The meaning of family for the person with arterial ulcer.

Objective: to understand the meaning of family to the patient with arterial ulcer. 

Method: qualitative study. Ten patients with arterial ulcer, treated at a specialty outpatient clinic of a municipality of Minas Gerais, were interviewed. The information in the interviews was analyzed by content analysis technique. This study project was approved by the Research Ethics Committee, Protocol No. 1752. 

Results: the demographic data showed ages between 30 and 81 years old and most individuals (six) were male. The following categories emerged from the testimonies: I- Motivation; II- Care x Dependency; III Solitude. 

Conclusion: the familiar presence reverberates significantly in fighting the disease, providing support, protection, comfort, safety and assisting in the adaptation process, in addition to the support for technical assistance to care for the injury.

Descriptors: Family Relations; Leg Ulcer; Family Nursing.
INTRODUCTION

Living with arterial ulcers implies changes in various aspects of individuals’ lives, in the economic, social, emotional, family and labor aspects, due to their specific characteristics such as pain, interference with mobility and the recurrent character. So, they can have a negative impact in these people’s lifestyle.1,2

Resulting from inadequate tissue perfusion, due to complete or partial blockage of the blood supply, chronic ulcers are defined to be of long duration or frequent recurrence. Arterial lesions are found mainly in the legs and feet, with peculiar characteristics, such as depth, and can affect muscles and tendons, presenting paleness, necrotic appearance and foul smell. They have small, rounded dimensions, of difficult and painful healing.3,4

The patient who experiences a chronic disease needs to share this confrontation with their family or with close people. There must be search for support and help in a context that requires individual and family rehabilitation so that the patient can receive the necessary aid.5,6

The family is of utmost importance both regarding the structuring of their emotional ties and regarding the supporting references and safety. The family develops critical and fundamental role in helping the patients in their adaptation process, particularly providing support, when there is available time, and sharing emotional affection and also by providing resources and funding to help their members in face of the difficulties arising from the experienced situation.5,6

The family care to patients with chronic disease occurs through daily living, in reflections and interpretations that arise in the process of interaction and directs to every family member, so there is growth, development, well-being, personal fulfillment, social inclusion and social contribution.7

It is emphasized the importance of family activities, in which family members demonstrate understanding of the situation experienced, helping to cope with the disease.8 The support found in household and occupation of time and thoughts with leisure activities are relevant to minimize psychosocial negative effects.8 This study aims to:

- Understand the meaning of family to patients with arterial ulcer.

METHOD

Data from this research emerged from a study on the impact of arterial ulcers on quality of life as perceived by patients, which showed the role of the family as fundamental in this context.

This is a qualitative study. Inclusion criteria were: being aged greater than or equal to 18 years old; having diagnosis of chronic arterial insufficiency recorded in the medical record; having exclusively arterial ulcer, without ulceration time limit, and agreeing to participate voluntarily in the study. Data were collected from all patients seen at the specialty outpatient of the Hospital das Clínicas of a municipality of Minas Gerais, in 2011, totaling 10 individuals, through a semi-structured instrument, prepared by the authors of the study.

This study was submitted to the Ethics Research Committee of the UFTM, and received assent under protocol No. 1752. Participants were informed about the study objectives and agreed to participate by signing the Informed Consent Form, according to Resolution 196/96. Their anonymity and complete freedom to give up the research at any time were guaranteed, ensuring the ethical precepts.

For the production of data, a list with the addresses of patients was requested to the Department of Systems and Methods (DSIM). Home visits were scheduled by telephone, according to the availability of patients. It is noteworthy that one of the patients was approached during hospitalization due to complications of the arterial injury.

In the interviews, it was used an instrument that consists of two parts: the first part referring to sociodemographic data, and the second part consisted of a semi-structured instrument with guiding questions that addressed the meaning of quality of life for patients with arterial ulcers, the feelings that arise by living with ulcers, the limitations imposed by the injury, the changes that have occurred in life on this pathway and issues related to the role of the family in the process of discovery of the diagnosis, adaptation and recovery.

The instrument was applied by the same researcher, who received previous training to perform this function. The responses were recorded and transcribed for further analysis. Each respondent received fictitious identification (eg. R1, R2, R3 ...), according to the order in which they were interviewed.

The data obtained through the collection instrument were analyzed and categorized...
using content analysis technique, which covers three stages: pre-analysis, material exploration and treatment of results. The content analysis method allowed the enrichment of depth reading, increasing productivity of data. This occurred through clarification of meanings, of which there was not, initially, understanding. Content analysis allowed exploratory attempts, increasing the propensity for new discoveries in the analyzed speech, providing data and information related to the meaning of family in contact with the patient who has arterial ulcer.

RESULTS

♦ Sociodemographic aspects
Sociodemographic data of the 10 participants showed that six patients were in the age range of 30 to 60 years old and four were in the age range of 61 to 81 years old; six were males and four, females. With regard to marital status, three people were single, four were married, two widows and one divorced person. All had three to four children. The predominant religion was Catholic (eight people). One person declared himself evangelical and one claimed not having religion.

One participant was illiterate and others attended from the third to the seventh grade from elementary school. Regarding their profession, they reported being: housewife, seamstress, tinker, mechanic, welder, gardener, artisan and mason. The monthly income of these families was between one and two minimum wages, and families were composed of up to five people.

By analyzing the data obtained in the interviews, it was possible to identify the dimension of the phenomenon of living with arterial ulcer and the relationship with the family. Thus, the following categories emerged: I- Motivation; II- Care x Dependency; III- Solitude, shown below:

♦ Category I: Motivation
It was showed in this study that the social environment in which individuals are inserted and the family presence exert significant influences on how these people face the situation of living with arterial ulcer, in the image that they build about themselves and how they perceive themselves and experience reality. It was found that patients seek motivation for their lives, share their daily lives, express their feelings and needs and seek coping possibilities in the home environment. This can be evidenced in the following sentences:

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I do everything to get up, mostly for my grandson. I think he needs me a lot. I hold steady for my grandson. He is the greatest strength I have in my life (R 3).

But I am overcoming. With the help of my sister, thanks God, I am overcoming it (R 6).

I have my kids, I think a lot about them (R 10).

Thanks God I am married (R 7).

The family proved to be motivating source for the patient to accept the situation of living with the disease, by contributing in acceptance, adaptation and compliance to treatment. The patient seeks encouragement to live in the family, by using strategies, like being important or essential for someone.

The careful and thorough analysis of the speeches enables highlight the presence or absence of the family directly interfering in how the patient experiences all stages of this process. From the discovery of the diagnosis of arterial insufficiency until the appearance of the lesions, the constant dressings and the routine established, the family's presence has an impact on the image that the patient has about him/herself and they how face the situation.

♦ Category II: Care x Dependency
Due to the specific characteristics of the arterial ulcers, it was found in this study that the patient experiences unpleasant situations such as pain, fear of the prognosis of the injury, fear of a possible amputation of the affected limb and fear of social rejection by family and friends, every day.

In addition to the demeaning self-image because of the foul odor emitted from the wound, patients also face fragility, body impairment and physical limitations such as walking, cleaning the house, hanging out with family, working, driving, cooking and providing care, since some have formerly being caregivers. In this light, the patient is prevented from carrying out their activities, and when there is someone who takes over these roles, they feel supported, as evidenced in the statements:

It is my granddaughter who cares of me. She takes care of the wound, makes the dressings every day, puts pain medication at night (R 5).

Thanks God my mother do the dressings for me (R 9).

It is my sister who takes care of the wound, makes the dressings every day, puts pain medication at night, when I cannot sleep (R 6).

Supportive care provided by family, as identified by patients' reports, range from the execution of functions previously performed
by the patient, such as home maintenance services, to direct care such as dressing changes, administration of medications, preparation of patient’s food, scheduling appointments for medical monitoring and conveyance and transport in the case of patients unable to walk alone due to amputation deriving from complications of the injury.

The testimony of the respondent 6 expresses the care provided:

I used to stay awake day and night because of the pain. She (sister) gave me medicines, took care of me. She cooks for me (R 6).

The reports also demonstrate the dependence by individuals with ulcers to the care provided, which reveals a paradox of satisfaction and security because they have somebody to turn to and, at the same time, sadness, at being dependent, due to their failure to perform activities. The statements express that the dependence of the family is seen as one of the main negative aspects related to the changes in life that occurred after the onset of ulcers:

Nowadays, my daughters do everything, I cannot do anymore. If they weren’t here, I do not know how it would be (R 3).

I think it’s bad when I have to go out and my sister has to push me in a wheelchair. It is she who takes me everywhere, pushes me in the chair, who takes me where I need (R 6).

Category III: Solitude

It was observed that one patient has no family ties and three complained about the absence of a family member. It is noteworthy that the individual who had not the presence of any family member presented features like bad habits of personal hygiene, neglect of the dressing, which had an aspect of dirtiness, because it was not changed daily, as recommended. The house was in poor hygiene and the patient expressed sorrow when referred living alone.

It’s just me and God, and no one else [silence]. Because my children, one is married, the other works, the other also works. To go out, I need a transportation. My son works, I need him here, and he never comes (R 4).

A study on the quality of life and sociodemographic data of people with chronic ulcers showed similar data on the characteristics of the sample. It was identified low education level, about three children per person, most Catholics and undefined current occupation.11,12

The literature also shows a low socioeconomic profile in people with chronic injuries, with income between one and three minimum wages and low education, most married.12-15

There was a predominance of males in a study about the clinical and sociodemographic variables of people with vasculogenic ulcers,12 just like in the present research. However, the literature indicates, in general, more frequency of these condition in females.13-15

Studies have shown the emotional support as one of the main care provided by the family to the patient in a situation of chronic disease, which is related to feelings of esteem, belonging, trust and respect, encouraging the person to express their fears, anxieties and sorrows.16,17

Affective care is extremely important for the rehabilitation of the patient, as it guides their decisions about the disease and treatment, supporting them in facing the reality experienced, revealing itself as a support to stimulate the patient to improve their self-esteem and self-image, so affected in such circumstances.16

The family seems to represent an essential guarantee of survival, development and full protection of the individual, providing emotional and material contributions, providing space to share everyday life, enhancing the capacity of coping this new process of living, and being a motivating source.16,18

The person who takes care is a family member, being mostly a female, in the role of a wife, daughter, daughter-in-law or sister. With this, the family caregiver is the main actor in the social dynamics of necessary personal care for the daily activities of people with injuries.19,20

The functional capacity, the autonomy to self-determination as well as the ability to run their own purposes are considered essential to health.21 So, when the individual is unable to perform certain tasks, resulting in the need for someone to perform them, feelings of dependence, limitation or losses in autonomy emerge, which translates into annoyance and loss of self-power, accompanied by other feelings like sadness, fear, worry, despair, disbelief and loss of pleasure.22,23

Study of individuals who live without family presence points the manifestation of need for affection, approval, support, sympathy and concern for the other, referring to feelings of longing and loneliness, as well as referring lack of family in almost every moments of existence.24
The fact of living alone can have a negative influence on health, engendering feelings of social isolation, abandonment, loneliness and depression. Thus, the maintenance of ties and family life can prevent these feelings. In this regard, studies show that living a wound provides a lot of changes in people's lives and their families. Some aspects that affect the lives of these patients are pain, dissatisfaction with physical appearance, fears, self-image disorders, psychosocial adaptation, mobility difficulty with impact on daily activities, relationships and leisure. It is under these circumstances that the family is so important, performing functions that aim to support the patient in the difficulties faced by the condition to live with arterial ulcer.

### CONCLUSION

Living with arterial ulcer causes significant changes in a person's life in its various aspects as labor, family, social and emotional capacity. The discovery of the diagnosis of arterial insufficiency, the emergence of wounds, the constant dressings and insufficient improvements reverberate negatively on the patient's and on their family's lives.

For the study participants, family presence is important at all times, ensuring protection, support and direct care, conveying comfort and safety, assisting in the acceptance and minimizing distress.

The family care has its intrinsic meanings of health and illness, with proper care practices originating from their sociocultural context and this should be considered when addressing the family and when involving them in the care of a patient with chronic injuries.

One must consider the fact that the family is not always prepared to give support and, thus, will also need to be looked after. In this sense, the Primary Care Units, as they are in close contact with individuals who have arterial ulcers and their families, can act to provide support to families in the management of these individuals in order to build a space of host to the individual, encouraging autonomy.

### REFERENCES


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