

Experience of adults and older people with adherence to venous ulcer care



Experiência de pessoas adultas e idosas frente à adesão aos cuidados com a úlcera varicosa

Experiencia de adultos y ancianos a la adhesión para el cuidado de las úlceras varicosas

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ABSTRACT

Objective: To understand the experience of adults and older people with adherence to venous ulcer care.

Method: A qualitative study based on the concepts of Alfred Schütz's social phenomenology was carried out with 12 adults and older people undergoing venous ulcer treatment in a specialized service in the state of Minas Gerais. The interviews were carried out from October to November 2015, analyzed, categorized, and discussed based on the theoretical-philosophical framework adopted and on thematic literature.

Results: The following thematic categories emerged from the interviews: "beliefs and personal and social activities hindering adherence to care"; "being protagonists in the care relationship with venous ulcers"; and "motivation for adherence to care".

Conclusions: The intersubjective relationship established between patients with venous ulcers and healthcare professionals emerged as a driving force for adherence to care. Promoting the reciprocity relationship of perspectives between these social actors may promote greater adherence to venous ulcer care.

Keywords: Varicose ulcer. Nursing care. Interpersonal relations. Nursing. Qualitative research.

RESUMO

Objetivo: Compreender a experiência de pessoas adultas e idosas frente à adesão aos cuidados com a úlcera varicosa.

Método: Pesquisa qualitativa fundamentada em pressupostos da Fenomenologia Social de Alfred Schütz, com 12 pessoas adultas e idosas, em tratamento de úlcera varicosa em Serviço Especializado, em Minas Gerais. Os depoimentos foram obtidos de outubro a novembro de 2015 e analisados, categorizados e discutidos a partir do referencial teórico-filosófico adotado e literatura temática.

Resultados: Dos depoimentos emergiram as categorias temáticas: "Crenças, atividades pessoais e sociais dificultando a adesão ao cuidado"; "Ser protagonista na relação de cuidado com a úlcera varicosa" e "Motivação para aderir ao cuidado".

Conclusões: A relação intersubjetiva estabelecida entre as pessoas com úlcera varicosa e os profissionais de saúde emergiu como força potencializadora da adesão ao cuidado. Valorizar a relação de reciprocidade de perspectivas entre estes atores sociais pode promover maior adesão ao cuidado com a úlcera varicosa.

Palavras-chave: Úlcera varicosa. Cuidados de enfermagem. Relações interpessoais. Enfermagem. Pesquisa qualitativa.

RESUMEN

Objetivo: Comprender la experiencia de adultos y ancianos en el cuidado de la úlcera varicosa.

Método: Investigación cualitativa fundamentada en supuestos de la Fenomenología Social de Alfred Schütz, con 12 personas adultas / ancianas, en tratamiento de la úlcera varicosa en Servicio Especializado, en Minas Gerais. Los testimonios fueron obtenidos de octubre a noviembre de 2015, siendo analizados, categorizados y discutidos a partir del referencial teórico-filosófico y literatura temática.

Resultados: De los testimonios surgieron las categorías: "Creencias, actividades personales y sociales dificultando la adhesión al cuidado"; "Ser protagonista en la relación de cuidado con la úlcera varicosa" y "Motivación para adherirse al cuidado".

Conclusiones: La relación intersubjetiva establecida entre las personas con úlcera varicosa y los profesionales de salud emergió como fuerza potencializadora de la adhesión al cuidado. Valorar la relación de reciprocidad de perspectivas entre estos actores sociales puede promover mayor adhesión al cuidado con la úlcera varicosa.

Palabras clave: Úlcera varicosa. Atención de enfermería. Relaciones interpersonales. Enfermería. Investigación cualitativa.

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■ INTRODUCTION

Venous ulcers (VU) are considered a result of chronic venous diseases, which promote the destruction of the dermis and epidermis, with the potential to affect deeper tissues⁽¹⁾. They represent a social problem because they demand continuous care, which implies financial costs for healthcare systems. In addition to restricting individuals' functional capacity, negatively affecting their quality of life, VU may cause the distancing from activities of daily living and changes in social coexistence⁽²⁾.

Globally, the prevalence of VU is higher than other low limb ulcers, reaching more than 80% of cases^(1,3). This condition requires interventions of specialized multidisciplinary teams able to develop care based on evidence and, at the same time, encourage individuals with VU in the adherence to care, thus contributing to co-responsibility⁽⁴⁾. Edema treatment has practical importance for VU healing and an appropriate compression therapy is considered gold standard for the care of this type of wound^(1,4-5).

Scientific studies show that individuals with VU present low rates of adherence to compression therapies⁽⁴⁾, practice of physical activities and rest⁽⁶⁾, and adoption of healthy eating habits for weight control⁽⁷⁾. Therefore, low adherence to care aimed at VU treatment may lead to the maintenance of the wound and a high recurrence rate (62.2% of cases)⁽⁵⁾.

To minimize low adherence to VU care, the multidimensionality of the factors involved in this adherence must be considered. These factors are related to the treatment itself, characteristics of the disease, patients, social problems, healthcare services, and healthcare professionals. In addition, they affect the behavior and capacity of patients to continue their treatment. Therefore, they must be considered in the care plan⁽⁸⁾ of the individuals affected by venous ulcers.

Because the therapeutic process is not linear, difficulties may occur, leading to times of higher or lower adherence to the treatment. Therefore, adherence to VU care is a challenge that must be continuously faced, not only by the individuals affected by this chronic condition, but also by healthcare professionals⁽⁹⁾.

Regarding individuals with VU, challenges are related to limits inscribed in activities of daily living, and beliefs and values on care developed throughout life in the family and social context⁽¹⁰⁾. One qualitative study that discussed the self-care of women affected by VU showed difficulties associated with their hygiene, clothing and footwear, pain control, in addition to lack of complete adherence to rest, and topical and compression treatments⁽¹⁰⁾.

With regard to healthcare professionals, their greatest challenge is to encourage patients with VU, having tech-

nical/scientific and humanistic/relational skills as a basis to make them active participants in their own care⁽⁹⁾. One phenomenological study with nurses who provided direct care to women with VU in primary healthcare services showed that these women prioritized domestic work and family rather than their own care. In addition, they showed demotivation and beliefs on the treatment and recovery, which hindered adherence required to the treatment. With the purpose of obtaining adherence of these women to VU treatment, nurses reported the need for continuous care, supported self-care, and standardization of behaviors in the treatment⁽⁹⁾.

Understanding the factors related to adherence to VU care, the importance in deepening the discussion on relational issues involved in this care and the need for further studies stand out, especially regarding the intentionality of individuals with venous ulcers for the care of this chronic disease, considering recommendations of healthcare professionals.

In this respect, the following guiding questions emerged from the present study: How do individuals feel with regard to adherence to venous ulcer care? What is involved in adherence to this care? The objective of the present study was to understand the experience of adults and older people with adherence to venous ulcer care.

The perception of individuals regarding adherence to VU care may assist nurses in the identification of aspects of the care relationship between healthcare professionals and patients, which may contribute to the development of healthcare practices according to the needs that emerge from the intersubjectivity produced in this care relationship.

■ METHOD

This was a qualitative study based on Alfred Schütz's social phenomenology, originating from a thesis⁽¹¹⁾ that used the concepts of the social motivation theory as a guiding principle⁽¹²⁾. Motivation, considered intrinsic to the human being (existential), results from experiences inscribed in the intersubjectivity that emerges from social relationships⁽¹²⁾.

The present study considered that adherence of individuals to VU care is a human action that occurs in the world of life (*Lebenswelt*), space of social relationships regarding interactions among people. Based on these interactions, they acquired experiences, which, added to information transmitted throughout life, constitute the pool of knowledge. This knowledge place human beings in a particular biographical situation that expresses their position in the social sphere⁽¹²⁾. Even being in different biographical situations, human beings similarly select and interpret common

objects when focused on reaching similar purposes. This happens due to the congruence of the social relevance system that denotes reciprocity of perspectives⁽¹²⁾.

In this perspective, the intersubjective relationship between individuals affected by VU and healthcare professionals responsible for their care is presented as a driving force for adherence to care, when enabling the reciprocity of perspectives among the actors involved in care.

The present study was carried out in a public service specialized in the treatment of venous ulcers of a city in the state of Minas Gerais, Brazil (*Serviço de Bota de Unna*, in Portuguese). The service assists up to 40 people from Monday to Friday, with four people in the morning shift and four in the afternoon shift.

In order to have access to the service, individuals with VU are referred by physicians of primary healthcare units to an angiologist, who undertakes the initial care and, after an assessment, if necessary, prescribes antibiotics and suggests measures for edema (physical exercises for the lower limbs, elastic and inelastic compression therapy, and rest) and nutrition control. Once admitted to the service and having carried out pre-scheduling, patients are sent to the stomal therapy nurse, who evaluates them regarding biopsychosocial dimensions and monitors the wound evolution, emphasizing recommendations for edema control, nutrition, skin care, and dressing care. The change of the inelastic compression device (Unna boot) and topical therapy are carried out weekly by nurses with assistance from nursing technicians.

The researcher in charge (in process of obtaining a doctorate degree) received authorization from the service for the development of the study and, based on the list of patients undergoing chronic venous insufficiency treatment, initiated the first contact with possible participants.

Later, in order to recruit the study participants, the researcher was present at the service in the opening hours with the purpose of establishing a close relationship with them, to later invite them to participate in the study. For those individuals who agreed to participate, dates and times were scheduled for the interviews, according to their availability.

The following inclusion criteria were considered for participants' selection: adults or older people registered in the specialized service for treatment of chronic wounds with a venous ulcer diagnosis. No participant was excluded because the interviews' content was enough to answer the study questions.

Data collection occurred from October to November 2015 based on the interview with the following open question: How do you feel following recommendations

from healthcare professionals to treat your leg wound? In addition to this question, socioeconomic information and length of time living with the venous ulcer were included in the interview.

Twelve people with VU participated in the study. The definition of the number of participants occurred when the researchers considered that the content was enough to allow deepening, comprehensiveness, and diversity in the process of understanding the object studied.

The interviews were carried out within the facilities of the healthcare service, in comfortable private rooms that allowed the participants to answer the questions without interruptions. The interviews had an average duration of 50 minutes.

The participants were explained about the study objective, as well as the importance of their participation and signing of the informed consent form. Permission for the use of a recorder during the interviews was asked, in order to enable the full record of the interviews and their subsequent analysis. To ensure anonymity, entries were identified by the letter I, as in interview, followed by Arabic numerals corresponding to the order of the interviews (I1 to I12).

For organization, categorization, and analysis of the material obtained, reading and re-reading of each interview in full were carried out in order to understand the meaning of adherence to venous ulcer care. The unstructured material obtained from the convergence of meanings was organized, establishing categories emerged from the experience lived by the participants⁽¹²⁾. The results were discussed based on the concepts of Alfred Schütz's social phenomenology and thematic framework.

The research project was approved by a research ethics committee under protocol no. 1.235.302 and CAAE no. 41049015.2.0000.5392.

■ RESULTS AND DISCUSSION

The present study was made up of seven women and five men aged between 45 and 70 years, mean of four years of education level, and monthly income of one minimum wage. Five participants were on work leave due to VU and the remaining were retired. Most were Catholic, self-reported black, with a mean time of 13 years living with the chronic leg wound.

The perception of individuals with VU on adherence to care with this chronic condition was expressed in the following categories: "beliefs and personal and social activities hindering adherence to care"; "being protagonists in the care relationship with venous ulcers", and "motivation for adherence to care".

Beliefs and personal and social activities hindering adherence to care

The participants reported difficulty in adherence to rest, appropriate nutrition, and compression therapy. They also reported difficulty in total adherence to recommendations, adjusting care according to their beliefs and personal and social activities:

They recommend rest, guide me not to walk and stand all the time... but we always exaggerate a little bit. Sometimes, I have to do some things at the bank and end up not resting appropriately. (I1)

I bought the stocking, but it hinders my job and I also did not adapt to it much because it annoyed me, it was difficult to put on, but bricklayers need to move. (I3)

The doctor said I could eat tuna and that it has nothing to do with the leg wound. I only ate once. I do not eat hot and strong things such as pepper and cabbage! (I9)

Some participants disregarded professional recommendations because of their beliefs and values, which are entrenched in the care experience:

They recommended physical exercise, but I do not do it because I cannot go to the gym with this wound... (I2)

When the wound healed for the first time, they recommended me to use the stocking, but I used it for a while and quit... after the wound returned, I went to the doctor and he asked me to use the stocking, but, with the open wound, it is impossible to use it. (E7)

Rest, physical activity, and compression therapy are of utmost importance for VU healing and prevention of its recurrence. One literature review showed scientific evidence that indicates simple and practical measures to assist in edema reduction of the lower limbs, such as raising the legs when lying and avoiding an orthostatic position for a long time⁽¹³⁾.

Regarding the need for physical activity, one randomized study that evaluated the impact of an exercise intervention on patients with VU showed that participants who adhered to the exercise program as an adjuvant to the standard treatment had more healing chances and better functional results than those who did not adhere to exercises together with the conventional care⁽⁶⁾.

In order to act on issues that hinder the undertaking of physical activities and rest, healthcare professionals, before

producing the necessary recommendations, must learn individuals' routine to adjust schedules and time to be spent with these activities without negatively interfering with social and working activities. In addition, the belief that the presence of VU hinders the undertaking of physical activities must be demystified.

Regarding compression therapy, one Brazilian study carried out with 50 patients older than 18 years with post-healing VU, monitored for ten years, showed that the most significant recurrence prevention measures were the use of elastic stockings, resting, and applying hydrating cream to the skin of the lower limbs⁽⁵⁾.

Elastic compression stockings were mentioned by the participants as a device of difficult use. Considering its importance as a VU recurrence prevention measure, this must be emphasized to individuals with chronic venous insufficiency in their first consultation, and reinforced at each return to the healthcare service. In addition, it is important to list types of stockings, compression levels, as well as describe and show how to use them and indicate accessories that facilitate the use of this compression device.

Regarding the importance of nutrition, a phenomenological study carried out in Brazil showed that women's beliefs that certain foods may cause ulceration or compromise VU healing led them to abstain from ingesting them, considering them contraindicated for individuals with wounds⁽¹⁰⁾. Learning the universe of beliefs that are influencing food choice, as well as investing in demystification, means respecting and considering the cultural world of individuals with VU, understanding the specificity inscribed in this care space. Therefore, the replacement of foods mentioned as harmful to the healing process for others of the same nutrition value that ensure the necessary amount of proteins, mineral salts, and vitamins must be considered.

It is clear, in the perception of the participants, that non-adherence to care was also influenced by healthcare professionals' beliefs, especially nursing technicians, who reinforce common sense when dealing with care:

They recommended to avoid eating pork meat, cabbage. I avoid these heavy hot things. (I4)

They recommended some things regarding nutrition, such as to avoid eating peanuts, pepper, these spicy and hot things that hinder healing. I had already stopped eating many heavy things before their recommendation. (I6)

One systematic literature review showed that individuals affected by VU, in addition to having their quality of life

negatively affected, often received inappropriate care and guidance from healthcare professionals during their routine consultations⁽¹⁴⁾.

Failure to observe practice based on evidence may weaken care and, as observed in the present study, may reinforce behavioral patterns dictated by common sense, making it difficult for individuals to take care of themselves assisted by the best evidence produced for their health condition. One Brazilian study that carried out the clinical validation of a care protocol for individuals with VU in high-complexity healthcare services showed that this can be an instrument to assist in the comprehensive recovery of health, in addition to allowing care standardization, bringing benefits for patients, families, and healthcare teams⁽¹⁵⁾.

Beliefs allocated in the pool of knowledge of individuals with VU often hinder the use of compression therapies and adoption of healthy lifestyles, such as alternation of physical activities with rest and nutritional food choice, which could favor wound healing. In this perspective, the biographical situation and pool of knowledge of both individuals with VU and healthcare professionals are relevant and must be considered when adherence to care for this chronic disease is sought.

Being protagonists in the care relationship with venous ulcers

The participants showed dissatisfaction with the way they are approached by healthcare professionals regarding the meeting of their needs. Therefore, they expect that their point of view is also considered in care:

I want respect from healthcare professionals when I am searching for guidance. Once, an angiologist of this service called me filthy because I caught hookworm. I found him unpleasant and stopped consulting with him. (I5)

I went to a doctor who did not uncover my wound. I think he should have seen what was happening. He only touched my foot and said that my blood circulation was good, and that I should change the dressing at the service. That is why we do not believe in their recommendation. (I8)

The wound never gets better. I feel like not going to the doctor anymore. The nursing aide wants to do some things and sometimes I do not agree with her. I know that doctors and nurses have more knowledge than me, but I can have my opinion. I respect their opinion, but they must also consider mine. (I10)

Dissatisfaction with the way they are approached by healthcare professionals regarding their needs indicates a relationship of trust between individuals with VU and these professionals must be established, regardless of the category to which these professionals belong. This relationship must be understood based on reciprocity of perspective, where care is an act in continuing transformation.

One study carried out in Belgium showed that trust in healthcare professionals is of utmost importance for adherence to care of patients with lower limb ulcers. In this respect, patients must receive information about their condition, in order to understand their treatment and recognize their role in the healing process. Giving attention, listening, and advising patients enabled their familiarization with professionals, generating safety, especially to those who had negative experiences throughout their treatment⁽¹⁶⁾.

The participants reported that lack of professional guidance hinders the decision of becoming proactive with regard to activities they want to undertake for their self-care:

I feel like using the treadmill, but I do not know if I can...I have no guidance on this. (I11)

They did not recommend any exercise. I am waiting for them to see if I can walk, because I love to walk. It makes me lose weight and makes me happy. (I12)

One study that described the therapeutic process of patients with VU in outpatient care in Brazil highlighted that the search for professional care is not always decisive and shows tensions resulting from the organization of a care network that does not favor appropriate and fair care provision in the public healthcare subsystem. It pointed out the existence of individuals, often solitary, in search for care that is their right by the constitution, as citizens facing a healthcare system that should ensure them comprehensive care, but that still presents major weaknesses⁽¹⁷⁾.

The leading role of individuals with VU in care leads to the need for healthcare professionals to establish a therapeutic relationship enabling these individuals to participate in the care of their wounds. It is worth mentioning that in the chronic disease context, longitudinal care must be adopted by individuals during their entire life, being able to bring positive implications in their future projects. However, it implies co-responsibility of healthcare professionals and institutions. In this respect, shared care presupposes dialogue for the joint development of planning based on a priority chosen in negotiation between healthcare professionals and patients⁽¹⁸⁾.

To act on issues that hinder adherence to VU care, healthcare professionals must deepen knowledge on the daily life of these patients, in order to adjust recommendations to their reality. One study carried out in a city in the southern region in Brazil identified strategies used by primary health care nurses to promote self-esteem, autonomy, and self-care of patients with chronic wounds. It emphasized the importance of multidisciplinary work in the perspective of comprehensiveness and valuation of the social environment, including family and religion, so care planning for this population may be established in order to help them assume their responsibility in the disease control⁽¹⁹⁾.

In the present study, the importance of the intersubjective relationship established between participants and healthcare professionals who provide care for patients with VU as a driving force in adherence to care stands out. Considering the intersubjective universe that emerges from the care relationship to this population will allow nurses to transform the mere biologic care (focused on wounds) into care that considers the comprehensiveness of individuals with venous ulcers.

In this perspective, individuals with VU must be protagonists in the care relationship, which strengthens the intersubjectivity and reciprocity of perspectives between healthcare professionals and users, with positive consequences in adherence to care of this chronic disease.

Motivation for adherence to care

The perspective of adhering to VU care refers to the possibility of improving the quality of life of these individuals, who, due to the presence of the wound, find themselves affected:

I want to follow the recommendations I receive because I am weak in several parts of my life, for example, I cannot walk or do certain exercises because I cannot force my leg. I cannot go to gym, do physical activities. (12)

I want to follow treatment and recommendations appropriately to be able to heal and wear skirts and dresses again... It is impossible to wear them because of the bandage and Unna boot... I want to go for my walks. I am restricted to do the things I like. (16)

I hope my wound gets better, because I want to cheer up... I will keep care, return to the doctor, rest... If the stocking is worn, I will go to the doctor and ask for a new prescription to buy another stocking. (19)

I want to do whatever I can to treat my wound. My life would be different without this wound. I would do more for others and for me. I would be free because I feel imprisoned. Everybody wears shorts, skirts, but how can I wear them with these legs? (111)

Due to the wounds, individuals with VU need self-care in order to recover health and socially reintegrate themselves. However, because it is a chronic disease, whose treatment is complex, they find difficulties in the management of this care⁽¹⁰⁾.

One study carried out in the northeastern region of Brazil compared the quality of life of patients with chronic venous diseases with and without an ulcer. It concluded that all aspects of quality of life were more compromised in individuals with VU, with emphasis on physical aspects and functional capacity, dimensions that showed the lowest scores, in addition to social and healthcare aspects⁽¹⁴⁾.

Reflection on the negative impacts of VU on the quality of life of the participants leads them to have as a goal, adherence to care guided by healthcare professionals to recover the integrity of the limb affected and recover their activities of daily living. One study carried out in the southeastern region of Brazil with people affected by VU using Unna boots indicated as main expectation, the maintenance of the compression treatment as a possibility of healing, prevention of recurrence, and improvement in quality of life, with the aim of recovering functional capacity and activities of daily living affected⁽²⁰⁾.

In order to achieve the purpose of wound healing and resume personal and social life, healthcare professionals and patients with VU must develop adherence as a possibility of shared care based on the reciprocity of perspectives of those involved in this therapeutic relationship.

■ CONCLUSIONS

In the perception of the participants, the possibility of improving quality of life and the desire to be protagonists in VU care proved to be important to achieve adherence to care of this chronic condition. However, beliefs and personal and social activities were factors that hindered adherence to the venous ulcer care. The social context emerged as a determining aspect, both in strengthening and weakening this adherence. Therefore, increasing autonomy of individuals with VU, understanding the biopsychosocial needs that emerge from their life context, adjusting care technologies to make them more horizontal, in addition to strengthening adherence to care, allow healthcare professionals to provide health care in a warm and decisive way.

As a limitation of this study, it is emphasized that the perspective of adherence to VU care was limited to the social group interviewed in a specific reality. As a characteristic of a qualitative study, the results found cannot be generalized. In spite of this, the ground of the findings based on Alfred Schütz's social phenomenology allowed reflections that enable to value the intersubjective relationship and reciprocity of perspectives between healthcare professionals and patients with VU, which may enable greater adherence to care.

These findings are expected to contribute to the health care of individuals with VU in the different services of the healthcare network; and improve education and healthcare knowledge, especially in the nursing area of stomal therapy. In addition, they are expected to encourage further studies with nurses as protagonists, with the aim of broadening the discussion on adherence to care by individuals affected by venous ulcers.

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