactory fit. Overall, according to the results, the proposed model was able to explain the biggest endogenous variables and it had predictive relevance and good global adjustment for its future use in interpreting which allowed to interpret the results obtained in the relationships between variables (Martin & Murrell, 2008).

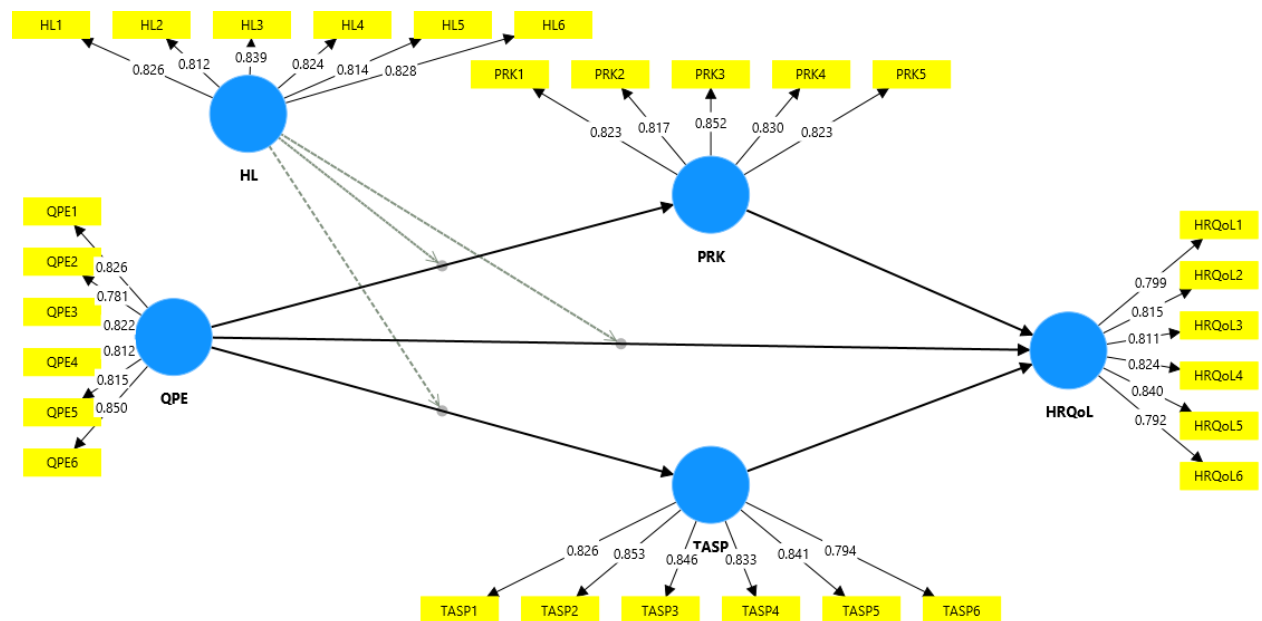


Figure 3: SEM with Factor Loadings

Table 2: Reliability, Validity and Variance Inflation Factor (VIF)

Construct/Items	Outer VIF values	Factor Loadings	Cronbach's Alpha	Composite Reliability	Average Variance Extracted (AVE)
Quality of Patient Education			0.901	0.901	0.669
QPE1	2.217	0.826			
QPE2	1.867	0.781			
QPE3	2.232	0.822			
QPE4	2.114	0.812			
QPE5	2.177	0.815			
QPE6	2.516	0.850			
Pemphigus-Related knowledge			0.886	0.888	0.687
PRK1	2.112	0.850			
PRK2	1.988	0.823			
PRK3	2.316	0.817			
PRK4	2.190	0.852			
PRK5	2.052	0.830			
Treatment Adherence and Self-care Practices			0.911	0.913	0.693
TASP1	2.215	0.826			
TASP2	2.561	0.853			
TASP3	2.440	0.846			
TASP4	2.319	0.833			

TASP5	2.406	0.841			
TASP6	2.026	0.794			
Health-Related Quality of Life			0.898	0.899	0.662
HRQoL1	2.029	0.799			
HRQoL2	2.105	0.815			
HRQoL3	2.081	0.811			
HRQoL4	2.235	0.824			
HRQoL5	2.337	0.840			
HRQoL6	1.969	0.792			
Health Literacy			0.905	0.907	0.679
HL1	2.302	0.826			
HL2	2.160	0.812			
HL3	2.358	0.839			
HL4	2.190	0.824			
HL5	2.044	0.814			
HL6	2.262	0.828			

Table 3: Collinearity Statistics (Inner VIF)

Relationship	VIF	Decision
HL -> HRQoL	1.127	No multicollinearity issue
HL -> PRK	1.025	No multicollinearity issue
HL -> TASP	1.025	No multicollinearity issue
PRK -> HRQoL	1.489	No multicollinearity issue
QPE -> HRQoL	2.127	No multicollinearity issue
QPE -> PRK	1.024	No multicollinearity issue
QPE -> TASP	1.024	No multicollinearity issue
TASP -> HRQoL	1.911	No multicollinearity issue

Table 4: Discriminate Validity Heterotrait-Monotrait (HTMT) Ratio

	HL	HRQoL	PRK	QPE	TASP
HL					
HRQoL	0.260				
PRK	0.242	0.548			
QPE	0.164	0.647	0.608		
TASP	0.328	0.675	0.465	0.715	

Table 5: Effect Size of Latent Variables

Path	f-square	Effect Size
HL -> HRQoL	0.003	Negligible
HL -> PRK	0.027	Small
HL -> TASP	0.077	Small
PRK -> HRQoL	0.054	Small
QPE -> HRQoL	0.043	Small
QPE -> PRK	0.403	Large
QPE -> TASP	0.719	Large
TASP -> HRQoL	0.136	Small, approaching medium

Table 6: Model Fit

	R-sq	Adj R-sq	Q ² predict	RMSE	MAE	Saturated Model	Estimated Model
HRQoL	0.468	0.462	0.319	0.828	0.666		
PRK	0.327	0.323	0.468	0.732	0.596		
TASP	0.476	0.473	0.352	0.808	0.657		
SRMR						0.038	0.038
NFI						0.931	0.931

Hypothesis Testing:

H1 : Quality of patient education had a positive and significant effect on health-related quality of life among patients with pemphigus.

The results confirmed that H1 was supported by health-related quality of life where statistically significant quality of patient education has a positive relationship with health-related quality of life ($\beta = 0.221$, $SD = 0.049$, $t = 4.492$, $p = <0.001$). This finding suggested that patients who felt the information they received from health care professionals was clearer, more understandable and more relevant to their life, had better health-related quality of life scores. The magnitude of the path coefficient was relatively low, but this was proof that patient education was a significant direct influence on patients' physical, emotional, and social health (Hussain et al., 2021).

H2 : Quality of patient education had a positive and significant effect on pemphigus-related knowledge.

The results confirmed that quality of patient education was having a significant positive effect on pemphigus-related knowledge, during the beta test, $SD (0.034)$, $t (15.326)$, $p (0.001)$ had a strong positive value while the others were negative. The results showed that provision of clear and informative information about the disease substantially enhanced patients' knowledge about pemphigus, its autoimmune origin, chronic course of the disease, need for treatment, warning signs, recommended self-care measures for the disease. The higher coefficient and t value indicated that the quality of patient education was important in determining disease-specific knowledge (Sánchez-García et al., 2022).

H3: Quality of patient education had a positive and significant effect on treatment adherence and self-care practices.

The findings were in line with hypothesis H3, which predicted that there would be a strong, positive, and statistically significant relationship between quality of patient education and treatment adherence ($\beta = 0.621$, $SD = 0.027$, $t = 23.377$, $p < 0.001$), and self-care practices ($\beta = 0.621$, $SD = 0.027$, $t = 19.661$, $p < 0.001$). The most direct relationship in the structural model was observed as shown in this above statement. The findings indicated that many of the patients who had received an understanding and practical education, and easily accepted patient-centred education would fulfill medication instructions, go to repeat visits, finish clinical monitoring, perform appropriate skin and oral care and seek professional help when troubles occur (Verma et al., 2020).

H4 : Pemphigus-related knowledge had a positive and significant effect on health-related quality of life.

From the results, H4 is accepted as there was a positive and significant effect of the pemphigus-related knowledge on health-related quality of life ($\beta = 0.206$; $SD = 0.041$; $t = 5.041$; $p < 0.001$). This finding suggests that improved knowledge of the disease and disease management was associated with positive quality-of-life outcomes. Kids with a deeper understanding of their disease might have been able to recognise symptoms; knew what to expect if & when the disease next relapsed, or if it responded to treatment; how to deal with uncertainty and; when/if it came back or their treatment suffered side effects (Kanwar & Vinay, 2012).

H5 : Treatment adherence and self-care practices had a positive and significant effect on health-related quality of life.

The results confirmed the hypothesis of the positive effect of treatment adherence and self-care practices on the health-related quality of life ($\beta = 0.373$, $SD = 0.047$, $t = 7.851$ and $p < 0.001$). The coefficient was greater than any of the other direct predictors of health-related quality of life, suggesting adherence and self-care practices had a significant impact on patient outcomes. Those that adhered to their

medications, monitoring and lesion-care, infection-prevention, and follow-up recommendations had improved physical functioning, emotional wellbeing, and daily-life management (Rahbar et al., 2014).

H6 : Health literacy moderated the relationship between quality of patient education and health-related quality of life.

The results failed to support H6 as the health literacy around quality of patient education had a negative but statistically insignificant relationship on health-related quality of life ($\beta = -0.030$, $SD = 0.032$, $t = 0.930$, $p = 0.353$). This finding showed that the connection between the quality of patient education and HRQoL was not statistically different by the health literacy level of patients. So, regardless of whether patients have relatively low or high health literacy, quality patient education seemed to have a positive impact on health-related QOL (Kanwar & De, 2011).

H7 : Health literacy positively moderated the relationship between quality of patient education and pemphigus-related knowledge.

However, the results confirmed H7 where interaction of health literacy and quality of patient education was statistically significant and positive in the Pemphigus-related knowledge ($\beta = 0.109$, $SD = 0.033$, $t = 3.251$, $p = 0.001$). The significant positive correlation between patient education and disease knowledge suggested strengthening of the connection with the rise in health literacy. Patients with higher health literacy were able to understand and evaluate more and retain more about the educational information received about pemphigus and treatment (Blomberg et al., 2017).

H8 : Health literacy positively moderated the relationship between quality of patient education and treatment adherence and self-care practices.

No treatment adherence and self-care practices changes according to health literacy and quality of patient education interventions were identified: the influence of both factors was

positive and statistically significant ($\beta = 0.114$, $SD = 0.029$, $t = 3.955$, $p < 0.001$). This indicated that an increase in health literacy led to enhanced ability to understand education information, and therefore, to behaviour which allows for treatment adherence and self-care. Hence the variability between patients regarding their ability to access, understand, appraise and apply health information means that the benefits of patient education for adherence and self-care were more salient for those who were better able to meet these requirements (Taurone et al., 2019).

H9 : Pemphigus-related knowledge mediated the relationship between quality of patient education and health-related quality of life.

Results showed that the specific indirect effect of association between health-related knowledge on pemphigus and quality of patient education on QOL was positive and statistically significant ($\beta = 0.109$, $SD = 0.022$, $t = 4.833$, $p < 0.001$) supporting the H9. The mediation was also determined as complementary partial mediation because the direct paths between quality of patient education and the health-related quality of life also were positive and significant. This discovery suggested that quality patient education benefited both directly and indirectly through promoting patients' pemphigus-related knowledge which consequently impacted health-related quality of life (Heelan et al., 2015).

H10 : Treatment adherence and self-care practices mediated the relationship between

quality of patient education and health-related quality of life.

The result showed that there was a statistically significant positive and significant specific indirect effect of quality of patient education on health-related quality of life via treatment adherence and patient self-care ($\beta = 0.232$, $SD = 0.031$, $t = 7.414$, and $p < 0.001$). The direct effect of quality of patient education on health-related quality of life was also positive and significant, resulting in the identification of complementary partial mediation. Patient education facilitated the indirect pathway of treatment adherence and self-care behaviours, which had greater effect than an indirect pathway through pemphigus-related knowledge on health-related quality of life, suggesting a stronger effect of patient education on obtaining the greatest benefit from the disease treatment through consistent use of treatment regimen and effective self-care practices (Ahmed et al., 2016).

In general, 9 out of 10 hypotheses were confirmed. Quality of patient education, in turn, directly contributed to enhancing knowledge, treatment adherence and self-care activities, as well as health related quality of life in regard to Pemphigus. Both mediators partly mediated the impact of patient education on health-related quality of life, and health literacy enhanced patient education's direct impact on knowledge and adherence as well as its direct effect on self-care, although there was no significant impact on the direct effect on health-related quality of life (Pezzolo & Naldi, 2020).

Table 7: Hypotheses Testing (Bootstrapping)

Hypothesis	Relationship	Path Coefficient	Standard deviation	t-Value	P-values	Result
H1	QPE $\rightarrow$ HRQoL	0.221	0.049	4.492	0.000	Supported
H2	QPE $\rightarrow$ PRK	0.527	0.034	15.326	0.000	Supported
H3	QPE $\rightarrow$ TASP	0.621	0.027	23.377	0.000	Supported
H4	PRK $\rightarrow$ HRQoL	0.206	0.041	5.041	0.000	Supported
H5	TASP $\rightarrow$ HRQoL	0.373	0.047	7.851	0.000	Supported

H6	HL x QPE →HRQoL	-0.030	0.032	0.930	0.353	Not Supported
H7	HL x QPE → PRK	0.109	0.033	3.251	0.001	Supported
H8	HL x QPE → TASP	0.114	0.029	3.955	0.000	Supported
H9	QPE → PRK → HRQoL	0.109	0.022	4.833	0.000	Complementary Partial Mediation
H10	QPE → TASP → HRQoL	0.232	0.031	7.414	0.000	Complementary Partial Mediation

Discussion

The purpose of the present study was to examine the correlation between patient education quality, patient pemphigus knowledge, adherence and self-care capacity, health literacy and health related quality of life in 513 patients of pemphigus followed up in selected health services for patients in Tirana, Albania. A series of hypotheses were tested, and nine were confirmed. The quality of patient education was positively associated with physical functioning, health related quality of life, pemphigus-related knowledge and treatment adherence and pemphigus self-care practices. Patient education was also positively linked to knowledge and treatment adherence and self-care practices associated with the pemphigus and partially mediated the link between patient education and health related quality of life. Health literacy also supported the rest of the pathway (patient education on disease knowledge and adherence to treatment and self-care), but was not found to mediate the direct effects of patient education on health-related quality of life. The findings showed that patients' understanding of the information being provided was a better education, and if it was transferred to sustained treatment and self-care behaviours (Ravn et al., 2017).

The positive association between the level of patient education and the HrQoL was used to support the H1. The pathway coefficient of 0.221 suggested that the understandable, relevant, and patient-oriented teaching directly affected the physical, psychological and social

status of pemphigus patients. In this regard, it can be concluded that the adoption of educational information to raise patients' PV-related knowledge has resulted in an improvement in the patients' knowledge content and their quality of life, which is in line with the results of Melchionda & Harman (2019). Similarly, Ujiie et al. (2022) have described the various roles of patient education in pemphigus treatment, including, but not limited to, lesion care, prevention of complications, monitoring for disease recurrence, and follow-up. The hypothesis that uncertainty would likely be reduced when it became less uncertain to patients through education and trust in the treatment, was supported by the data obtained.

Nonetheless, the direct impact on health-related QOL of patient education was relatively small compared to its impact on knowledge and adherence and self-care. This is supported by the study conducted by Maronese et al. (2022) which showed that patients with PV had poor QOL even after using targeted therapies. Similarly, Gupta et al (2011) reported that some clinical and oral disease parameters significantly influenced the oral pemphigus patients' quality of life. They did not prove that educating patients was detrimental in any way, however, as these results indicated, health related quality of life was a multi-faceted phenomenon, and further affected by disease activity, painful oral and skin lesions, treatment side effects, obvious deformity, worry about the recurrence of the disease, emotional distress, and functional ability. Patient education might have hence helped

improve quality of life (QOL), but not necessarily reduce the burden of the clinical or psychological importance of active pemphigus (Ormond et al., 2018).

Strong correlation was established between the Knowledge on Pemphigus and Quality of Health Education offered to the patients and thus the validation of H2 was confirmed. The path coefficient of 0.527 and a high effect size of 0.403 indicated that quality of education received from the health care providers was an important determinant of patients' understanding of pemphigus, the continual nature of the condition, its need for medical treatment, possible adverse effects, signs of relapse and recommended self care. The results were consistent with that of (Jin et al. (2016) where patient knowledge increased following instruction by a programme guide. It was also confirmed by Schmidt et al (2021) who reported that only 40.5% for them could accurately describe Pemphigus as an auto-immune disorder and only 59.5% knew that it was chronic disorder. They also observed a strong association between education and knowledge about the disease which indicated the need to customize information from which patient education should proceed. The present findings, therefore, were presented in simple language about repetition of crucial information, addressing misconceptions, leaving time for questions that patients might have on their own, and checking if the educator had been successful in communicating the information he gave.

Support H3: Quality patient education had a strong positive influence on adherence to treatment and self-care. The path coefficient 0.621 showed the highest direct effect in the model and effect size 0.719 was considered large. This discovery meant that education was not just a way to improve actual knowledge as patients also learned to follow their medication regimes, not to alter courses or discontinue treatment without consulting a health care professional, attend follow-up sessions, perform follow-up laboratory monitoring, treat their oral and skin lesions, avoid self-infection, and call for help when they had warning signs. The study of

Sadeghi et al., 2015, also demonstrated that education intervention, based on the HBM model, was effective on self-care behaviours of PV patients. Meggitt et al.(2011) emphasized the importance of correct health education, lesion evaluation, correct treatment with topical medicine, avoiding complications and constant monitoring during the treatment of Pemphigus. In addition, Sadeghi et al. (2014) reported that 85.7% of the patients were given a drugs and 90.5% of the patients, were taking precautions in reducing steroid side effects. The results of these studies constitute the point that the practical/behaviour education was a factor which caused patients to be taken to active roles in the long-term OM management (Tsujiimoto & Osafune, 2022).

H4 was accepted as it was shown that there was a correlation towards higher knowledge levels of Pemphigus and improved HRQoL. The pathway coefficient (0.206) indicated that the patients who had better knowledge of pemphigus and how it is being handled had better QOL outcomes. Patients' increased knowledge may have helped them notice that they should expect the disease to return, provided with rational reasons for the evolution of disease, reduce the risk of the disease not being adhered to, lessen misunderstandings about being contagious, and improve their ability to communicate with their health care providers. This is consistent with Hegazy et al (2022) 's study which showed a significant and positive association between the illness perception and the QOL in patients with pemphigus. Treatment control and personal control are disorder beliefs seen as predictors of better outcomes, whereas unpredictability, regularity and psychological causation of the disease were predictors of poorer quality of life. According to these findings, the more accurate knowledge that was provided might have helped to minimize uncertainty and improve patient's sense of control over the conditions (Angunawela et al., 2013).

The magnitude of this association between pemphigus-related knowledge and health-related quality of life was insignificant, however. This

meant that knowledge on its own had limited value for getting meaningful and transformative change in disease managing practices without knowledge translation. According to Valikhani et al. (2007), there was an association between the severity of the disease and involvement of the oral mucosa with the quality of life. Despite taking appropriate precautions and obligations as mentioned by Achini-Gutzwiller et al. (2022), some patients were still diagnosed with mental health and career related consequences. These findings are in line with the restriction of knowledge effect, where patients might have already known about their disease but still experience pain from the lesions, social embarrassment, side effect of the treatment and difficulties, fear of further disease occurrence. The need for knowledge was found, but was not enough to decrease the burden of pemphigus in totality (Smith et al., 2018).

The results were consistent with H5, and health related quality of life was positively and significantly associated with treatment adherence/self-care practices that supported the hypothesis. The highest path coefficient (0.373) and the largest effect size (0.136), close to the medium effect level, were found for the dimensions that included ADHD symptoms. This result suggested that those patients who adhered strictly to any of the treatment recommendations, monitoring, lesions, oral care, and infection prevention guidelines, were more likely to have better functioning and feelings of well-being during the day. Rapid Medications' association with the improvement in quality of life among patients with bullous pemphigoid and pemphigus was also found by others (Wan et al., 2021). In their study 82.1% of the participants showed high adherence and mean DLQI scores were lowered at three months from 14.11 at baseline to 4.86. Similarly, the same (Al-Saedi et al. (2016) reported that high levels of adherence to medication, frequent follow up and preventive practice related to steroids also occurred for patients with PV. This suggested that there was a strong association between adherence to continuous treatment and

self-care behaviours, and better patient-reported outcomes (Li et al., 2022).

Care must be taken, however, when judging (Ellebrecht & Payne, 2017) results because of the small number of patients (28) and the combination of pemphigus and bullous pemphigoid patients by the investigators in the study. This improvement in quality of life may be unrelated to medication adherence, as there are other factors that could enhance it over time (during treatment). In the present study adherence and self-care had a significant but not fully 'medium' effect on quality of life, indicating that the right behaviours got the patient the desired treatment benefits, but not sufficient to reduce treatment burden, emotional distress, social limitation or disease-related pain. The interpretation is in line with the more general one by Padniewski et al. (2022) who found that the factors affecting quality of life in autoimmune bullous finally were physical, psychological, social and treatment related which were interacting factors (Goldsmith, 2005).

The direct association between the quality of patient education and health related quality of life and the health-literacy was not included because of the lack of interaction. The interaction coefficient was negative (-0.030) with a p-value of 0.353, showing that there was no significant difference in the direct effect of patient education on the QOL for the lower health literacy group and higher health literacy group. One suggestion was that authorised education communicated in an understandable and practical way, with opportunities to clarify the information and for confirmation of understanding, across various types of literacy levels. Another explanation had been that QOL associated with health issues had been a downstream variable and that a number of clinical, psychosocial, as well as treatment associated variables played a role in patients' understanding of health information. This was confirmed by the results of (da Silva Brandão & dos Santos, (2013) and Tavakolpour (2017), which demonstrated that some factors included in the illness perception (IP), such as illness

perceptions, oral involvement and burdens of persistent illness treatment, disease severity and negative information, were significant quality-of-life determinant factors.

Inconsistencies with previous research, though, showing a relationship between health literacy and outcomes of chronic diseases, suggested that there may not be a relationship at all between H6 and outcomes. However, the difference could also be attributable to the fact that most previous research studies have looked only at the direct relationships of health literacy with self-care and adherence to medication and not the moderating effect of health literacy upon a distal outcome that relates to quality of life. A moderate positive association between health literacy and self-care has been found by a systematic review and meta-analysis of research studies on chronic diseases, carried out by Izumi et al. (2019). Their findings indicated that health literacy has an impact on outcomes primarily through intermediate pathways like disease knowledge, decision making, empowerment, communication with health service and execution of selfmanagement behaviour. Consistent with the present results, the moderating effect of health literacy accounted for the association between education and knowledge and adherence to the standard and/or adherence to self-care, but not in the case of health-related quality of life (Grando, 2006).

Health literacy positively moderated the link between QPE and pemphigus-related knowledge, hence, its inclusion in the model for this study. The interaction coefficient between education and disease knowledge was positive (0.109) and the coefficient was generally high, thus indicating that there was a positive stronger effect of education on disease knowledge when health literacy increased. Higher levels of health literacy might have allowed patients to have evaluated the information sources more effectively, retained medical concepts and information from treatment, and integrated new medical information into their prior knowledge. It was correlative with the findings of Lee et al. (2018) who showed higher education level to be

correlated with better knowledge about cause and treatment related information about Pemphigus. Patient's ability to relate to information they are given by the health care provider was not synonymous with their educational status, but was associated with health literacy. The findings therefore, highlighted the significance of adapting patient-centred learning for those with limited literacy in their language: using easy to understand materials, repetition, pictures, demonstration, and teach back (Fattahi & Salako, 2025).

Secondly, health literacy was found to be a positive moderator between the quality of patient education and treatment adherence and self care practices, thus supporting H8. To achieve an interaction coefficient of 0.114, scores for health literacy were more likely to be associated with doing behaviors more educationally when the patients scored higher on health literacy. The findings are also in line with that of Tomasello et al (2025) who reported that there was a significant correlation between health literacy and autoimmune antihistamine use in individuals with autoimmune bullous diseases. Patients reported that many of their patients had a range of poor health literacy and poor adherence, and that enhancing their health literacy skills would aid better adherence to medication. The finding also corroborated with a meta analysis conducted by Ahmed et al. (2025) which indicated a positive association between health literacy and self care with chronic diseases. The current results further supported this evidence by demonstrating that health literacy complemented the need for quality education; that is, health-literate patients didn't make quality education redundant, but rather contributed to the quality of their use of the information they had received (Esen et al., 2024).

The results of the mediation analyses interested and complemented H9 and H10, providing insight into the patient education relationship with health-related quality of life. For knowledge about pemphigus the later activities had a more significant indirect effect of 0.232 while the treatment adherence and self-care activities was

0.109. Positive and significant direct and indirect effects were observed in both pathways for partial mediation which resulted in some complementary mediation. Both showed that education resulted in improvements to QOL partly because it enabled increased awareness and, as importantly, allowed the patient to 'own' this and carry the information forward in their own ways through consistent treatment and patient treatment behaviours. Pinto et al. (2025), found that an education intervention could enhance practice in lesions care, prevention, monitoring and follow up, which is similar to the results in this reading done by Amerson et al.(2022) who correlated an educative intervention with improved self-care behaviour and Vollono et al. (2024) who correlated adherence with improved quality of life.

It argued that the direct effect on the children's health through their behaviour rather than knowledge was greater than the indirect effect of their knowledge and adherence to treatment and thus, on their treatment practices. Patients who received education to let them know their condition were more likely to have improvement in quality of life and so were those who practiced at least one of the following: taking medication as directed, attending followup sessions, followup of treatment complex, Skin and oral care. The extended value of the direct pathway from patient education to health-related quality of life suggested that there could also have been indirect pathways between patient education and health-related quality of life (such as emotional reassurance, improved communication, increased trust in healthcare professionals, and reductions in perceived uncertainty and in perceived health-related control). The illness perception scores that Ramien et al (2022) reported supported the potential for communication and perceived control to support a quality of life as well as knowledge and observable self-care behaviours.

Overall, this study contributes to the literature, expanding the evidence by including information about patients, pemphigus knowledge, treatment adherence and self-care, health information literacy, and health-related

quality of life within a unified explanatory model. The findings indicated that just informing the patient about information in writing is not an effective form of patient education. When patients were adequately informed about the chronicity of the disease, medication, side effects, oral and skin care, infection prevention and signs of relapse were focused on, testing education was adequate. Education also required being adapted to the health-literacy level of the patients with the use of 'plain language' and 'demonstration', 'repetition', use of visual materials, and patient reminder sessions confirming understanding. These recommendations are consistent with the recent literature which has emphasized the need for literacy-sensitive teaching, continued counselling, management care of any skin lesions and regular evaluation of their skin lesion care and knowledge (Grover et al., 2025).

This study design (cross section) did not allow for causality and time methods to be assessed in the results so that the results were only interpreted with caution. Self-reports also could have led to socially desirable reports of adherence and self-care, the recall bias, and the common-method bias. Additionally, only selected institutions were included in Tirana and the generalizability of the knowledge and attitudes of patients receiving care outside these institutions (and on other regions of Albania) is limited. Wendelken et al.(2024) showed a large variability in the outcome measures used in pemphigus clinical trials with disease-severity and quality of life measures. Further studies are needed to verify whether disease knowledge, adherence, clinical disease activity, disease relapse rate, treatment side effect, and health-related quality of life (QoL) benefited in the long run after literacy-based education was applied (Shojaeian et al., 2024).

Theoretical Implications

The results provided support for the link of patient education to quality of life directly and indirectly through patient actors, and contributed to the Wilson & Cleary Quality of Life model. The Wilson-Cleary framework

connected clinical and individual factors to symptoms to functioning to perceptions of general health (forthcoming) to total quality of life, but did not spell out how educational communication, specifically, might impact these domains. The present study considered new quality of patient's education as an explanatory antecedent, and pemphigus-related knowledge, treatment adherence and self-care behaviors as mediational variables that might account for the relationship between education and health-related quality of life. Finally, even though there was no direct interaction with patient education in the model, education had a large, direct effect on the patient's quality of life, suggesting that patient education could have an effect on other components of this model (e.g., reduction of the patient's perception of uncertainty, which leads to better communication; increase in the sense of control for services, which leads to a greater level of confidence during treatment). Similarities with the interpretation made by Chen et al.(2023), who concluded that illness perceptions and perceived treatment control were correlated with the QOL of the people with pemphigus and to Gabusi et al. (2025) who concluded that illness perceptions and aspects of treatment control were correlated.

The study further confirmed the Information – Motivation – Behavioural Skills theory, which highlights the need for information to be understandable, by demonstrating its ability to predict the understanding of the disease followed by treatment and self-care behaviours. The quality of patient education, as well as the HRQOL-related knowledge and treatment adherence self-care practices, were good predictors of HRQOL and both of these in turn predicted pemphigus-related knowledge and treatment adherence self-care practices. The indirect effects of knowledge were more evident than the indirect effect through treatment adherence and self-care as information seemed to have more value when it related to patients' implementation of self-care practices and adherence with treatment. Within this study, the separation between theory learning and action of behaviours required for learning how to

manage Pemphigus was finer grained. It was based on the assumption that information is a required factor but unlikely to yield best outcomes if patients don't have the motivation and behavioral capacity to engage in recommended treatment and self-care (Pacheco-Tovar et al., 2024).

Further, the parallel nature of the mediation results supported patient-education theory wherein pemphigus knowledge and treatment adherence and self-care activities were complementary and not mutually dependent. The partial transmission of the education-substantively components of the education-quality of life association indicated though, that the education part made up only a portion of the association, the stronger behavioural pathway indicated that just coming to know the best practices would not necessarily replicate the better outcomes for the patients in the same way. This separation aligned with prior research on pemphigus that although knowledge and nursing practices improved with involvement in education, no difference was found in pemphigus health burden that included the presence of blisters, treatment side effects, distress or limitations of function, despite having reasonable levels of knowledge (Sparling & Butler, 2024).

The scores of the moderation confirmed and refined the theoretical role of health literacy. Strengthening health-literacy did strengthen the patient education, pemphigus-related knowledge and patient adherence and a strengthening effect was found in the linkage between patient education and health-related quality of life, however, these were not significant. The pattern has been that using health literacy to improve or understand health information has seemed to be more of an "enabling" factor rather than a universal moderator associated with a more distal endpoint of disease management (e.g., post-treatment, post-procedure, or quality of life). This is similar to the approach taken by Nutbeam which took health literacy to be both functional and interactive, and critical. This interpretation is in keeping with Nutbeam's understanding of health literacy including the

functional capacity, the interactive capacity and the critical capacity of utilizing health information. Similarly, poor health literacy has been associated with poor adherence with medication use by patients suffering from autoimmune bullous diseases (Kubrak et al., 2025).

For the third, there was no theoretical "bounded condition" when considering the moderation effect for the health related QOL provided. The benefits of patients being able to understand education did not restrict to those with high health-literacy patients; and treatment toxicity, social functioning, psychological adjustment, clinical severity, oral involvement, and skin involvement were associated with stress/distal quality of life. And so was health literacy not the sole element that would result in better quality of life of patients. Instead, the results provided support for a multilevel model that health literacy affected the way patients were educated and how education influenced the patients' experiences regarding health and quality of life, whereas the clinical and psychosocial factors remained influential in their quality of life even after accounting for health literacy (Patrascu, 2022).

Practical Implications

The results showed that structured and standardised patient-education protocols should have been introduced in the health care institutions that cared for the patients suffering from pemphigus and not during informal explanations in the examination room. The immune and non-contagious nature of pemphigus itself, and the non-contagious nature of all the diseases involved in treating it, should have been explained as should the chronic and relapsing nature of the disease, the purpose and timing of prescribed drugs, as well as the potential side effects, laboratory monitoring parameters and potential signs for recurrence, and situations where immediate medical advice is needed. It should have included information about the care of skin lesions, oral hygiene, prevention of infection, and avoidance of any kind of skin trauma, dietary changes in the case

of oral involvement, and follow up. Further recent studies of pemphigus also highlighted the importance of establishing the curriculum for disease education, providing guidance for the long-term use of drugs, disease monitoring, and practical and self-care support (Spindler et al., 2023).

Show educational experiences should have been more action oriented, because of the strong relationship established between quality of patient education and adherence and self care behavior is particularly reflected. In addition to explaining to the healthcare professional why the pemphigus had happened, the healthcare professional should have provided written medication plans, monitoring and follow-up plans with patients, and instructions related to attempting to avoid the relapse and instructions on lesion and mouth care. In addition, the patient should have been provided with suggestions for future when discharged from the hospital. It was conducted because adherence to treatment and self-care practices had the greatest direct effect on the health-related quality of life and more potent interaction between these two mediators with adherence to treatment. Prior research in AIBeds also showed adherence to medicines was also a clinically relevant concern and that an improvement in patient-professional communication could lead to medicines adherence enhancements and to increase patient safety (Ptasiewicz et al., 2022).

As health literacy contributed to the connection between education and knowledge with self-management, the educational communication was modified according to the understandings of the patients. Materials should have been simple, with a minimum of medical terminology, short sentences, and visual illustrations, and should have been organized well. Healthcare providers should have been asking patients a question such as; using the teach-back approach, "tell me what you just heard using your own words. No evidence suggests that these strategies actually served to reduce the relationship between education—quality of life—but they should be used non-selectively with all patients and not just those that are

determined to be more limited in literacy status. Healthcare organizations' response, plain-language communication, and teach-back procedures were recommended by the World Health Organization and the Agency for Healthcare Research and Quality to help lower levels of complexity in the healthcare system and facilitation understanding across all levels of literacy (Altowairqi et al., 2025).

The results also used for Mother Teresa University Hospital Centre and the University Hospital of Trauma, Pegasus Med Clinic, also EB Dermatology clinic. Healthcare practitioners working with patients should have been trained in patient centered communications, on literacy sensitive counselling, assessment of adherence and teach back skills. A common checklist for education could have streamlined any differences between public and private clinical environments, and created uniformity of information, across institutions. Rewated nurse activities included further education about lesion care, oral care and medication safety and monitoring; and reeducation of pharmacists about medication schedules, interactions and adherence issues. A comprehensive guidance on pemphigus had a special emphasis on the follow up and supportive care aspects of pemphigus treatment, particularly in light of ongoing blood or exudative lesions, complex treatment (Anghelache-Dobrescu et al., 2025).

The partial mediation results indicated that patient education should be assessed as the levels of knowledge and behaviour, and not as a consequence of patient education, or simply in terms of the provision of knowledge. Medication Adherence checks, Short Knowledge checks, checks for self-care and checks for quality of living might have been carried out at the follow-up visits. When the patients knew about the disease, but rarely took treatment, the need was for some simple interventions, behavioural and practical about it, but if not too familiar, it required repetitions or explanations of some basic information about the disease. Patients with good knowledge and/or adherence but subjective assessment of poor quality of life needed evaluation of disease

activity, pain, oral involvement, side effects of the treatment, anxiety, stigma, and social/occupational limitations. It is differential approach due to the fact that the impact of disease and treatment factors remained prominent after controlling education and behaviour related factors on pemphigus-related QOL (Belzer & Parker, 2023).

Finally, the study enabled it to be designed and tested a programme on the education of PENV, based on the principles of Literacy. As a last element the study emphasized the principles of designing and evaluating a programme on pemphigus education, responsive to the literacy of the target population – in question also Albanian. Such a programme could have included an Albanian-language patient handbook, illustrated care directions and medication / monitoring cards, structured counselling sessions, and telephone follow up and referral systems to psychological/ social services. The data from the present study, however, were conceptualized in a cross sectional study design and self reported in questionnaires, and as such should not be presumed to make robust causal inferences. Therefore the proposed programme had been evaluated predictively with indexes of disease activity, adherence, treatment complications, relapse and measures of quality-of-life in the context of a longitudinal or controlled intervention research design. A more recent Clinical review also pointed out the requirement of a standardized and a consistent reporting of the quality of life outcomes in pemphigus research (Zhou et al., 2024).

Conclusion

This study intended to explore the importance of patient education in enhancing the health-related quality of life of patients suffering from pemphigus, in health care units of the Albanian State in Tirana, where not much was known about this. Limited health literacy – due to the systemic treatments required for pemphigus, its treatment protocol demands longer duration, opportunities for regular review of treatment, adequate management of the skin rash, and the

need for close involvement of the person receiving the treatment – was a particular issue. When analysed in correlation with the study variables, 513 patients were the respondents; quality of patient education was found to be beneficial in improving healthcare related quality of life, patients knowledge and adherence, and self-care practices related to pemphigus. With regard to treatment adherence and self-management practices, these effects were more prominent demonstrating that knowledge in treatment was an important domain of patient education, in which patient education was clear, relevant and comprehensible, and applied to changed disease-management behaviour. Compliance with treatment and self-care behaviors had a positive relationship with HRQOL, and an education intervention was found to play significant explanatory role in the relationship between patient education and HRQOL; the same relationship can be seen between pemphigus-related knowledge and self-care and adherence practices. The indirect effect, through adherence and self-care demonstrated greater benefits arising from patient education, specifically in taking medicines as prescribed, attending follow-up appointments, completing monitoring, caring for skin/range of mouth lesions, not having complications and seeking clinical assistance when needed. Enhancement of the direct relationship between patient education and the knowledge of the disease enhanced the direct relationship between patient education and the adherence and self-care and knowledge of the disease, but not that of patient education with health-related quality of life (HRQoL). In turn, the discovery suggested that the definition of health literacy which underlies it is about understanding and utilizing the patient's schooling experience, and that its action on the quality of their experience is transmitted through a variety of clinical, psychological, social and treatment-related factors. The study therefore extended the theoretical ground of patient education by emphasizing two patient education 'paths' that bridge patient education and patient outcomes: knowledge and behavioural self-management and the third (the healthy condition) of

establishing health literacy as a 'healthy condition' both at the knowledge and at the behavioural self-management stage. In practice, the findings have been incorporated into structured education programmes based on both structured literacy and behaviour, using visual material, repeating and re-reading education using teach-back technique and medicine plans, plus self care demonstrations and follow-up counselling on what to do with relapses, all in plain Albanian language. Healthcare institutions should be used to commence a monitoring of the patients adherence, self-care qualities, era of patients knowledge, as well as educations being given to patients. Although statistically no causal inferences can be drawn (due to the cross-sectional design) and response bias may have occurred because this was a patient self-reported report, the results were used to develop and prospectively test standardized patient-education interventions that will hopefully result in improved long-term disease management and QoL for pemphigus patients in Albania.

Limitations

A few limitations marred the study for which the reader should take the following into consideration: First, the cross-sectional design failed to establish the temporal sequence of events or causal relationships between the extent of patient education and the patients' knowledge, treatment adherence and self care practices within the samples of patients with pemphigus and between health literacy and health related quality of life. Results from the mediation model showed that there were significant indirect effects with neither the patient education as a predictor of changes in knowledge nor the changes in behaviour as a predictor of improvement in quality of life. There might also have been reverse and/or reciprocal relationships; patients who gave higher ratings to the QOL aspects, and/or more favorably attaking the education might have been both engaged in improving their QOL, and it might have rated it better.

Secondly, non-probability sampling method was used in the respondents using purposive

consecutive sampling method from Mother Teresa Hospital Center, University Hospital of Trauma, Pegasus Med Clinic and EB dermatology clinic in Tirana. The multicentre sample was comprised of 513 patients who may not have been representative of all patients with pemphigus in Albania since it was unlikely to capture those treated in institutions not in Tirana, small regional hospitals and primary-care facilities or in rural settings. Some patients who attended the specialist services regularly may have received the information, monitoring, and treatment more than other patients who did not see the specialist for follow up. So, the outcome the researchers found may only apply to all the population of the Albanians with pemphigus as a whole.

Third, The data obtained in the research was self data returned in the forms of the questionnaire. People were able to over-report adherence, follow-up visits, and fit into the 'good' self-care because there was a difficulty in recall or socially acceptable answers. Patient experience in the clinics, patients' activity, patients' satisfaction with care provided and mood may also have influenced their judgment of the quality of patient education and how patients felt with relation to health-related quality of life. Although these statistical procedures were followed, a risk assessment was performed to examine the possibility of common-method variance due to the fact that all data were collected the same way from the same group of subjects, via the same survey at the same time.

Fourth, the measurement items were found to be changing after the literatures that had been constituted in the famous patient education, health-literacy, adherence, self-care and quality-of-life previously and adapted, for the Albanian pemphigus context. The translation and back-translation, both expert and pilot testing, reliability and validity assessment, as well as the expert review were further sources of support, but external validation on independent Albanian samples had not yet been carried out for the adapted 29 items questionnaire. Multiple complex constructs, such as treatment allegiance and self-care practices, encompassed behaviours

of all kinds, including medication intake, self-care behaviour, prevention and monitoring of infection, lesion care, and follow-up attendance. These behaviours may not have had the same importance to patient outcomes and may have been researched as separate aspects.

The model did not include other clinical and psychosocial factors that could have impacted HRQOL, as they are outside the scope of this study. Other factors which may have contributed to further variability in QOL include duration of treatment, exposure to corticosteroids, treatment side effects, history of relapses, anxiety, depression and perceived stigma, family support, and financial burden for oral and skin involvement and pain. The model accounted for 46.8% of the variance, this is an acceptable proportion because it means that the model is doing a good job of explaining the variance but that more than half of the variance was due to other factors than were included in the model.

Finally, the respondents were not healthcare professionals from other institutions, which means interactions that they may have had with staff of different lengths, different educational material, other treatment plans etc., and differences in follow up were not assessed separately. Because it is possible that the patient's experience was influenced in part by the institution at which he/she was treated, the patients were thus considered independent observations. Furthermore, the study failed to measure the health literacy of organisations and the prevalence of health health literacy services, and it did not consider other aspects of health quality, such as the comprehensibility of and efforts to be comprehensible and accessible in organisations' health-health information and services to their employees.

Future Research Directions

Longitudinal study should be used in future research to determine the temporal relationship between patient education, disease knowledge, treatment adherence, self-care practices and HRQOL. Patients would have the opportunity to be assessed before, after and at several time

points after education, to assess for maintenance of knowledge, behaviour change and whether any improvement in knowledge or behaviour was followed by any improvement in disease status or relapse outcomes, and any improvement in quality of life. For the relationship between patient education and patient outcome to be substantiated by evidencing the mechanism, however, a longitudinal mediation analysis should be provided.

A structured literacy responsive pemphigus education programme should also be tested using RCTs or quasi-experimental study.” Interventions might be provided as simple Albanian-language materials, pictorial self-help instructions, medication reminders, teach back, lesion-care demonstration, relapse action plan, or follow up counselling, or they may be available digitally and others. Between the intervention groups and usual care groups, patient reported and clinical outcomes including disease knowledge, treatment adherence, self-care practices, quality of life, pemphigus disease activity score, confirmatory necropsies performed, treatment complications, hospital admissions, health service use, etc. can be compared.

An enlarged group of patients should be involved from other public and private health care units in Albania for further studies. To increase representativeness of the population and allow comparison, regional hospitals, rural areas and patients who do not have access to specialist dermatology services should be included. Alternative ways to reduce selection bias include probability-based recruitment, or establishing a national pemphigus registry, to provide a more comprehensive basis for sampling of rare-disease studies.

There is need for further study using self-reported and objective measures. Medication adherence assessment may be done by the health care provider, by the patient through prescription filling, pill count or by an e-monitoring system. Use of such a facility would be verified in the medical record and laboratory

monitoring would be used for disease severity, using an existing clinical activity index. A combination of both subject and objective data will minimize the impact of recall and social desirability bias, and determine whether the improvement in education and behaviour was clinically significant.

It has to be modified and validated in a separate set of Albanian samples through confirmatory factor analysis, test-retest reliability and measurement-invariance analysis, and criterion validity. The sex, age, educational level, healthcare facility, pemphigus subtypes, and duration of disease differences should be tested for equality (homogeneity) in the effect of the measurement model and also be considered as separate first order dimensions of a higher order, overall measurement to determine which behaviour is most correlated with good quality of life.

Other clinical, psychological, social and health care system characteristics will need to be added to future models. The following entry items could serve as predictors, mediators or moderators as well as the severity of the disease, oral involvement, pain, treatment toxicity, anxiety, depression, perceived stigma, self-efficacy, social support, patient-provider communication, patient trust, financial burden and access to specialist care. These additions are likely to account for the lack of moderation in this direct link between patient education and quality of life and might indicate specific patient populations in which greater levels of support are needed.

The method of mixed-method would also be able to give the better understanding to the patients' educational experiences. Qualitative interviews or focus groups could be used to explore what information was helpful for patients, what aspects of treatment were challenging to understand or troublesome, how cultural and/or family factors influenced patients' self-care, and what any impediments were to incorporating clinical advice. These results of the qualitative findings could then inform the adjustment and creation of education

materials and development of contextually appropriate interventions.

Finally there is still a need for more research at both an individual and organisational level of health literacy. Existing institutional variables, including standardisation of interventions given in education, the availability or absence of trained nurses, duration of consultation,

availability of any written resources, digital communication elements and follow-up systems, might be measured to determine whether they influence patients' prognosis. The study of the four institutions listed or the analysis of other centres might have revealed the best practices in service delivery that were associated with enhancing the knowledge of pemphigus patients, service adherence, self-care and quality of life.

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