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## Evidences related to the care of people with pemphigus vulgaris: a challenge to nursing

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### ABSTRAC

**Problem:** Taking care of people hospitalized with pemphigus vulgaris is a complex process, since it is an autoimmune disease that leads to the formation of lesions of the skin and/or mucous membranes in an isolated or generalized form.

**Objective:** To identify the nursing care recommended for people with pemphigus vulgaris.

**Method:** Integrative review of the literature, using the keywords *nursing care* and *pemphigus* and the inclusion criteria: complete works with online availability, published between 2006 and 2010 in Portuguese, English and Spanish, covering the object of the study.

**Results:** Of the 129 articles found, only four were selected, characterizing evidence levels 4 and 5. There is a predominance of authors and physicians who favored disease and drug treatment.

**Discussion:** Nursing care is mentioned without addressing its importance in promoting comfort and the sustenance of life.

**Conclusion:** The reality points to the need for the construction of a body of knowledge of nursing on this issue.

**Keywords:** Nursing, Nursing Care; Dermatology, Pemphigus.

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## INTRODUCTION

The experience of caring for people affected by pemphigus vulgaris over twelve years has revealed the importance of skilled nursing care for the prevention of aggravations, promoting the welfare/comfort and lifetime maintenance of those affected. The complexity of the picture presented by the patient hospitalized with the pathology cited is due to the pain involved, the severe prognosis, the disfiguring character of the extensive injuries, and their impact on the social and emotional spheres. Therefore, to take care of these people in full, knowledge and sensitivity are essential for the nurse, not only because of the specificity of care, but also the shortage of specialized inpatient services and specialized nursing staff, a fact that makes nursing care a real challenge.

Understanding care as a phenomenon resulting from the care process, one can describe it as the development of actions, attitudes and behaviors in order to promote, maintain or restore human dignity and completeness. These actions are based on scientific knowledge, experience, intuition and critical thinking, and are made for, and with, the person who needs care<sup>(1)</sup>.

In the multifaceted reality of everyday nursing, the nurse is considered an agent of the work process in health, and who has been provided with a generalist education<sup>(2)</sup> In this universe of action dermatology stands out as a specialty requiring expertise in the areas of clinical supervision, surgery and cosmetics. It is a specialty which has been introduced to the hospital environment over the past four decades.

Given the shortage of nurse specialists in the field of dermatology, which is an area little explored by these professionals, one of the challenges it presents for the generalist nurse is developing such a care, lacking specific knowledge that goes beyond his area of expertise, leading him to ethical and moral dilemmas in coping with the requirements imposed. Therefore, having under his responsibility clients affected by skin and mucosal diseases such as pemphigus vulgaris, means involving inexperienced staff, as well as the

lack of a proper environment and an insufficient mastery of care technology, which are prerogatives for a risk free service<sup>(2)</sup>.

Pemphigus is an autoimmune disease, with unlimited evolution and severe prognosis, clinically characterized by blisters. There are two major clinical forms: the vulgar and foliaceus. Despite the fact that the etiology is unknown, there are references showing that the base of the autoimmune process would be desmosomes, structures acting as adhesion plates connecting epidermal cells known as keratinocytes<sup>(3)</sup>. For unknown reason, the desmosomes become antigenic, stimulating the production of antibodies that cause their own destruction and, consequently, loss of adhesion in a process called acantholysis. In the case of pemphigus foliaceus, acantholysis occurs in the granular layer; in pemphigus vulgaris, it occurs in the deepest layer of the epidermis, above the basal, this being the most severe form<sup>(3)</sup>.

In pemphigus vulgaris, this process leads to the formation of little ephemeral tense bullous lesions that arise in an isolated or generalized form in the apparently healthy skin. The fragility and consequent disruption of these bubbles lead to eroded, exudative and ulcerated injuries, which may result in loss of fluids and proteins, predisposing the person to dehydration, anemia and deep malnutrition<sup>(3)</sup>.

Although the individual with this condition may present large areas of healthy skin, it is noteworthy that the entire epidermis is vulnerable to further injury. Thus, any pressure on the skin, even during routine nursing care, may increase the injured area, a fact confirmed by the positive Nikolski sign (+). This signal is characterized by partial or complete detachment of the epidermis, due to the pressure of the finger on perilesional skin<sup>(3)</sup>.

Another common aggravating factor in the case of the aforementioned disease is the appearance of lesions in the oral mucosa, hindering the swallowing of food<sup>(4)</sup>. Esophageal, laryngeal and tracheobronchial injuries may also be present, causing

dysphagia, hoarseness and coughing. Eventually, injuries in the conjunctiva, cervix, urethra and rectum may arise<sup>(3)</sup>.

Given the cutaneous and/or mucosal lesions that are normally large, and the frequently debilitating nutritional condition, the person affected by pemphigus vulgaris becomes totally vulnerable to a range of risks, including infection, especially when in a hospital environment. This vulnerability is enhanced by a treatment based on high doses of corticosteroids, commonly used to control the disease<sup>(4)</sup>. In the irresponsive forms, treatment consists of the common administration of methylprednisolone, associated sometimes with immunosuppressants such as methotrexate or methotrexate<sup>(3)</sup>.

Pain is typical and complaints of itching may occur. In most cases, the lesions exude a characteristic foul odor, which leads to the attraction of insects that could cause myiasis infestation<sup>(4)</sup>.

The ignorance of the nursing staff, in relation to this clientele, can cause feelings of insecurity, fear and even loathing during the service. The expressions and actions as a result of these feelings, causing increasing stigma and suffering, counters a culture focused on improving the quality of care, aiming at humanization<sup>(5)</sup>.

Given that the professionals working in this area have a crucial role to play in promoting comfort, in the prevention of complications and even in the maintenance of the life of people with this disease, we present the following research question: What is the recommended nursing care for people with pemphigus vulgaris? To answer this question, the following goal was developed: to identify appropriate nursing care for people with pemphigus vulgaris.

Given the understanding of nursing as a profession that has its own and specific functions, in addition to the administration of prescribed medications, and the importance of these functions for the recovery of clients, we have chosen to use the philosophy of Virginia Henderson as a theoretical framework of this research. The choice was made

principally due to the fact that Henderson envisioned the role of the nurse as specific, autonomous and independent<sup>(6)</sup>.

In terms of autonomy and independence, Henderson emphasizes that it is necessary to understand the nurse as the central element in the life of the ill person, since it is this professional who, besides having his own functions, even when sharing it with other professionals, ensures that the requirements of the health staff are fulfilled. Thus, she states that the functions of the nurse and physician overlap, and also that society counts on the nurse, in view of the absence of other professionals who are prepared to play such a role<sup>(7)</sup>.

Henderson uses the following concepts: Person: she believes that mind and body are inseparable, highlighting the physiological, psychological, sociological and spiritual components. Society/Environment: it is focused on the individual; she argues that society needs nurses with the highest level of education. Health: she defines health as the individual's ability to become independent. Nursing: she highlights the need for the nursing culture as basis for the practice of individualized care and for solving scientific problems<sup>(6)</sup>.

## **METHOD**

The research involves a descriptive study, undertaken through an integrated literature review (LIR), which provides for the incorporation of scientific evidence into nursing practice. This method provides a synthesis of the knowledge available and the incorporation of the research results in practice<sup>(8)</sup>.

In this sense, we highlight evidence-based practice, which is a cyclical process of identifying clinical problems, followed by rigorous search of evidence as part of a critical evaluation, and the synthesis of the results for decision making in clinical practice<sup>(9)</sup>.

Thus, the results obtained using this method can support the implementation of interventions in the care of people; in this study specifically, those with pemphigus vulgaris. Therefore, it is necessary to develop devices, in the context of scientifically-based research, which are able to define more concise methodological stages and provide better use of the evidence.

Therefore, it becomes necessary to undertake six specific steps: 1) elaboration of the guiding research question; 2) searching or sampling; 3) data collection; 4) critical analysis of the selected articles; 5) discussion of the results; and 6) presentation of the review/synthesis of knowledge<sup>(8)</sup>.

Given the above, in the first stage, we considered the research question, as presented in the introduction, which is: What is the recommended nursing care for people with pemphigus vulgaris?

In the second stage, the inclusion criteria were set: we considered articles on pemphigus vulgaris available in full online, published in English, Portuguese or Spanish in national and international journals, from 2006 to 2010, related to the topic of the research. The electronic databases used were: SciVerse (SCOPUS), EBSCOhost research databases Online, U.S. National Library of Medicine (PUBMED), Wolters Kluwer Health (OVID), Nursing Database (BDENF), Scientific Electronic Library Online (SciELO), Literature of Latin American and Caribbean Health Sciences (LILACS). The search took place in January 2011, using the following key words: "nursing care" and "pemphigus".

In total, 129 articles were found, of which 91 were found in the Scopus database; 24 in EBSCOhost, 7 in PubMed, 7 in Ovid, and no articles in BDENF, SciELO or LILACS. Given the predominance of articles found in Scopus, we chose to use this one as a first option for the selection of articles, followed by EBSCOhost and PubMed. From reading the abstracts, 121 articles were discarded for not meeting the inclusion criteria mentioned. The full texts were accessed on their databases or on the journal's website. Of the eight

articles selected, it was observed that two were repeated in two databases, reducing the number to four articles. The distribution of the included articles is depicted in [Table 1](#).

**Table 1: Distribution of the articles found through Databases. Rio de Janeiro, 2011.**

<i>Databases</i>	<i>Articles Found</i>	<i>Articles Selected</i>	<i>Articles Repeted</i>	<b>Articles Included</b>
<i>Sci Verse</i>	91	3	2	<b>1</b>
<i>SCOPUS</i>	24	3	2	<b>1</b>
<i>EBSCOhost</i>	7	2	0	<b>2</b>
<i>PUBMED</i>	7	0	0	<b>0</b>
<i>Ovid</i>	0	0	0	<b>0</b>
<i>BDENF</i>	0	0	0	<b>0</b>
<i>SciELO</i>	0	0	0	<b>0</b>
<i>LILACS</i>	129	8	4	<b>4</b>
<i>Total</i>				

In the third stage, we performed the data collection. To determine the information to be extracted from the selected studies, we designed a form composed of the following variables: database, journal, article title, name(s) of author(s); professional category, year of publication, type of study and country of origin; summary of results; evidence of the study. Thus, data were collected from each article, using the criteria for the analysis of scientific communications<sup>(10)</sup>.

In the fourth stage, the critical analysis was undertaken based on the concepts of approaches to qualitative research. During the review process, we chose content analysis, a set of communication analysis techniques that uses systematic and objective procedures to describe the content of the messages. Such procedures are detailed and allow an understanding of the contents of the documents so that the contents of the documents can be unraveled<sup>(7)</sup>. It is noteworthy that the use of the hierarchical classification system in terms of the quality of the evidence includes studies adopting either a quantitative or a qualitative approach towards the assessment of the selected works.

This classification is made in six levels: level 1: evidence resulting from the meta-analysis of multiple controlled and randomized studies; level 2: evidence from individual studies using an experimental design; Level 3: evidence from quasi-experimental studies, temporal series or case-control studies; level 4: evidence of descriptive studies (non-experimental or based on a qualitative approach); level 5: evidence from case reports or experience; level 6: evidence based on opinions of expert committees, including interpretations of information that are not based on research, regulatory or legal opinions<sup>(12)</sup>.

Regarding the interpretation of the results, which is the fifth stage of the LIR, it is noteworthy that the data disclosed by the analysis of the articles were compared to the theoretical framework. From this analysis, it became possible to identify potential knowledge gaps, raise suggestions for further study, and expose conclusions and the biases of the research<sup>(8)</sup>.

In the last stage, we made a summary of the main results. This is a work of extreme importance since it accumulates the existing knowledge about the topic under consideration. This synthesis is organized into two thematic categories: A – a profile of the scientific productions in terms of care of the client with pemphigus vulgaris, from 2006 to 2010, and B - results regarding the assistance to clients with pemphigus vulgaris in evidence, which presents two subcategories: A - Drug therapy care, B - Nursing procedure care.

## **RESULTS**

### **Profile of the scientific productions related to the care of clients with pemphigus vulgaris, from 2006 to 2010.**

The four selected articles are presented in [Table 2](#).



**Table 2: Profile of the publications relate to the topic. Rio de Janeiro, 2011.**

<i>Database</i>	<i>Journal</i>	<i>Title</i>	<i>Author(s)</i>	<i>Professional Category</i>	<i>Type of study/ Country</i>
<b>Science Verse (Scopus)</b>	Koohsiung J Med Sci 2009; 25 (11)	Silver-containing hidrofiber dressing is an effective adjunct in the treatment of pemphigus vulgaris	Chich-Shan, Hui-Yu Hsu, Stephen Chu-Sung Hu, Hsiu-Hui Chiu, GwoShing Chen <sup>(13)</sup>	Physician and Nurses	Case study; China (Taiwan)
<b>Pubmed</b>	Dermatology Nursing. 2007; 19 (3): 269-272.	Pemphigus vulgaris: A short review for the practitioner	Guillen, S, Khachemoune A <sup>(14)</sup>	Physician dermatologist	Case study; USA
<b>Pubmed</b>	Dermatology Nursing. 2006; 18 (1): 20-25	Autoimmune Bullous Diseases: Diagnosis and management	McCuim, J.B., Hanlon, T., Mutasin,, D.F, <sup>(15)</sup>	Resident physician and Physician dermatologists	Review article; USA
<b>Ebsco host</b>	Nursing 2006; 36 (8)	Wound & skin care. Understanding pemphigus	Not specified <sup>(16)</sup>	Not specified	Review article; USA

All articles were published in English. Two were from North American authors, one from Chinese authors and another without any identification of authorship. It is noteworthy that, although the majority of articles were published in nursing journals (two in Dermatology Nursing and one in Nursing), there is a predominance of medical authors and/or co-authors. It is observed that only one article has a nurse as a co-author. Regarding the method, there are two case studies and two literature reviews, rated in evidence levels 4 and 5<sup>(12)</sup>. (See Tables 2 and 3)

**Table 3: Synthesis and evidence of the selected articles. Rio de Janeiro, 2011.**

Title of the article	Synthesis of the articles and Evidences
Silver-containing hidrofiber dressing is an effective adjunct in the treatment of pemphigus vulgaris <sup>(13)</sup>	Comparison of the evolution of a client with pemphigus vulgaris with 62% of body surface area affected. Before, the treatment used was conventional with hydrotherapy and the subsequent application of silver sulfadiazine and gauze. It was suggested that hydrofiber, with silver after cleansing with sterile saline and dressing change, be used every 3 days. Despite clinical improvement after four weeks, with pain reduction, less discomfort and time saving, further studies are needed to evaluate its efficacy. Case Study - Level of Evidence 5.
Pemphigus vulgaris: A short review for the practitioner <sup>(14)</sup>	It privileges clinical aspects, diagnosis and systemic treatment; it mentions the topical treatment with antibiotics and corticoids as adjuvants, aiming at local analgesia and the prevention of secondary infection. Case Study - Level of Evidence 5.
Autoimmune Bullous Diseases: Diagnosis and management <sup>(15)</sup>	Description of bullous diseases, including pemphigus vulgaris, favoring the diagnosis, physiopathology and drug therapy, including topical treatment with corticosteroids. It cites the care of lesions as an important component in the treatment plan. It refers to the use of occlusive dressings (extensive lesions) for the absorption of fluids. It recommends the treatment of erosions and ulcerations with compresses of clean and heated water 2 times a day, followed by the application of gauze with antibiotics or hydrophilic ointments. It points to the importance of the prevention of pressure ulcers and secondary infections. Literature review - Level of Evidence 4.
Wound & skin care. Understanding pemphigus <sup>(16)</sup>	It describes the signs, symptoms and complications of the disease. It cites the control of fluid loss, infection prevention and the promotion of reepithelialization. It refers to the use of high doses of corticosteroids, immunosuppressants, immunoglobulin and plasmapheresis. It mentions the importance of monitoring weight, blood pressure and performing hydric balance, in addition to the administration of corticosteroids after meals. It contraindicates the use of adhesive tape on the skin and points to the need to prevent hypothermia. It recommends administering analgesics before the treatment of lesions. It alerts to the possibility of weight loss and hypoproteinaemia in the cases of oral lesions, highlighting the need for oral hygiene, besides the use of oral analgesics or anesthetics. It contraindicates the use of mouthwash with antiseptic solutions containing alcohol, and indicates the use of chlorhexidine gluconate. It suggests a non-annoying cold scheduled diet with high protein levels and high calories, in addition to the use of supplements or parenteral nutrition. It suggests the use of lanolin or petrolatum for moisturizing the lips. It recommends a support group. Literature review - Level of Evidence 4.

### Pharmacotherapy care

One of the articles highlights that the three main goals of the treatment of the client with pemphigus vulgaris are suppressing the immune response (antibody production), inhibiting the inflammatory response and taking care of injuries<sup>(15)</sup>. It was found that, even within those articles published in nursing magazines, there was a predominant

focus on aspects related to the disease. These articles deal with the definition of the disease, the physiopathology, the clinical features, the signs and symptoms, and especially the systemic drug therapy<sup>(13-16)</sup> in specifically medical way, considering the topical treatment as merely complementary. Such a fact is certainly due to the fact that the selected publications are predominantly authored by medical professionals rather than by nursing professionals.

Systemic corticosteroids are cited as the basis of treatment<sup>(13-16)</sup> and the immunosuppressants as adjuvants in an attempt to reduce the dose of corticosteroids and thus, its side effects. Other medications, such as methotrexate, gold and tetracycline with niacinamide, are also referred to as complementary<sup>(14)</sup>, in addition to plasmapheresis, immunoglobulin and rituximab<sup>(14,15)</sup>. The choice of drug therapy is associated with the assessment of the client and the severity of the disease<sup>(14,15)</sup>.

Another fact that stands out in the articles is the lack of other aspects directly related to the administration of these medications, restricting themselves to the mechanism of action and side effects.

In relation to topical therapy, two studies mention the use of topical corticoids and antibiotics<sup>(14,15)</sup>, one of which recommends topical corticosteroids to control mild to moderate disease<sup>(15)</sup>. One of the articles mentions that the application of a topical immunosuppressant called tacrolimus may be succesful<sup>(14)</sup>. Only one article recommends the use of hydrophilic ointment to skin lesions<sup>(14)</sup> and another, petrolatum or lanolin to the lips<sup>(16)</sup>.

It is noteworthy that, although these articles recommend the topical application of these drugs, they do not address issues related to injury cleaning, the application of the product, and the protection of lesions<sup>(14,16)</sup>, which are extremely important for the care of these clients. Only one of the articles recommends that the erosions and ulcers should be treated with warm compresses and should be cleaned twice a day, with subsequent

application of antibiotic or hydrophilic ointment and gauze<sup>(15)</sup>. Only one article describes a study that aimed to evaluate the use of a dressing composed of carboxymethylcellulose, hydrocolloid polymer, water and silver ions<sup>(13)</sup>. Despite the positive aspects mentioned in the results, this study, as it was conducted on a single subject, does not prove the effectiveness of this coverage, hence the need for further studies.

Given the complexity involved in the care of this clientele and the range of nursing activities required for promoting comfort and preventing diseases, it can be stated that the articles found reflect a paradigm of care that is fully aimed at the biomedical model, focusing on the disease and the administration of drug therapy, without addressing other aspects concerning the completeness of the human being.

### **Nursing procedures care**

It is observed that the selected articles cite nursing care discreetly, in a few lines, usually at the end of the article, highlighting topical care as a complementary therapy to drug treatment<sup>(14-16)</sup>.

One of the articles highlights the need for preventing secondary bacterial infection, emphasizing that it may lead to sepsis. The importance of preventing crust formation on the lesions is also stressed, since it delays healing<sup>(15)</sup>. This article also mentions the need for frequent changes in position in order to prevent pressure ulcers, but it does not list the specifics of this nursing action with regard to a clientele that has already a fragile epidermis, in addition to extensive cutaneous lesions. With regard to the care of injuries, the use of a moisturizer dressing is recommended in an attempt to prevent excessive fluid and electrolyte loss, and the use of warm and clean compresses twice a day, and subsequent application of antibiotic or hydrophilic ointment and gauze<sup>(15)</sup>.

Another article, even though it deals with aspects of the disease, when mentioning nursing care, does not limit them to the care of injuries, citing other precautions such as measuring blood pressure; glucose monitoring; administering pain medication before the

execution of injury care; not using adhesive tape on the skin; preventing hypothermia; applying topical analgesics or anesthetics to the mouth after careful hygiene care; using mouthwash with antiseptic solutions such as chlorhexidine gluconate and avoiding those containing alcohol; encouraging the ingestion of foods that are cold, non-irritating and providing fractionated meals that contain hyperprotein, hypercaloric, oral or parenteral nutrition supplements, if necessary, and moisturizing lips with lanolin, petrolatum or lipstick. In addition, it also recommends providing emotional support to the client and sending him to a support group<sup>(16)</sup>.

It is also noteworthy that the social, emotional and spiritual aspects involving the education of the client and his family are not featured in any of the articles.

Given these results, it can be seen that there is a distinct shortage of bibliographic references and clinical studies focused on nursing care with regard to people with pemphigus vulgaris. This fact contributes to a service based on the biomedical model, that is, heavily slanted towards the fulfillment of prescriptions and basic care such as hygiene, the measurement of vital signs and referrals for exams.

Given the historical commitment of nursing to the maintenance and recovery of skin integrity, there is a need to offer a reflective criticism. This discussion may be centered on the complexity involved in nursing care for this clientele, and on the need to build a body of specific knowledge, taking into account the autonomy and independence of the nurse as advocated by Henderson<sup>(8)</sup>. In this regard, it is noteworthy that the content of the articles analyzed is superficial, and does not address the necessary details and the complexity involved in the process of nursing such patients, considering their physical, emotional/mental, social and spiritual dimensions.

Besides the above, the importance of scientific knowledge, of the experience and critical thinking performed for and with the person<sup>(1)</sup> is noteworthy, in an attempt to promote the dignified care that a human being deserves. In this sense, it is highlighted that the

presence of the nurse at the client's side is crucial, because only through this direct contact, will it be possible to build a specific body of knowledge.

Thus, such a construction will be developed in the context of the work process. It will be focused on the real needs of the person, and therefore recommended to nursing staff. As Virginia Henderson said: "I think the function performed by the nurse is basically a function of independence - of acting in the patient's place, when this patient lacks knowledge, physical strength or will to act for himself, as he would normally do when healthy, or in the execution of the prescribed therapy. This role is seen as complex and creative, as if it offered limited opportunities for the application of physical, biological and social sciences, as well as skills development based on it"<sup>(7)</sup>. In the eyes of the author, the nurse should never forget that care is the foundation of science and the art of nursing. The commitment to care also involves self-care, self-esteem, self-worth, altruism and respect for the person who takes care<sup>(6)</sup>.

## **CONCLUSION**

Despite the significant and indisputable importance of nursing care for people with pemphigus vulgaris, it can be concluded that there is scarcity of publications and especially research addressing the referred topic. The predominance of publications with evidence levels 4 and 5 is also unfortunate in the sense that this fact reveals the absence of clinical studies. There is an urgent need to undertake such studies, since they are important to the decision making process that provides welfare/comfort for the hospitalized patients with this pathology, thereby reducing the suffering caused by the disease and, consequently, hospitalization time and hospital costs.

Given the small sample with regard to the subject analyzed in this paper, and mainly because they do not include publications from Brazil, it is emphasized that this reality points to the necessity for building a specific body of knowledge for nursing in order to fill the gap in knowledge. Such a body must include the physical, emotional, social and

spiritual well-being, namely, the integrality of the human being, who, at some point in his life, was affected by this disease.

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**Euzeli da Silva Brandão:** Drafting the guiding question of the research, establishment of the criteria of inclusion and exclusion of articles, search for articles in databases, data collection, critical analysis of the selected articles, discussion of results, presentation of the review/synthesis of knowledge, elaboration of the article according to the standards of the journal.

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