

Subjective Aspects of People with Chronic Ulcers: a Qualitative Study in Brazil and Portugal

ORIGINAL

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Abstract

Introduction: The experience built in the process of living with chronic ulcer is marked by changes such as the inability to work, to relate socially and causes the need to adapt to a routine care. Understanding this network of meanings is important to develop techniques of individual or collective care.

Objective: To understand impregnated subjectivities in the everyday experiences of Brazilian and Portuguese patients with chronic ulcers, in the light of the Oral History of life.

Method: Comparative study with a qualitative approach, using Oral History as method and technique. The network of collaborators, formed by males and females, aged 39-82 years, was structured into two groups, one consisting of 06 people in Natal/RN, Brazil and another composed of 10 people in Évora/Portugal. In both groups, the narratives were collected through open questions, which were recorded, transcribed and analyzed by the technique of thematic content analysis.

Results: Through the analysis, three themes were revealed: Social repercussion in Brazil and in Portugal; Trajectory of the injured person; and Coping mechanisms.

Conclusion: Changes were observed in social life, leading contributors to isolation, in addition to confronting the stigma experienced. There were also identified points as the reinterpretation of chronic wound carrier about their disease and coping strategies of their chronic condition.

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Introduction

Chronic ulcers, now called complex wounds, are considered a public health problem and entail significant loss in the quality of life of affected people. Among these ulcerations, venous origin is the most common [1]. People with venous ulcers need support from health professionals for the treatment of the wound, and helping in the management of conducive conditions to healing and prevention of relapse [2].

The most affected aspects of quality of life, by the presence of ulcers, are: physical appearance, functional capacity, social and physical health aspects [3]. The existence of venous ulcer limits the person to work activities, so that the experience built in the process of living with venous ulcer is marked by changes such as the inability to work and to socially relate, causing the need to adapt to a routine care. The long period of treatment and the difficulty to walk usually result in removal of professional activities, leading to retirement due to chronic condition [4]. This situation favors economic, emotional, social and leisure activities changes, as well as search for new care.

Despite being the most common cause of leg wounds in adults, chronic venous insufficiency (CVI) is not the only one. The leg wounds are also caused by Diabetes Mellitus (DM) and arterial insufficiency, producing similar problems, diminishing the quality of life of people with chronic leg wounds. There is also the fact that these etiologies are responsible for most of amputations of lower limbs [5, 6].

To consider the meanings attributed by those networks in different cultural contexts requires the researcher's immersion in different socio-cultural universes, especially with regard to concepts and concerns about health and human illness, present in all societies. Each group is organized collectively - through material means, thought and cultural elements - to understand and develop techniques in response to experience or episodes of illness and

misfortune, whether individual or collective, acute or chronic [7].

On the assumption that the socio-demographic aspects, the health care and the clinical evolution of the lesions may have significant impact on people with chronic ulcers, there was a concern in studying this subject in different situations through the following research question: which are the meanings attributed by patients with chronic ulcers in the cities of Natal/Brazil and Évora/Portugal that influence aspects of their daily lives? Two research objectives were developed from the mentioned issue. In this article we aim to grasp the impregnated subjectivities in the everyday experiences of Brazilian and Portuguese patients with chronic ulcers, in the light of the Oral History of life.

Method

This is a comparative study with a qualitative approach that has Oral History as method and technique, showing the world views of the people interviewed, constituting a systematic process previously planned in a project, in which orality is registered and transported to the written form, allowing to perform analysis of the social and individual context, which should be interconnected and interdependent [8, 9, 10].

It was named collaborators to the respondents of this survey: a group of 6 people in Natal/RN, Brazil, and another one composed of 10 people in Evora/Portugal. The choice of the collaborators who formed the network and the *zero point* identification was made by registration service in Health Primary Care units in Brazil and Portugal, based on the following selection criteria: older than 18 years, with venous wounds, arterial or neuropathic chronic diabetic, active or healed, attended and accompanied by Primary Health Services.

Situated in the Alentejo region, Évora is the capital of the District of Évora, with a population of 56,596 inhabitants [11]. Capital of the State of Rio

Grande do Norte, located in the northeast of Brazil, the municipality of Natal has a population of 862,044 inhabitants in 2014 [12].

Data collection followed the steps of the oral history: Prior contact with employees occurred in the pre-interview, explaining the objectives of the project and scheduling interviews in which a script with guiding questions was used, simultaneously taking place in the period from August to December/2014 in Primary Care Services Health in the city of Natal/RN and Évora/Portugal. After the interview, we proceeded to the following steps: transcription, textu- alization, transcreation and checking by employees with the signing of the transfer license, authorizing the use of transcreation without restrictions.

Life stories were analyzed using thematic content analysis [13], following the proposed steps: initial reading; constitution of the *corpus*; selection of units of analysis (context: paragraph and registra- tion: sentence); categorical process (subcategories and categories) and interpretation.

The research was based on assumptions of Re- solution No. 466/2012 of the National Health Coun- cil [14], which provides for research with human beings given the ethical and scientific requirements, where the informed consent of research collabo-

rator was treated with dignity, respected in their autonomy and advocated in their vulnerability.

To preserve anonymity, the employees were iden- tified by flora elements of their region, connected to their life stories: the northeastern backlands for 6 employees of Natal/Brazil (Juazeiro, Aroeira, Umbu- zeiro, Carnaúba, Angico-Branco and Algaroba) and the Alentejo region for the 10 employees of Évora/ Portugal (Sobreiro, Azinheira, Azereiro, Azevinho, Ulmeiro, Freixo, Aveleira, Castanheiro, Carvalho- Negral and Pinheiro Silvestre).

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Results

Regarding the characterization of the contributors to the study, in Natal, the age ranged from 57 to 79 years old and, in the city of Évora, it ranged from 39 to 82 years old. In both cities, the predominant gen- der between employees was female. Other data are distributed in synoptic tables (**Table 1** and **Table 2**).

Table 1. Characterization of network collaborators, Natal/RN, 2014.

Collaborator	Level of education	Profession	Income* (R\$)	Comorbidities	Time of active ulcer
Juazeiro	Elementary School	Woodworker	Has no source of income	IVC Anemia	22 years old
Aroeira	Incomplete Elementary School	Artisan	724,00	IVC Hypertension Dyslipidemia	28 years old
Umbuzeiro	Incomplete Elementary School	Merchant	1000,00	IVC Obesity	10 years old
Carnaúba	Incomplete Elementary School	Housewife	724,00	IVC Hypertension Dyslipidemia	3 years
Angico-branco	Without instruction	Retired	724,00	IVC Hypertension Dyslipidemia	3 years
Algaroba	Incomplete Elementary School	Merchant	724,00	IVC DM Arterial Hypertension Dyslipidemia	22 years old

Source: Research data, *: Minimum wage in 2014 in Brazil: R\$ 724,00.

Table 2. Characterization of the Health Unit staff of Évora, 2014.

Collaborator	Level of education	Profession	Income* (€)	Comorbidities	Time of active ulcer
Sobreiro	Higher Education	Retired	900,00	IVC Arterial Hypertension	3 months
Azinheira	Not informed	Teacher	1800,00	IVC DM Arterial Hypertension	1 year
Freixo	Higher Education	Teacher	4500,00	DM	2 years
Aveleira	Not informed	Retired	450,00	IVC	6 months
Azevinho	Not informed	Retired	750,00	IVC Arterial Hypertension	5 months
Castanheiro	Not informed	Retired	505,00	IVC	3 months
Ulmeiro	Not informed	Retired	505,00	IVC DM Cardiopathy	3 months
Azereiro	Not informed	Retired	505,00	IVC DM Arterial Hypertension	2 months
Carvalho-Negral	Not informed	Public Employee	1200,00	IVC Arterial Hypertension	3 months

Source: Research data, *: Minimum wage in 2014 in Portugal: \$ 505,00€..

Regarding the analysis of narratives, by applying the technique of thematic content analysis, it considers three themes: Social repercussion in Brazil and Portugal, Trajectory of the person injured and Coping mechanisms.

The "Social repercussions in Brazil and Portugal" axis is about the complexity of social relations and the changes experienced by the contributors of the study, due to chronic ulcers. The adaptive strategies across the different stages of developing and living with chronic ulcer, with adaptations and changes in lifestyle, are addressed in the thematic area "Trajectory of the person injured"; while "Coping mechanisms" shows the reinterpretation on the self-image, self-esteem, work, social and family life, so that personal identity goes beyond the idea of being hurt. Denial of the disease as coping strategies of chronic condition is also cited.

Discussion

It is necessary to know the target population of the healthcare actions to promote efficient and resolutive healthcare actions [15]. Social determinants have a strong impact on the prevalence of chronic diseases, whereas social inequality, differences in access to services and information and low level of

education determine a higher prevalence of chronic diseases and their complications [16].

It is observed that the socioeconomic profile of employees corroborates with data of research developed in Brazil, especially of people presenting lower education and income lower than the minimum wage. The level of education is certainly an important factor with respect to self-care, and sometimes it is an impediment to adequate treatment [16]. The lack of material resources available for self-care, the failure of adherence to guidelines at postdischarge time, the dependency on the healthcare services and no modifiable factors related to underlying disease are directly related to the time of active ulcers, higher among Brazilian people than Portuguese people, according to the collaborators.

Those who have declared having no income from social security benefits also mentioned precarious financial situation, equal to or less than the minimum wage, which implies the care that this condition needs, becoming a destabilizing factor in the family's financial balance [3, 16].

Chronic ulcers relapse-related factors are closely related to comorbidities, being identified in this study as systemic hypertension, DM, dyslipidemia and heart disease, corroborating other authors [16]. The

presence of comorbidities reflects the need for a comprehensive health monitoring, directed not only to a disease, but to minimize impairments and improve quality of life [17].

Relapses are present in Brazil and Portugal, given the pathophysiology of the underlying disease, etiology of ulcers, most significantly that of venous origin. However, the ease of access and continuity of care in the Portuguese healthcare centers decrease the active ulcer time as the best technical preparation and the presence of clinical protocols ensure an essential condition for the systematization of nursing care in order to comprehensive care to people with venous ulcers, corroborating study in Évora/Portugal [3].

The characterization of the collaborators and the correlation with literature research allow early immersion in the study scenarios, subsidizing the analysis of life stories and the experience of owning the wound, making it possible to meet the dimensions left unsaid in the interviews.

Social repercussion in Brazil and Portugal

The appearance and chronicity of a wound, whatever its origin, is a traumatic situation in the collaborators' lives, making this event a milestone in their lives, with an abrupt change in their daily activities and routine. The complexity of the situations encountered during the process of chronic condition interrupts the natural course of the daily lives of people who, in turn, undergo periods of adaptation to new situations.

Contributors showed difficulty describing their perception of the wound, converging in their reports. Despite this, the scenario of the sensations referred to in this study consisted of pain, discomfort with the wound and bandages, changes in the pattern of sleep and rest, changes in self-image, changes in affection/sexuality, fears and prejudices suffered and marked in your lines:

Before appearing it here, I liked to go to bars, I was very funny. My life was pretty good, I walked, drank, had a lot of fun, I dated... so today I don't even care anymore. After the wound, the ulcer, everything has changed. I have no desire to have fun.

Algaroba/Brazil.

It's hard, hard... I took a lot of time in the hospital, with all treatments; It (the adaptation) was a "little bit" costly to achieve.

Castanheiro/Portugal.

Pain is a common symptom in patients with chronic ulcers. It is known that both high levels of pain in short periods of time, as well as low levels of pain experienced for long periods, have similar effects in reducing patients' state of health [16]. It is predominant symptom in the contributors' speech, who ascribe to it one of the largest physical discomforts present and directly related to the physical (intolerance to activities of daily living and physical activities), social (separation from society) and psychological losses (change in self-image, mood swings, decreased libido), that interfere directly in their daily lives.

I can't stay long sitting. I do it but it soon swells. There is time that it hurts a lot, then I walk and it hurts, then there's nothing I can do... My life is like this.

Algaroba/Brazil.

I have so much pain in my legs that I can't go to the gym, I can't go swimming...

Algaroba/Brazil.

People with chronic ulcers report that the experience of pain persists even after closing the lesion, significantly interfering in daily life activities and work relations [18]. Even after the closure of ulcer, Carnaúba said to feel pain in the daily activities, in his domicile. In reference to the IVC, nociceptive

pain is persistent in the area healed, since skin retraction causes painful feeling [19].

The leg swelled, and I should rest, but here there is a lot of work and I go up and down, I don't like to sit still. I like to do things and it seems that the more we get stuck, it hurts, isn't it?

Carnaúba/Brazil.

There is a leg that is amputated, which is not this one with the wound in the finger and heel; that one (the other leg), when it was amputated, we thought about the placement of the prosthesis and I did physiotherapy accordingly. I could help a lot in transfers ... but then a wound began to appear in the other leg, which was not yet healed, and the whole process of rehabilitation was delayed...

Castanheiro/Portugal.

Castanheiro's report refers to the limb amputated due to CVI complications. The physical loss lies permeated by social and psychological aspects, and is irrevocable, so that the amputee needs to assign it a sense. After the amputation, there is the process of adaptation to limb loss and physical adaptations, including level of functional ability, stump pain, phantom pain (pain in the amputated limb) and psychological pain, related to emotional reactions such as anxiety, depression, anger, sadness, disappointment, guilt, anxious self-image and social discomfort from which emerges a story of quiet and "not palpable" pain [20, 21].

The disturbance in sleep patterns and comfort is often in the contributors' statements, of both countries. Night pain has great impact on the quality of life of patients with chronic ulcer since it impairs sleep and limits the mobility and activities of everyday life [22].

I couldn't stand it anymore, I used to spend evenings and nights awake, I couldn't sleep at night and day, there was pain, burning pain, that I got up at night, that warmth, put a wet cloth to see if it got better, but nothing happened.

Carnaúba/Brazil.

Yes, and then my life has always been like this... always suffering. Sometimes more, sometimes less, and we're going, we're going ahead until God wants

Ulmeiro/Portugal.

The contributors' report of pain refer us to the role of the professional in the care of people with chronic ulcer in health services, where often the complaint is ignored. Understanding the meaning and subjectivity of pain is the first step of an evaluation of the changes occurred in the individual, whereas the expression of it, being it verbal or behavioral, may be influenced by multiple factors: gender, pain thresholds, complaints related to the wound, psychosomatic changes; closely related to the meaning attributed to the pain felt [22]. The current context of health requires more attention, to give emphasis to the promotion of health, not only related to risk factors, but all the determinants of quality of life of people [23].

In order to minimize these changes, chronically injured people fit their lifestyle to the disease; developing strategies to accomplish seemingly easy tasks. The interference that chronic ulcer causes in carrying out daily life activities are closely related to the physical constraints, financial difficulties and suppression of labor activities. For those who still maintain professional activities, work turns to be informal or small business, activities incompatible with the constraints of mobility and rest imposed by chronic ulcer.

It was hard to get used to not working. I started working very young, nowadays I'm more used to it.

Aroeira/Brazil.

Or you stay at home to rest or you are there working. We cannot come to rest at the workplace.

Aroeira/Brazil.

Contributors stressed that there was no significant change in family relationship pattern, although they cite the care burden, distress and anxiety as family stressors. Just one collaborator, Juazeiro, reported estrangement from other family members, including his son, living a loving relationship at distance, due to his health problems and fragile family situation of his companion.

And so the relationship with my family has not changed, I had a little problem only with my sister, which loathes me, she said she loathes me... But apart from that, no one has problem with me, everyone kisses me, holds me, because it has no smell and I do everything.

Algaroba/Brazil.

I have no problem, there is no difference between before and after having the problem of chronic wound. I managed (the problem).

Freixo/Portugal.

For contributors, the process of adaptation of life is marked by suffering, expectation, anxiety, frustration, social isolation and anger. The functional disability, changes in self-image and changes of affection/sexuality are the main psychoemotional elements modified by the presence of chronic ulcer.

Trajectory of the person injured

In the development of adaptive strategies in the presence of chronic ulcer, each individual has different stages in this process, considering the performances achieved in the face of inevitable changes arising from the chronicity of the disease, the chan-

ges proposed by treatment and changes experienced as possible alternatives to the new reality, such as adaptations of daily living activities, confrontation of limitations, effective adherence to specific treatment and completion of self-care [20].

This disease is funny, my daughter... when I think I'm getting better, here comes something else

Algaroba/Brazil.

First I did it day in, day out; first I did it like this, every day, and now as the wound is closing, I come now and then only Tuesday, twice a week.

Algaroba/Brazil.

From the psycho-emotional point of view, the chronicler can be considered as a suffering that leaves deep scars and, from the social point of view, they are seen as a stigma that affects the relationships between people, because it represents a derogatory mark [24]. The failure of improvement, the deepening of the ulcer, the worsening of initial injury or the onset of new wounds lead the person to processes of psycho-emotional suffering flagged by attitudes of apathy, aggression or depression. Depressive symptoms manifested by negative body image, grief and self-depreciation, found in this study, may lead to the desire to abandon the treatment, since this phase is marked by a sharp loss of hope, with serious negative impacts on quality of life, resulting in hopelessness and frustration, and it can lead to suicide.

I was still young, had a lot to offer to society and felt very embarrassed for not being able to travel, I could not get many days off in places that were not near my house because I had to change the bandage daily. I felt depressed, so for a while I thought to exterminate my life. Later, I went back to rethink and took that idea away of the mind, there wasn't the answer for me, it was not the solution to my life.

Juazeiro/Brazil.

Well yes, it is difficult, but it is so, I think it's ... depending on the people, but I think I adapted, I accepted the problem. As well as others have it, this problem happened to me.

Algaroba/Brazil.

Anger manifested with feelings of rebellion and resentment; at this stage, it is customary to question the motives for their living situation and the Nursing staff may have greater difficulty in dealing with people who go through this time.

Sometimes I go to the minister and ask why it appears so much trouble for me, if I did not smoke, did not drink, not ruined me, and there is the guy who drinks a lot and lives 80 years, and go further than me, I'm 67?! But God knows.

Umbuzeiro/Brazil.

I've lived almost all my life with this ... I'm not a special patient...

Freixo/Portugal.

The self-concept relates to the perception that the person has of himself, and this comes from interactions between the subject and the social environment. Considering that self-concept contains a descriptive character (self-image) and an evaluative character (self-esteem) [25]. Thus, self-image is a description that the person makes of herself and how others evaluate her.

Now I bought an ointment to see if this black mark goes away from my leg... It depends on the skin of the person, but all the people who have it, show this thing on the leg. I think it's ugly. But this skin has to go away, when I apply sunflower oil, few things go out, passing gauze slowly not to hurt.

Angico-Branco/Brazil.

I remain at home, I do not go out anymore, I do not get animated, I'm a happy/sad man... I'm happy because I'm alive, I'm living my life the way God wants, but I'm sad on the other hand, because I cannot live like others in society.

Juazeiro/Brazil.

I move a lot, but I do not do longer walks, but I'm not very sedentary, I do not sit on the couch and stay there all afternoon, no! I move a lot, though I do not walk kilometers, isn't it?

Sobreiro/Portugal.

Body acceptance is absolutely necessary for the psychological development and for individualization. The search, production and care management trajectories in the illness experience are taken by the ill person and his/her family for solving the health needs.

Thus, there is a full of ways route, both in Brazil and in Portugal, driven by people seeking care and treatment, called therapeutic itinerary, consisted by all movements triggered by individuals or groups in the preservation or restoration of health, that can mobilize different resources ranging from home care and religious practices, to biomedical devices. In this cross-cultural study, the therapeutic itinerary was similar both in Brazil as in Portugal [26].

Coping mechanisms

The reframing is a process of subjectivity by which the person appropriates her suffering, rearranging it in her feelings and thinking, providing a new design of her reality, allowing her to move on. For the person with chronic ulcer, the body is something they can't manipulate as their will, even though it is insufficient to represent their personal identity, the skin surrounding the body is an opening to the world [27].

I do not let anything bring me down. When I'm at home, to do not spend all day sleeping, I come here, I help the girl at the grocery store, I help with washing, ironing cloth, sweeping. My life is not too bad, I have a good life, I've got my health, I don't take medication for anything, just for high pressure when I have a headache, but I'm a happy woman, yet, even with a broken heart to just be able to use it (the pants).

Algaroba/Brazil.

Look how this finger is, how this fingers... but it will, it will improve.

Castanheiro/Portugal.

In the speeches it is clear that, consistent with the illness, there is the search and the meeting of healthy factors by the subject, so that he/she does not take the disease as the only form of personal identity, focusing on the positive and healthy aspects that are kept.

And I like to do my things at home. If they take these things away from me, I think I'll die soon, you know? I always say and ask much to God that I stay alive until the day I can do my things, when I won't be able do to them, so take me away, because I think I'm not going to hold it, not be alone...

Castanheiro/Portugal.

Based on narratives, highlighted changes relate to the self-image, self-esteem, work, social life and family life. The categories presented herein have congruence between the two scenarios - Brazil and Portugal - and have differences, mainly related to the denial of chronic disease, as seen below:

No, absolutely nothing! I have no discomfort, no pain, nothing. I don't feel a change that causes me discomfort

Sobreiro/Portugal.

I don't have a wound "that way". How do I live now? Well! I don't have any wound that compromises me. What is a chronic wound? What do you call a wound?

Aveleira/Portugal.

That wound happened in cleanups at the door of the house... a rock. I was cleaning out the garage, and there was this big, big stones, with more or less of this size, and 4 fingers thick, that were inclined. If one falls, another slips and over and they hit me in the leg.

Algaroba/Brazil.

Denial works as a ruse to avoid mental facts, ideas, fantasies or painful feelings that are experienced. The permanence of the denial threat adherence to diagnosis and treatment and to the search for non-scientific therapies [28].

In Brazil, resilience takes place showing that there is a reinterpretation, as envisioned in the following report, perhaps the time of active lesions influence more advanced coping stage than in Portugal:

I have complained a lot about my leg, my condition, but now I do not complain any more, you know, there are people worse than me. As once said a man there in the post, there are people who live on a bed or can't even drink some water if it is not given by another person... they can't do anything if not with the help of others.

Aroeira/Brazil.

Acceptance is characterized as a phase when the person seems to enter into conciliation with her own sick body. Meeting other patients can help find new forms of care and assimilate a new lifestyle and overcome difficulties. When confronted with others in a similar situation, one can find reason to value other aspects of life, preventing the wound still ranks as the center of the concerns. In this space, one can still find people who will help

you build new relationships, exchange experiences that will help getting in balance with chronic illness situation [29].

I had a good life! I feel uncomfortable to go out, because I cannot wear a skirt, a dress, I have to cover it... but my life is good today, I have my granddaughter now to enjoy.

Algaroba/Brazil.

All contributors reported a desire to regain their health, to go back to a life without the itinerary of bandages and without the processes involving skin lesion. Health professionals can direct their actions to promote the health of individuals with ulcers, with acceleration of the healing process and promote the quality of life [30].

Conclusion

The analysis evidenced the changes in social life, leading contributors to isolation, motivated by shame in exposing themselves to other people's eyes and suffering discrimination. They presented feelings of anxiety, depressive symptoms, trauma/fear infections, being the main limiter on their social interaction. In addition to these events, they are facing the stigma of skin tags and changed body image, low self-esteem, feeling dirty and frustration. The reframing of chronic wound carrier about his/her disease and the chronic condition coping strategies were points also identified.

During the data collection, it was found that health professionals, especially nurses in Primary Healthcare Services in both countries, have difficulties in properly caring for the patient diagnosed with chronic wound and especially in performing the proper management of these feelings and symptoms of injury. This management includes listening to the particularities of each person, and when not performed, it interferes in the self-image and self-esteem process. This difficulty is greater in Brazil, because there is a clearance of the nurse of

the direct provision of care, as this activity is delegated to nursing technicians, a category that does not exist in Portugal.

Human beings are complex, physical wounds can cause emotional wounds that, in turn, hinder the adherence to treatment and self-care, causing worsening of clinical picture and diminished quality of life, making a vicious cycle that can be broken with appropriate assistance to the physical and emotional aspects of people with chronic wounds.

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