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Representations and practices of patients with vasculogenic ulcers on quality of life

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Representações e práticas de pacientes com úlceras vasculogênicas sobre qualidade de vida

Representaciones y prácticas del paciente con úlceras vasculares sobre la calidad de vida

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ABSTRACT

Objective: To identify the social representations and practices of patients with vasculogenic ulcer about their quality of life.
Method: Qualitative research that applied the Social Representations theory. Participants were 30 patients with vasculogenic ulcers registered at a health unit in Rio de Janeiro. Data was collected through semi-structured interviews, and lexical analysis was applied. Results: The social representations about the quality of life of the patients were built from the affections arising from the changes in their lives. Thus, losses arising from the reconfiguration of daily life led to a negative symbolic construction about themselves and their lives, which resulted, on the one hand, in proactive self-care behaviors and, on the other, in less self-care.
Conclusion: Care for health promotion and social support is required to re-signification of life with ulcer and the adoption of new coping practices.

Keywords: Quality of life. Leg ulcer. Psychology social. Nursing. Primary health care.

RESUMO

Objetivo: Identificar as representações sociais e práticas de pacientes portadores de úlcera vasculogênica acerca da sua qualidade de vida.
Método: Pesquisa qualitativa, com aplicação da teoria das Representações Sociais. Os participantes foram 30 pacientes com úlceras vasculogênicas cadastrados em uma unidade de saúde do Rio de Janeiro. A coleta de dados ocorreu por meio de entrevistas semiestruturadas, e a análise foi lexical.
Resultados: As representações sociais sobre a qualidade de vida se construíram a partir dos afetos oriundos das mudanças na vida dos pacientes. Assim, as perdas oriundas da reconfiguração do cotidiano direcionaram a uma construção simbólica negativa sobre si e a sua vida, a qual resultou, de um lado, em comportamentos proativos de autocuidado e, de outro, com menor cuidado de si.
Conclusão: Cuidados de promoção da saúde e suporte social são requeridos para a ressignificação da vida com a úlcera e adoção de novas práticas de enfrentamento.

Palavras-chave: Qualidade de vida. Úlcera da perna. Psicologia social. Enfermagem. Atenção primária à saúde

RESUMEN

Objetivo: Identificar las representaciones sociales y prácticas de los pacientes con úlceras vasculares sobre su calidad de vida.
Método: Investigación cualitativa, con aplicación de la teoría de las representaciones sociales. Los participantes fueron 30 pacientes con úlceras vasculares registrados en una unidad de salud en Río de Janeiro. La recolección de datos ocurrió a través de entrevistas semiestructuradas, y se realizó el análisis lexical.
Resultados: Las representaciones sociales sobre la calidad de vida se construyeron a partir de los afectos derivados de los cambios en la vida de los pacientes. Así, las pérdidas derivadas de la reconfiguración de la vida cotidiana llevaron a una construcción simbólica negativa sobre sí mismo y su vida, que derivó, por un lado, en conductas proactivas de autocuidado y, por otro, en un menor autocuidado.
Conclusión: Se requieren cuidados para la promoción de la salud y apoyo social para la construcción de nuevos significados sobre la vida con la úlcera y adoptar nuevas prácticas de afrontamiento.

Palabras clave: Calidad de vida. Úlcera de la pierna. Psicología social. Enfermería. Atención primaria de salud.

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INTRODUCTION

Ulcers of vascular origin are a serious problem worldwide, as they account for high morbidity and mortality rates and cause a significant social and economic impact, due to their recurrent nature and the long time between the time of onset of the ulcer and healing. These wounds are characterized by a chronic, painful, recurrent process, with a negative impact on the quality of life of patients (1).

According to the World Health Organization, quality of life is defined as the individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns(2). This concept is marked by subjectivity and involves the physical, psychological, social, cultural or spiritual components.

Studies show different aspects that substantially affect the quality of life of patients with vasculogenic ulcers (3–6). Pain is one of the most reported symptoms. A systematic review of symptoms and health-related quality of life in patients with venous leg ulcers indicated that treatment-related pain has significant impacts on sleep, mobility and mood (3).

Regarding psychosocial aspects, different international studies address this type of impact on quality of life (4–6). One study aimed to describe the negative social impacts and damage to the quality of life of patients with chronic venous leg ulcers. It was found that their ability to work, to carry out household tasks and perform personal hygiene could be compromised. The patients also experienced negative feelings such as shame, loneliness, frustration, with higher levels of depression and anxiety (4).

The findings are supported by a study that assessed anxiety, depression, self-esteem and loneliness in 102 patients with venous leg ulcers. Patients had higher scores on the anxiety and depression scale compared to healthy patients, and women's anxiety and social isolation scores were higher than men's (5).

The impacts of vasculogenic ulcers reported in the literature indicate that quality of life is an object of social relevance (7) for this group. Therefore, the theoretical assumption that these individuals elaborate social representations (SR) about their quality of life was considered. These social representations would influence the way individuals with vasculogenic ulcer relate to themselves and to the world around them, guiding behaviors that portray the way they face the condition and adhere to the therapy prescribed.

As for the identification of SR phenomena, it should be noted that the selected group does not always represent a certain object, as this object must have social thickness and sociocultural relevance to the group (8). Therefore, since quality of life is considered a phenomenon of psycho-sociological knowledge for this group, it is understood that the referred object has an imagery dimension that portrays this social thickness.

This can be explained by the fact that body image and aesthetic aspects are overvalued in today's society, in which great importance is attached to desirable bodily characteristics. This ideal body image is not possible for individuals with venous leg ulcers, and they are stigmatized. Thus, patients with leg ulcers fear social exposure and are not satisfied with their bodies. They have low self-esteem and negative feelings about their bodies (9–10).

This social image of people with venous leg ulcers mobilizes thoughts and feelings that result in pressure for the subject to produce explanatory theories, which are the starting point of social representations and practices (7).

Finally, analysis of American and Caribbean Literature in Health Sciences (LILACS) and Online Medical Literature Analysis and Retrieval System (MEDLINE) databases) led to the identification of 542 articles with the crossing of descriptors "leg ulcer|" and "quality of life". After application of the selection criteria and exploratory reading of the contents, 20 articles on the subject were analyzed. Of these, 16 were quantitative studies that aimed to measure quality of life, validate instruments and/or test their effectiveness and three attempted to understand subjective dimensions of the quality of life of patients with vasculogenic ulcers.

Therefore, based on this analysis, knowing the socio-symbolic meanings of patients about quality of life, how such meanings are constructed and how they affect the actions of these individuals is relevant, as it will contribute to expanding knowledge in this psychosocial perspective on the quality of life of patients with vasculogenic ulcers.

Furthermore, the knowledge generated can be applied in the proposition of care technologies that meet the comprehensive health needs of patients with vasculogenic ulcers, to improve their quality of life. Therefore, the present study aims to identify the SR and practices of patients with vasculogenic ulcers regarding their quality of life.

METHOD

Qualitative research based on the Social Representations theory, in the procedural aspect. The SR concern the way individuals think and interpret phenomena, considering the relationships they establish with others in their daily routine, which allow them to construct a framework of references that guides them and facilitates the interpretations of their own lives [7].

Regarding the phenomenon of investigation, having a chronic wound that does not heal, or takes a long time to heal and may recur, totally interferes with someone's quality of life. Therefore, the choice of approaching the object in the light of social representations offers theoretical support to analyze the participants' experiences related to quality of life, establishing links with the modes of expression of this subjective experience in the lines of action established by the patients, especially with regard to self-care.

The research was conducted in the city of Rio de Janeiro, Brazil, in a "Clínica da Família" – a large basic health unit composed of teams of the Family Health Strategy, and the locus was the Dressing Room of the unit, a sector that assists an average of 20 patients daily. At the time of the research, 86 patients were registered in the sector. They were undergoing clinical follow-up for chronic ulcers (neuropathic, vasculogenic) and acute injuries (operative wounds, excoriations, abscesses). Care was provided by nursing technicians, under the occasional supervision of a nurse.

Patients selected according to the following criteria participated in the research: age group over 18 years old; no neurological limitations that interfered with speech; patients with vasculogenic ulcers in the lower limbs for more than 90 days, which is the time during which the tissue can heal, so that the ulcer is no longer a chronic ulcer.

Patients with vasculogenic ulcers who had other chronic diseases or severe comorbidities were excluded from the study, as these conditions significantly affect quality of life and could impact the elaboration of the SR; and patients who showed signs of cognitive deficits at the time of data production, which were evaluated for the coherence of responses to questions made by the researcher during field exploration**.**

Following approval of the project by the Research Ethics Committee, the researcher collected the data in the study setting, from September 2017 to January 2018. Then she approached the individuals assisted in the Dressing Room and the staff, in order to create a bond with these people and become familiar with the reality to be investigated**.**

After this initial contact in the study setting, 30 of the 86 registered patients were included, based on the research inclusion criteria. The reason why only 30 patients, who accepted the invitation to participate in the research, were selected is the fact that the operation of the unit was discontinued during the research period, due to lack of inputs. After a detailed analysis of the collected material, it was concluded that the material was sufficient to the understanding of the phenomenon and dimensions of Social Representations. Furthermore, the number of selected participants reached a consensus among experts in qualitative approach on the adoption of a minimum amount of 30 participants for analysis with density of the phenomenon[11].

Data were collected through semi-structured interviews. A guide divided into two parts was used: the first part aimed to outline the sociodemographic profile of the participants. The instrument contained data on age, time since ulcer onset, education, professional activity, family income and physical activity**.**

The second part of the interview guide explored information related to meeting the research objectives. The 11 questions in this section concerned patients' daily life, i.e. daily activities, changes in life, difficulties, contact with the health service. The interviews, which lasted an average of 20 to 30 minutes and were recorded on an mp4 digital device, were carried out in a room of the unit, after the patient had the bandage changed, to avoid any interference.

Data from the application of the instrument to identify the sociodemographic profile were used in the construction of command lines that separate the interviews that constitute the corpus. The latter was revised, organized and submitted to Alceste software, version 2012. Alceste's objective is to quantify the text in order to extract its most significant structures. In the present study, the software performs a lexicographic analysis, in which the statements are classified and lexical profiles are compared. It seeks to apprehend the lexical worlds that structure the subjects' speeches and give coherence to their statements [12].

In lexical analysis, the words of the corpus were counted, and progress was systematically made towards the identification of the holistic dimension of the text. The process involved the identification of the total number and the types of words used in the vocabulary.

In this process, the semantic roots of the words were grouped and the lexical classes were defined, considering the function of the word. Association of the vocabulary and variables characterizing the participants to the classes was expressed by a chi-square value (Phi^2). In this article, the result of the Descending Hierarchical Classification (DHC) was used for further analytical analysis. The DHC aims to classify and group the statements into classes marked by vocabulary contrast. Thus, after crossing reduced forms and elementary context units (ECU), the classes of ECU that have similar vocabulary and which differ from the vocabulary of ECU of other classes. Thus, the relationships of content between classes, of opposition and similarity, were analyzed with a tree diagram (hierarchical cluster) and based on ECU and excerpts from interviews selected by the program (12).

The project was approved by the Research Ethics Committee of the study field, under protocol no 1.836.571. An Informed Consent Form was signed by the participants. The confidentiality of the participants was guaranteed through identification by a coding generated by Alceste, in which Ind=individual is followed by the Arabic number of the order of selection of the participant.

RESULTS

Regarding the sociodemographic profile of the participants, the following characteristics stand out: 60% were women; 50% were married; 50% were aged 51-70 years; 57% had a family income between two and three minimum wages; 70% had incomplete primary education; for 45% the time elapsed since ulcer onset was 3 to 10 years; 47% were evangelicals; 90% did not practice physical activity.

In the corpus composed of interview recordings with 30 participants submitted to the Alceste software,2,983 different forms or different words were obtained, with 32,182 occurrences. The corpus was divided into 679 ECU and, in two descending hierarchical classifications the same subdivision into two building blocks of classes was maintained, and a total of five lexical classes and 63% of use as shown in Chart 1.

The corpus was initially divided into two parts: one that originated classes 1 and 2, and another that generated class 5 separately. Then, this second part was divided again to generate classes 3 and 4. Thus, two large building blocks of lexical classes were organized. Analysis of the approximations and distances between the lexical classes showed that the block of classes that was structured around classes 3, 4 and 5 revealed aspects of the quality of life of patients with vasculogenic ulcers, the difficulties faced and the effects of the disease on their lives, which is the focus of this article.

Class 5 was formed by 55 ECU, and corresponded to 13% of the corpus. This class was characterized by the statements of patients with vasculogenic ulcers about the physical repercussions of this condition and the limitations faced by the patients in their daily lives. The lexicons "sitting/to lie down" that made up class 05 were the ones that had the greatest statistical association (Phi^2) and referred to the patients' need for rest, due to the physical repercussions of the presence of a vasculogenic ulcer.

> *So I do almost everything while sitting. At night, as I don't sleep early and watch movies, I stretch my leg up on the couch until my foot touches the wall* (ecu no 21, ind 01)
>
> *I spend most of my time lying down rather than standing; when I walk I usually feel a lot of pain, I lay down for a long time, watching television. When I feel better, I prepare a meal, but sometimes I can't even do that... if I stand for a long time, I feel pain.* (ecu no 172, ind 11)

The lexicons "difficulty", "food", "bath" referred to the efforts made by the patients to perform their daily activities due to the physical limitations caused by the wounds. Thus, these difficulties impact the performance of routine activities such as taking a shower, preparing a meal, as well as going up or down stairs.

> *Nothing is normal, not even my bath. I haven't taken a regular shower in years because of the dressing on my foot. I take a shower sitting on a chair because I'm afraid of losing my balance... my life has completely changed.* (ecu no 506, ind 23)
>
> *Yes, there are a lot of things I can't do for a long time, like standing up for a long time, I just can't. If I have to wash dishes, I can't stand up all the time... I can take a shower by myself, because I place my foot on a chair during the shower so as not to get it wet, but not for a long time* (ecu no 43, ind 03)

Pain was the main physical symptom expressed by patients who have this type of wound, as expressed by lexicons "pain/it hurts", "swollen". The testimonies of patients about the variable intensity of pain indicated that the pain manifests itself according to the etiology of the wound. Among the main effects caused by pain mentioned by patients, change in sleep pattern was one of the most frequent, expressed in lexicons "I sleep/sleeps".

> *No, I can do everything. Sometimes I feel pain... I had a burning and itching sensation in the wound area because I didn't change the dressings. The wound usually only hurts at night and I can't always sleep well because of that, I don't sleep well, it's like a bird that is always pecking, pecking.* (ecu no 36, ind 02)
>
> *At night, I can watch the soap opera, read the Bible a little, but the pain, the pain interferes with everything,*

CLASS 1		CLASS 2		CLASS 3		CLASS 4		CLASS 5	
Form	**Phi**	**Form**	**Phi**	**Form**	**Phi**	**Form**	**Phi**	**Form**	**Phi**
Find	0.29	technique	0.43	children	0.41	lunch	0.51	sitting	0.44
problem	0.23	nursing	0.43	create	0.37	coffee	0.48	to lie down	0.38
treatment	0.20	calls	0.38	grandson	0.37	to wake up	0.41	sleeps	0.36
I know	0.19	fair	0.29	woman	0.33	machine	0.30	foot	0.35
cure	0.19	assisted	0.29	party	0.28	street	0.30	pain	0.28
of	0.17	to ask	0.27	bus	0.28	morning	0.27	mad	0.25
better	0.17	I arrived	0.26	to	0.25	owner	0.26	food	0.25
good	0.16	Monday	0.26	beach	0.25	schedule	0.26	difficulty	0.25
to live	0.16	Friday	0.24	car	0.24	hour	0.24	to stay	0.24
to close	0.15	ointment	0.22	to	0.23	work	0.24	above	0.24
person	0.15	Unna's boot	0.21	to catch	0.21	school	0.23	normal	0.24
lack	0.14	change	0.21	to die	0.21	I go	0.21	whole	0.22
treatment	0.14	bandage	0.20	to study	0.21	dinner	0.21	I sleep	0.21
ulcer	0.14	antibiotic	0.20	to teach	0.18	square	0.21	example	0.21
angiologist	0.13	serum	0.20	almost	0.18	I give	0.21	chair	0.19
thinks	0.13	father	0.19	will	0.18	afternoon	0.21	swollen	0.18
government	0.13	did	0.17	to see	0.17	to wash	0.20	it hurts	0.17
must	0.12	oil	0.17	hurry	0.18	to take	0.20	I do	0.17
physician	0.12	sir	0.16	corner	0.18	to like	0.19	larger	0.17
of this	0.13	I came	0.16	I met	0.18	with	0.19	If there is	0.17
condition	0.12	nurse	0.15	shopping	0.18	hunger	0.18	leg	0.16
to complain	0.12	calls	0.15	to like	0.15	course	0.18	bath	0.15
abrir	0.11	cuts	0.14	brother	0.14	to separate	0.18	equal	0.15
health	0.12	type	0.14	to stop doing	0.15	son	0.18	home	0.14
materials	0.12	exam	0.14	travelled	0.15	clothe	0.18	much	0.15
appointment	0.12	hospital	0.14	man	0.15	home	0.17	to relax	0.15

Chart 1 – Dendrogram of Descending Hierarchical Classification, Rio de Janeiro, RJ, Brazil, 2018

Source: Alceste Report. Rio de Janeiro, RJ, Brazil, 2018.

> *this pain is terrible, I don't wish it on my worst (enemy).* (ecu no 407, ind 20)

In the following statements, the patients showed that pain reminds them of great suffering, something that evokes a negative meaning, causing discomfort, distress, affecting the perception of their well-being.

> *And it's not a pain that lasts for an hour or half an hour, it can last for seven, eight hours, or even all day and night. I'm in pain again now. I can alleviate this pain by sitting all day with my leg up. No, I feel a lot of pain, it's bad, because I would like to walk, to do something* (ecu no 408, ind 20)
>
> *I don't wish this pain on my worst enemy. It's terrible, and when it is cold the pain is excruciating and sometimes I wish I could chop off my leg to be free from this pain.. May God forgive me for this, but it is awful.* (ecu no 476, ind 22)

Class 4 consisted of 40 ecu, which corresponds to 9% of the corpus. It had links with class 5, as it described how patients experience their daily lives expressed in the morning, afternoon and night shifts. They reported that despite the difficulties, they try to perform their daily activities.

It was found that the words lunch, wake up and coffee provided a reference for dividing the periods of the day by the patients. Their routines are inserted based on this division. The patients try to keep their routines by performing simple and common actions, expressed in the action verbs I go/I give.

> *My routine is similar to any housewife's routine.. I wake up, make coffee for myself and my husband, my son leaves for work, then I clean the house and my husband helps me He goes out to buy food for lunch, if necessary.* (ecu no 640, ind 29)
>
> *I wake up, make lunch, sweep the house, wash the bathroom and hang the clothes on the clothesline. I do my homework. I don' like going out, I never did.* (ecu no 153, ind 10)

The statements of this class revealed the important role played by women, identified in the ecu of participants 10 and 29, where despite having to take care of themselves because of the clinical manifestations of the disease, women keep their identities that direct them to the role of caring for their families. Thus, despite the difficulties, they try not to neglect their social function at home. On the other hand, the lexicons "street", "work" and "square" showed that many patients also try to carry out their daily tasks at home, reconciling them with work activities or other tasks.

> *So I wake up and try to get the children ready for school as soon as possible. If I'm at home, I clean the house, I prepare lunch and go straight to work, because I work two shifts: there are days when I work from noon to seven pm.* (ecu no 373, ind 19)
>
> *My routine is hectic, I wake up at dawn around four o'clock in the morning to work, I don't have breakfast at home, I only have breakfast when I arrive at the firm. I work from 8 am to 6 pm.* (ecu no 115, ind 07)

Living with a vasculogenic ulcer causes changes in routine and activity planning, increasing responsibilities with health care, because the patients must go to the health unit. This responsibility was observed in the approximation of the verbs "to wake up and I come", linked to the fact that after carrying out their activities at home, patients must go to the health unit for the dressings.

> *I wake up, make coffee, put clothes in the washing machine, go out to buy bread, and after everyone leaves, I come to the health unit. I like coming here to the health unit in the morning because sometimes when my dressing is very wet, even the mattress gets wet.* (ecu no 540, ind25)
>
> *This is my routine: I wake up around five-fifteen in the morning. I have breakfast, go to work at the newsstand where I stay from six to three in the afternoon. I go back home for lunch, then I come here to the unit for the dressing and finally go home.* (ecu no 105, ind 06)

Class 3 was composed of 34 ecu corresponding to 8% of the corpus content. It was based on the testimonies of patients who addressed the importance of family processes and restrictions related to social interaction and leisure practices. Support strategies created to deal with such restrictions were also reported.

The impact of changes related to vasculogenic ulcers on family life causes the social withdrawal of patients affected by this condition. Because of the smell of the wounds, the need for daily dressings and the repercussions of dressings on self-image, patients tend to avoid social interactions. This statement is supported by the ecu below, which portrayed social habits before and after the ulcer expressed in the verb to go/used to go:

> *I rarely go to Niterói, because staying at other people's houses is a bit complicated. When I used to go there, I usually stayed for a week, or about fifteen days. My sisters have a house in Mangaratiba, on the beach.* (ecu no 450, ind 21)
>
> *I hardly ever leave home. Last year I didn't even visit my sisters, I only went to Mass on Sundays. The disease interferes with many things we want to do, such as traveling. I like to travel because I have relatives in São Paulo.* (ecu no 449, ind 21)

When respondent no 21 reported that she likes to travel, to go to church, to go out to see her family, but rarely manages to do this, it can be affirmed that the presence of this type of injury significantly interferes with freedom/autonomy. This interference brings out family solidarity and the social support network. The patients rated as positive the fact of visiting or receiving a visit from their family members, and as negative giving up seeing their family members because of the wound.

> *The only thing that is positive for me is when my family visits me at home on the weekend to see my grandchildren, my children. This happens at least once a month as I cannot visit them. I consider everything else negative, such as not being able to do everything I've always done.* (ecu no.606, ind 27)
>
> *Not being able to see my relatives when I want, not being able to go to the places I want, when I want is something negative. I helped to raise my grandchildren and today I rarely see them.* (ecu no 645, ind 29)

Social support networks play a decisive role in the greater or lesser impact of the ulcer on people's lives. This is explained by the fact that patients with these wounds depend on others to carry out their daily activities, that is, to get around/ displacement. The lexicons "bus" and "car" illustrate the influence of the difficulty of getting around on a bus and the importance of a car in maintaining the patient's active social life, which can generate a feeling of dependence.

> *Sometimes I would go by car, or take a ride, but depending on others is not good, I don't like it very much.* (ecu no 414, ind 20)
>
> *Something besides money. A car would be useful because I would no longer depend on buses. Sometimes I take a van, but they are not easily accessible to me.* (ecu no 491, ind 22)

The lexicons "party", "shopping", "to travel" were related to social interaction and leisure aspects that patients gave up because of the vasculogenic ulcers. Thus, physical limitations lead patients to stop performing the social activities they liked the most and the activities they performed. The verb "to stop" indicated these social losses, meaning "to stop doing something".

> *I think I could do that, but I felt discouraged. Before this condition, I had a normal life. I used to go out and dance when I was younger, to parties, to the beach, to malls, everywhere.* (ecu no 526, ind 24)

On the other hand, some patients tried to overcome this challenge, seeking support in religion, at work and in their own family. Some reports suggested that hope is related to faith in a superior/divine existence, which gives strength and nourishes the desire for improvement and cure, reducing anxiety in the face of this situation.

> *Well, I work from 5 to 9 pm. I really enjoy it. I can't stay still. I don't think it is bad, I'm not sad. I try to stay active to keep my mind busy. I'm afraid of worrying too much because I've already had a thrombosis. (ecu no 34, ind 2)*
>
> *So I learned that, I learned how to take care of myself. You must have a God inside you, ask that God to give you strength, this is the best solution, strength and self-control.* (ecu no 593, ind 26)

DISCUSSION

Social Representations can be understood as a modality of knowledge that measures behavior and guides communication between individuals, helping to understand social changes. They are based on the social influences of communication, constituting the reality of everyday life and are the main vehicle for establishing the associations with which people connect with each other (13).

Thus, the concept of SR makes it possible to understand how social actors apprehend common life events, environmental data, circulating information, as well as capturing thoughts, feelings and shared life experiences, through different communication modalities related to the social context to which they belong (13).

Regarding the SR on the quality of life of patients with vasculogenic ulcers, the thought about living well/living better is built from the impacts of this condition on the maintenance or change of the patients' daily life activities, due to the presence and intensity of the clinical manifestations of the disease and the therapeutic care needed.

These impacts circulate in the conversations of the social groups, especially the shared experiences of the presence of pain, which include negative affections, negative"; "everything is negative". Pain is described as "the worst thing"; that causes suffering; "terrible" like the image of an enemy.

This connotation is relevant because, in addition to the physical effect of the pain that sometimes provokes in the individual the desire to "rip off his/her own leg", the occurrence and intensity of pain reconfigures the patients' daily lives, because of the need to avoid it or minimize its effects through the adoption of behaviors that restrict their lives. This reconfiguration is identified in the statements of patients who compare their past lives to their present lives.

Therefore, patients use expressions such as: "I can't do it anymore"; "I would like to do it again"; "I don't do it anymore" to address the changes experienced. These changes bring to light the restrictions imposed on the individuals in their daily care (nutrition, hygiene, physical activity), illustrated, for example, in the following report: "I haven't taken a normal bath for a long time"; and they also expose social losses, when patients fail to perform social integration activities, such as traveling, visiting family members, going to church, because of their physical limitations, due to the need for medical follow-up or embarrassment due to the social image, or else the views that others have of them.

The current reconfigured life is characterized by long periods of rest, referred to as: "I spend more time lying down than standing"; "just lying down, sitting". This affects the autonomy and independence of the patient, who needs the help of others to perform his/her routine activities, bringing up his and his life's affections.

Quality of life must be understood from a multidimensional perspective, encompassing components that have a complex and dynamic organization. These components include "the being", what the human being is in the individual field, which has to do with the physical, psychological and spiritual aspects, and encompasses nutrition, physical fitness, values, individual skills, and experiences; "belonging", which refers to connections with the environment, home, work, community, social groups; and "becoming", what one does to reach their goals, involving leisure practices, personal growth, skills development (14).

Considering this comprehensive understanding, from the analysis of the participants' reports, it can be seen how living with a vasculogenic ulcer prevents patients from living life to its fullest, impacting their ability to be, to belong and to become. Hence, this negative influence experienced daily by patients affects their social representation about quality of life and is expressed in the practices adopted**.**

Regarding the aspects that cause this negative influence, investigations have shown pain as the worst sensation for such patients (3,6,15) . [a] A study that evaluated the quality of life of 53 people with chronic wounds in outpatient care and compared this index with clinical parameters found that the overall index values and also the values of the individual domains were high. Pain was identified as the clinical parameter that most negatively affected quality of life, especially in patients taking painkillers who continued to feel pain at rest or when walking (15).

A study carried out in the United Kingdom found that participants described pain as a constant reminder of their ulcer and this contributed to their feelings of loss of control. The authors reported that pain was related to loss of mobility, sleep disorders, negative psychological effects and decreased quality of life (6).

Affections, personal history and the subject's position are incorporated in the Social Representations of an object. This is explained by the fact that the object must be relevant to the subject and the group to trigger SR. Moreover, the institutionalization of SR only occurs in everyday practices, which are undertaken by the subjects according to their context and social identity (13).

The present study reported loss of autonomy in the life process of patients with vasculogenic ulcers due to the reconfiguration of their routine. However, quality of life involves several aspects such as independence, functions and social relationships, physical appearance, entertainment, work and financial situation (2,14). These individual and social losses mobilize the affections of this group, and based on such affections the individuals build meanings and adopt coping practices that contribute to the construction of their identity. Therefore, the SR indicate that people with vasculogenic wounds do not assume a neutral stance regarding their bodies, regarding their own lives.

Some patients some patients seek support from their families, religion and the help of professionals to overcome the challenges of their daily lives, as it can be seen in the following statements: "to ask God to give me strength"; "my family visiting me at home is something positive".

Patients who have this social support act on behalf of themselves and their families and take the care measures necessary for their recovery, expressed by frequent visits to the health unit for dressings; they try to readjust their daily lives to be able to carry out their activities despite their physical limitations, especially those related to household affairs. This reveals the role of identity in the attitudes of patients, who seek to follow the guidelines of professionals regarding rest and nutrition.

However, in view of the negative effects of the disease, the difficulties in social and family support, the financial difficulties, there are patients who feel discredited, discouraged to face the changes. This sometimes implies more passive attitudes towards life, and these patients move away from social life and do not adopt all the necessary care.

Social and family support to deal with the psychosocial impacts of having a vasculogenic ulcer is demonstrated in a study that described the experience of patients with chronic venous insufficiency, in order to explore how this chronic disease affects the quality of life. The patients pointed out that living with chronic venous disease and venous ulcers causes physical discomfort and mentioned the inconvenience caused by the need for frequent visits to the doctor and the nature of the treatments. The participants mentioned the importance of counting on a strong social network of friends and relatives, as well as maintaining a good relationship with their medical service providers to better deal with the disease process (16)

A study showed that a fragile family and community support network influences the emergence, chronicity and delay in healing of wounds (17). On the other hand, an investigation into the social networks of patients with chronic injuries revealed weaknesses in these links because the primary social network formed by neighbors and family members, with low density and few exchanges is small-sized, and the nurse is the main link of the secondary network (18).

According to these Social Representations, in contrast to the research issue, it is worth reflecting on the role of nurses on the improvement of the quality of life for these patients. In this regard, studies have shown the importance of ensuring adequate training of these professionals on venous ulcers, so that they can provide better care to the patients (19–20).

One of these studies suggests the importance of nurses' specialized knowledge, as when it compares the levels of accuracy of diagnoses and judgment of the need for treatment between specialist nurses in skin integrity and general practitioners in community care in the United Kingdom, it showed that specialists were more accurate in the judgments of diagnosis and treatment (19).

Another study evaluated the effectiveness of an internet-based education program on venous ulcers regarding the level of theoretical knowledge and attitudes of home care nurses, comparing the group of nurses who participated in the program with the group who did not. There was a significant increase in the level of knowledge, while the attitude remained unchanged (20).

CONCLUSION

The SRs on quality of life were built from affections resulting from changes in patients' lives, caused by the presence of pain and the need to adopt therapeutic care for the disease. Thus, the reconfiguration of daily life led patients to have a negative representation about themselves and their lives, and this negative representation was expressed in these patients' coping practices. On the one hand, some patients behaved actively, adapting their daily lives to be able to perform routine activities. On the other hand, there were patients who were discouraged and unmotivated with their lives, and adopted behaviors that did not prioritize self-care and led to withdrawal from social life.

Therefore, it was found that the patients' difficulties to deal with individual and social losses resulting from the reconfiguration of their lives impacted the coping practices selected. Thus, from the perspective of the conceptual framework adopted, this study contributes to the proposition of technologies that lead patients to re-signify the changes that affect their autonomy.

One of these technology proposals is the creation of a care group focused on the referred clientele, whose actions are based on the paradigm of health promotion and encourage changes and adaptations in lifestyle habits, stimulating self-care and social support. This care group is supposed to work with the expressive dimension of nursing care, which includes mobilization of internal forces, motivation, self-belief and self-image, family support, instilling faith and hope.

The present study had methodological limitations related to the level of use of data in the processing carried out by Alceste, which requires new investments in the corpus to refine the analysis of the phenomenon.

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