



# Journal of Nursing

Revista de Enfermagem

UFPE On Line

ISSN: 1981-8963

## ORIGINAL ARTICLE

### EXPERIENCE OF THE INSTITUTIONALIZED ELDERLY WITH AMPUTATED LOWER LIMBS DUE TO COMPLICATIONS OF DIABETES MELLITUS VIVÊNCIA DO IDOSO INSTITUCIONALIZADO COM MEMBROS INFERIORES AMPUTADOS DECORRENTES DE COMPLICAÇÕES DO DIABETES MELLITUS LA VIVENCIA DE LOS ANCIANOS INSTITUCIONALIZADOS CON EXTREMIDADES INFERIORES AMPUTADAS DEBIDO A COMPLICACIONES DE LA DIABETES MELLITUS

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#### ABSTRACT

**Objective:** to know the experience of the institutionalized elderly with lower limbs amputated due to complications of Diabetes Mellitus. **Method:** descriptive study with a qualitative approach, carried out in an Institution of Long Permanence in Maceió-AL, with diabetics and amputees elderly. The production of the data was collected through interviews and observation of patient records. The research obtained approval of the Research Ethics Committee, opinion n° 1293/12. **Results:** it was evidenced that the process of amputation involves feelings of loss, dependence and social isolation. To be diabetic with amputation means experiencing a life permeated by difficulties and limitations, and suffer from other people's dependence to perform basic activities of daily living. **Conclusion:** to know the experience of amputee fellow is fundamental to make the more integrated assistance, valuing the singularities, and facilitate the process of rehabilitation. **Descriptors:** Elderly; Diabetes Mellitus; Amputation; Experience.

#### RESUMO

**Objetivo:** conhecer a vivência do idoso institucionalizado com membros inferiores amputados decorrentes de complicações do Diabetes Mellitus. **Método:** estudo descritivo, com abordagem qualitativa, realizado em uma Instituição de Longa Permanência para Idosos de Maceió-AL, com idosos diabéticos e amputados. A produção dos dados foi realizada por meio de entrevistas e observação de prontuários. A pesquisa obteve aprovação do Comitê de Ética em Pesquisa, parecer n° 1293/12. **Resultados:** evidenciou-se que o processo de amputação envolve sentimentos de perda, dependência e isolamento social. Ser diabético com amputação significa vivenciar um cotidiano permeado por dificuldades e limitações, e sofrer pela dependência de outras pessoas para realizar atividades básicas de vida diária. **Conclusão:** conhecer a vivência do sujeito amputado é fundamental para tornar a assistência mais integrada, valorizando as singularidades dele, e favorecer o processo de reabilitação. **Descritores:** Idoso; Diabetes Mellitus; Amputação; Vivência.

#### RESUMEN

**Objetivo:** conocer la vivencia de los ancianos institucionalizados con extremidades inferiores amputadas debido a complicaciones de la Diabetes Mellitus. **Método:** estudio descriptivo con un enfoque cualitativo, realizado en una Institución de Permanencia Prolongada de Maceió-AL, con ancianos diabéticos y amputados. La producción de los datos fue realizada a través de entrevistas y observación de registros de pacientes. La investigación obtuvo la aprobación del Comité de Ética en Investigación, opinión n° 1293/12. **Resultados:** se constató que el proceso de amputación implica sentimientos de pérdida, dependencia y aislamiento social. Ser diabético con amputación significa vivir una vida impregnada por restricciones y limitaciones y sufrir por la dependencia de otras personas para realizar actividades básicas de la vida diaria. **Conclusión:** conocer la vivencia de los sujetos amputados es fundamental para hacer que la asistencia sea más integrada, valorando las singularidades y facilitar el proceso de rehabilitación. **Descriptors:** Ancianos; Diabetes Mellitus; Amputación; Vivencia.

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## INTRODUCTION

The demographic aging is a growing worldwide phenomenon. The way the individual gets older is influenced by multiple factors in the whole way of life, including biological, genetic factors and life habits. In this way, the individual can get old healthily or not.<sup>1</sup>

Studies show that, proportionally to the increase in life expectancy, it has been observing an increasingly significant number of elderly institutionalizations. However, the transfer of the elderly for an Institution of Long Permanence for Elderly (ILPE) is an important potential to produce damage such as: depression, confusion, loss of contact with reality, depersonalization, sense of isolation and separation from society, and consequently, decline of functional capacity.<sup>2</sup>

In addition to the transfer of their home to an ILPE it constitutes a risk factor to produce damage to the elderly, the presence of diseases and chronic non-communicable diseases, such as Diabetes Mellitus (DM), represents another potential for the decline of the functional capacity of these individuals.<sup>3</sup>

Given the high prevalence of DM and because it is often associated with complications that compromise productivity, quality of life and survival of individuals, the DM has become an important public health problem<sup>4</sup>. Among its main complications are: cardiovascular disease, retinopathy, nephropathy and diabetic neuropathy, and diabetic foot.<sup>5</sup>

The aggravations in the lower limbs are due to peripheral vascular changes, which may cause neuropathic foot conditions or even amputation of the limb. The lack of proposals for an early and appropriate treatment of these chronicle complications echoes in a high statistical index of lesions that, if untreated, can lead to Amputation of the Lower Limbs (LL).<sup>6-8</sup>

In Brazil, the DM is a major cause of amputations of LL, being a considerable factor of incapacity, disability and preventable deaths, and representing a significant impact in functional level, especially in the elderly, affecting the ability to perform Basic Activities of Daily Living (BADL), making the elderly very vulnerable to physical and functional deterioration and compromising the quality of life and survival of individuals.<sup>9</sup>

It should be noted that the loss of a body part brings repercussions on the existence of the elderly, because the incompleteness

experienced by these subjects will require an upgrading of the living and an understanding of the world perspective.<sup>7</sup> In general, the amputees are concerned about dependence and have difficulty to visualize actions that they can perform. The elderly, especially, are dependent for daily activities, and it is important that the health professional will stimulate the patient to self-care, to the acceptance of their limitations and the return to the activities.<sup>10</sup>

Some authors discuss that the first reactions experienced by the diabetic amputee are primarily, the shock, the disbelief and anguish. Once the first phase of pain passed over, diabetics tend to go through a longer phase of intense psychic suffering. In this lamentation journey, they blame themselves, they isolate themselves from the world and demonstrate willingness to die. Finally, there is the forming phase, consisting of the moment in which the individual accepts the reality and seeks a recovery mechanism.<sup>4,11</sup>

Considering that the loss of a part of body usually carries negative repercussions in the existence of being, the humanization in assistance to these individuals is essential for the health care professional carries out its activities more effectively and complete.

The previous information combined with the experience of one of the authors on the subject, when in the course of an activity in an ILPE, when observed a considerable number of elderly who underwent amputations as a result of DM, aroused the interest in this study. And it is in that perspective that focuses the following guiding question: What is the perception of the elderly with an amputation as a result of complications of Diabetes Mellitus?

The present study is relevant for providing subsidies to the awareness of diabetic's elderly, in particular, those that have some type of amputation, about their limitations, to encourage the work of health professionals, preparing them for a more suited performance to the reality of these elderly seeking a greater knowledge about the subject. Its importance is based on the sociocultural impact to the elderly of the whole society.

To look at the amputated person, from their perspective, it allows a care directed to the singularity of the person and the particularity of the lived experience.<sup>8</sup> Thus, this study aimed to know the experience of the institutionalized elderly with amputated lower limbs due to complications of Diabetes Mellitus.

## METHOD

This is a descriptive nature study with a qualitative approach. The descriptive research have as primary objective the description of the characteristics of a particular population or phenomenon, or, the establishment of relationships between variables.<sup>12</sup>

The qualitative approach is particularly important, since not always the world's social and psychological phenomenon can be adequately quantified. It works with the universe of meanings, motives, aspirations, values and attitudes, which corresponds to a deeper relations space, processes and phenomenon that cannot be reduced to the operationalization of variables.<sup>13</sup>

The search scenario was an ILPI of Maceió, in which resided 68 elderly - 28 women and 40 men. Of these, 12 were diabetic and five had amputation of the lower limbs due to complications of DM. The sample of the study was census conducted with all diabetics' amputees who had conditions, according to the result of applying the Mini Mental State Examination (MMSE), responding to the questions.

Of the five elderly with lower limb amputations resulting from complications of DM, residents in the study scenario, only three showed no cognitive deficit, according to the MMSE and, therefore, they were able to participate in the study, composing the sample.

The data production occurred in the month of August 2012, by a semi-structured interview script, which was recorded (MP4), with variables that made possible to characterize the subject; and questions about their life after amputation; application of Katz Index (KI) and Comorbidities Charlson Index (CCI); in addition to the observation of the records.

In this process of constant discoveries, the interviews were analyzed following three moments: a) Pre-analysis: It refers to the ability to understand the language of the subject; reading in that arise hypothesis or guiding questions, being systematized the main ideas; b) Exploration of the material: it consists in the operationalization of ideas built in the previous phase. It will be spontaneously perceived discrimination in the descriptions of the subject when the researcher assumes a psychological attitude and the certainty that the text is an example of the phenomenon researched. It is characterized by analytical description and selection of analytical units or meaning units;

c) Treatment of the results: the researcher condenses and highlights the information for analysis, culminating in the referential interpretation and/or categorization process.

It is worth mentioning that it was used content Analysis, thematic Analysis mode, from the perspective of Bardin, which consists of an analysis method that appears as a tool for the understanding of meaning that the social actors passing in the speech.<sup>14</sup>

## RESULTS AND DISCUSSION

Among the interviewed, two are characterized by being female and one male. This female predominance is confronted with other studies<sup>15,16</sup> conducted in Brazil, in which the higher incidence of amputation as a result of DM was in males. However the literature still does not define clearly the relationship between amputation and the male, but the same studies indicate that this fact can be associated with the greater self-care held by women, thus enabling preventing the risk factors related to the amputations caused by the DM.

The researched subjects are between 64 and 75 years old. This data corroborates a research conducted at a vascular clinic of a public hospital of a city in the Northeast, in the year of 2011, at it was noted increased frequency of amputation in diabetic subjects with age range between 60 and 70 years old in relation to more advanced tracks.<sup>17</sup> According to the literature, the majority of patients undergoing amputation is elderly, and this number is increasing because of aging population and the prevalence of peripheral vascular disease. The incidence of amputations on these members increases after the age of 55, mainly in males.<sup>18</sup>

Of the total subjects, one was coming from the interior of Alagoas and two from the capital. Two were single and one married. The number of children referred to them varies between two and seven.

Among them, the education level is variable, because one of them is illiterate, one has incomplete elementary school and one completed high school. It is known that the condition of low education can hamper the access to information, resulting in smaller learning opportunities regarding health care especially when considering that in DM patients develop much of their care and, therefore, they need to have some knowledge about the disease.<sup>6</sup>

About the residence time in the institution, all subjects had an average of three years. Regarding the existence of a caregiver to

assist them in their activities, all individuals denied. As regards the time of discovery of the DM, the subjects were between three and 28 years, showing that respondents have a considerable diagnostic time, finding themselves in a position to reflect on their experiences. In relation to the time of amputation, the respondents were between one and three years.

When discussed on locomotion, all elderly responded that they require wheelchair assistance to perform this action.

It is known that the Amputation of Lower Limbs configures one of the chronic complications with great crippling potential and high morbidity. To note the dynamics of installation disability both in aging process and chronic degenerative diseases and its aggravations, the application of IK proved to be useful.

Compared with BADL, evaluated by the KI, it was found that the first of those surveyed was dependent for the implementation of all functions, the second was independent for all functions except bathing and one more additional; and the third was independent for all functions except bathing, dressing, toileting and one more additional. Each of these respondents interviewed represented 33.3% of the sample.

When they were asked about the existence of health problems that could affect the performance of activities of daily life, the study's participants reported, in its entirety, to present anxiety/panic disorder, DM, Hypertension and insomnia.

Through the analysis of the lines, in relation to the experience of the elderly after the amputation, there were three categories, which were able to extract cores of meaning for each one of them as described below.

**The first category aimed to understand how was the route to amputation.** As a sense of cores, it was obtained information that the DM was controlled, that there was nothing and the account of the appearance of ulcers and caring for them.

On the lines of the subjects, reports of presentation of injuries precedents to amputation and the elderly responsible caregiver for their current situation-amputation were prevailed. As well as the oversight was in the health center, having the injury a terrible trend, with reports of creating bugs.

*It formed two bubbles behind, in the heel, the calf was this thick, I couldn't even touch it (I3).*

The experience of amputation is reported from the beginning, when the predisposing factors (blisters and sores) appeared, with a serie of events that culminated in the amputation of the limb. Initially dressings in the Healthcare Unit were conducted, but the care with the member were not sufficient to prevent the progress of the injury, as the doctor is sought and, because of advanced stage of the lesion, the problem has only one solution: amputation. This fact is evidenced from the speech of I2:

*They gave a knot on my leg that it held the circulation [...], then it created a wound in the blister and became an ulcer. I didn't care. [...] I was taking care myself in the health center and it was even creating bugs in my foot, then I had to amputate it (I2).*

Only one elderly said not having presented continuity solution before the amputation.

*I had nothing, I ate nothing, never. The pressure and diabetes were controlled (I1).*

Studies<sup>4,6</sup> indicate that about 87% of amputations cases in diabetics are preceded by foot ulcerations, characterized by skin lesions with loss of epithelium, which extend into the dermis or cross it and reach the deeper tissues, involving sometimes bones and muscles. However these diseases can be prevented with appropriate multidisciplinary monitoring, and the help from relatives in the control of diabetes and self-care with the risk foot.<sup>4</sup>

**In the second category, in which individuals were asked about what represents to be diabetic with amputation,** four nucleus of meaning were able to extract: it means experiencing a life permeated by difficulties and restrictions; represents sadness; error report in the clarification of information about the amputation process and regrets about having submitted to it; and it means to realize the constant threat to present other complications. The first unit of significance is about the limitations imposed by health status, in which one subject reported feelings of anguish and restrictions, as observed reading the following speech:

*It's not good, I don't think it's good. [...] The foods that I like to eat I can't eat because of diabetes, because if I'm eating, it increases. Even not eating it, it increases the glucose, it is worse if I eat (I3).*

One of the difficulties of accepting the diabetic condition was compared to the pleasures of food, considering that the surrounding world represents an appeal to the taste. When a complication arise as the amputation of limbs, the dietary recommendations should be followed, more

rigorous, generating more opportunities for transgression and feelings of rejection.<sup>19</sup>

The diabetic diet should keep the glucose in the blood as close as possible to the normal physiological level, in order to prevent or retard the development and progression of renal, ocular, neurological, cardiac and vascular complications.

Another feeling referenced by one of the subjects of the study was the sadness, evidenced from the following speech:

*It was sad. Yes it was, that I lost my leg. Every day I cry (I1).*

With the amputation, patients tend to be experiencing a tragedy, since the experience of mutilation is devastating. Depressive symptoms are mentioned frequently by people with amputations, because they present sadness, sorrow, crying episodes, social isolation, loss of appetite, difficulty sleeping, among others. Symptoms such as sadness and sorrow are expected responses after the loss of the limb, however the individual in the postoperative period must be accompanied with more cautious by the health team and family, because the emergence of a depression can result in further complications, to represent a significant risk for increased morbidity and mortality in these patients.<sup>20</sup>

At this stage of pain for the loss of the limb, patients tend to show repentance for having undergone the amputation. According to the literature, no other human emotion is so distressing and painful as repentance. This can, sometimes, become a terrifying feeling, since we are directly responsible for a loss we have suffered, even if it is necessary. When there is a genuine loss, the feeling of remorse, it is often violent and persistent.<sup>11</sup>

In the speech, a participant is still not satisfied with his physical state, leaving across the feeling of betrayal by the professional who gave information about the surgical procedure to which he would submit.

*She warned me before he'd cut it, but it didn't hurt, and it was just in the leg. She didn't said it was the thigh. If I had known it was in the thigh I hadn't gone there. Losing the leg for fun (I1).*

In the preoperative period, the goal of the health team should be getting the patient's active in the discovery of the treatment process, so he participates with autonomy from the decision to amputate it until the rehabilitation process.<sup>20</sup>

Health professionals must be open for questions and clarifications about the patient wants to ask, establishing open communication. In this communication process between the health professional and

the patient, it is necessary an individualized attention from professional to the patient, to have active listening, to open space for questions and answer them honestly, using an accessible language, offering the patient a sense of control and encourage his active participation in the decision-making process.<sup>20</sup>

Communication between the health professional and the patient must, therefore, be honest and realistic, evaluating the acceptance and understanding of the information received, as well as ensuring the aftercare and support to face the situations that will occur.<sup>20</sup>

It was possible to extract, from the lines of the subjects, the fear feeling with the possibility of coming to present other complications of DM. I2 demonstrates affliction to the dependency situation he can evolve.

*I'm afraid to lose this other one. [...] Here's a woman who has both legs amputated. If I get to that point I don't know what I will be (I2).*

The person who has experienced an amputation previously discovered the pain of loss and feels the constant threat of a new amputation, and is something that may or may not be coming. Fear is unveiled from preview amputation of the own member, is the dread, since there is the possibility to come to present other complications, which is something known and familiar.<sup>19</sup>

People with ulcers and/or previous amputation are important risk factors for relapses, since the existence of any of these complications increases at about 14.5 times the possibility of individual suffering another amputation, since they present the vascularization compromised.<sup>21</sup>

In addition to the increased risk of the patient need to undergo other amputations, diabetic amputee has a dismal prognosis, considering that the percentage of survival is 50% after three years of the first amputation and, within 10 years, the mortality rate reaches the estimate between 39 and 68%.<sup>11</sup>

Therefore, it is of great value to strengthen the guidelines for diabetics, especially those who have already been subjected to any amputation, about the importance of skin care, inspection and the use of proper footwear that will not push the foot, and to protect him from extrinsic injuries.<sup>6</sup>

**The third category of the study made possible to meet the difficulties experienced by the subject after the amputation.** During the lines of individuals, it was possible to highlight three nucleus of meaning: the constant need of the assistance of other



people to perform basic activities such as bathing; the commitment of walk; and social isolation.

The difficulty most referred by study subjects was the limitation that they suffer from no longer being in possession of a "complete" body. Of the three respondents, two supported the current physical status to the feeling of dependence.

*To go to the bathroom there has to be a person, to take a shower there has to be a person (I2).*

*There are times that I think "Oh, who I was and who I am now, right?" [...] When I was good I was walking, traveling [...], I went to parties. [...] I used to work. [...] Yes, now I am not being able to walk or do anything (I3).*

The commitment of health due to the DM often involves the loss of organs through mutilating surgeries, as well as changes in habits and customs, leading to a lowering of self-esteem and self-concept.<sup>4</sup>

With the amputation, daily activities will be more limited, imposing difficulty on performing simple tasks, as well as causing a different body image, which can be rejected and hard to be accepted. This fact may be evidenced in both the amputee who lost only one or two fingers, as well as the individual who lost all the fingers or even a complete member.<sup>4</sup>

Commonly, the image that the individual amputee has is of a "disabled" person, unable, often becoming a nuisance for the family and people close to them. Relying on someone to even the simplest of activities generates a feeling of worthlessness, sadness and even rejection of the own body.<sup>22</sup>

Another consequence of amputation referred in the respondents' lines was the removal of friends, as evidenced below:

*Roberto's sister didn't want to know about me. She always came. [...] Now she is not coming anymore (I1).*

The isolation that the disease causes in the lives of the amputees is often featured and arising from the restrictions, limits and diminished possibilities of "living life" because of the difficulty of moving, the need to deprive of the coexistence of other people, or inability to continue working and even have their moments of leisure.<sup>8</sup>

The social stigma is present in many social groups, however there is still the possibility of some individuals amputees using the defense mechanism of the projection of their negative feelings about the other, since consciously they do not accept these feelings and

conveying them to others or to society as a whole, blaming them for their problems.<sup>20</sup>

The changes that happen in the daily life of the individual of amputation are large, are high impact and signify a hard experience to be diabetic amputee, when they show suffering caused by dependence, by social isolation that is the result of dependence on accessibility and other factors. Amputee individuals referred to loneliness, they would like to participate actively in the social, family and community life. In this way, the amputation causes the limitation and, with it, the accommodation of the individual.<sup>23</sup>

## CONCLUSION

According to the obtained results, it was noted that all subjects had more than one year of amputation of limbs, which evidences that they already had policies, in matter of time to reflect on their experiences.

It was noted that the trajectory for amputation in 66.6% of the subjects, had as previous factors the injuries amputation and foot blisters. Such results could have been avoided with a systematic follow-up of diabetic, with emphasis on examination of the feet, as well as, with the early diagnosis of disease and health professional guidance to the bearer of DM.

It was evidenced that experiencing amputation is a sad experience, painful, distressing and hard. However the way individuals can face the situation varies from subject to subject, depending on the values and emotional from each of them.

The difficulties found by the subjects after the amputation were related to social relationship, which has become compromised, and physical dependence, as showed the result of Katz index. They were worried with the dependency, referencing a world marked by suffering.

Experiencing an amputation generates feelings of sadness, guilt for being with the body changed, the wish for something lost, in addition to making individuals feel segregated from the environment in which they live, by having a body part missing, different of other members of society. Therefore, knowing the live of the subject is essential to make the amputee assistance more integrated, to enhancing the singularities, besides favoring the rehabilitation process.

When meeting the experience lived by them, it is learned that health professionals, here, specifically, nursing, rethink their strategy of elderly care in a broader context, as well as to provide a more directed

performance to real need of singularities of diabetics and amputees elderly. We realize that, only from the understanding about the experience of these, it is possible to become the assistance more integrated, in a manner that encourages the active presence of the individual in its treatment process, stimulating autonomy and thus favoring the rehabilitation process.

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Submission: 2012/12/09

Accepted: 2013/11/26

Publishing: 2014/01/01

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