AMPUTATION IN THE PERCEPTION OF THOSE WHO EXPERIENCE IT: A STUDY UNDER THE PHENOMENOLOGICAL VIEW[1]

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This study aimed to understand the implications and feelings associated with the experience of amputation. The literature review allowed the knowledge of this phenomenon under several perspectives, besides the appropriation of some ideas of the philosopher Merleau-Ponty about body and perception. After this initial knowledge, interviews were performed with people who underwent amputation, by living in their world and listening to their statements. By sharing these moments, it was possible to understand meanings from the perspective of those who experience it, which led to six thematic categories. In addition to understanding those who underwent amputation in their context and in their essence, some facets of this phenomenon were revealed through the phenomenological referential.

DESCRIPTORS: amputation; nursing; rehabilitation

LA AMPUTACIÓN BAJO LA PERCEPCIÓN DE QUIEN LA VIVE: UN ESTUDIO DESDE LA ÓPTICA FENOMENOLÓGICA

Frente a las circunstancias de amputación, sus implicaciones y sentimientos vividos, este estudio fue realizado con la propuesta de comprender este fenómeno. Inicialmente, la revisión de la literatura permitió conocer el tema desde diversos enfoques, además de permitir la adquisición de algunas ideas sobre el pensamiento filosófico de Merleau-Ponty con respecto al cuerpo y la percepción. Posteriormente al obtener conocimiento sobre esta óptica fueron realizadas entrevistas con las personas quienes fueron sometidas a una amputación, para poder introducirnos en su mundo y escuchar sus expresiones. A partir de esos momentos se pudo comprender el significado de quien lo vive; manifestaciones que son descritas por medio de seis categorías temáticas. De esta forma, fue posible mostrar algunas fases del fenómeno de amputación bajo la óptica del referencial fenomenológico, así como, comprender a la persona amputada en toda su magnitud, tal como ella se manifiesta en sí misma en su esencia.

DESCRIPTORES: amputación; enfermería; rehabilitación

A AMPUTAÇÃO NA PERCEPÇÃO DE QUEM A VIVENCIA: UM ESTUDO SOB A ÓTICA FENOMENOLÓGICA

Diante da inquietação com a questão da amputação, suas implicações e sentimentos experimentados pela pessoa que a vivencia, realizou-se esse estudo, com a proposta de compreender esse fenômeno. Inicialmente, a revisão da literatura possibilitou conhecer esse tema sob diversos enfoques, além de permitir a apropriação de algumas idéias do pensamento filosófico de Merleau-Ponty sobre o corpo e a percepção. Após o conhecimento sob essa ótica, realizou-se entrevistas com as pessoas submetidas à amputação, habitando seu mundo, ouvindo seus depoimentos. Compartilhando desses momentos, pôde-se compreender seus significados, a partir da experiência de quem os vivencia, expressando-os sob a forma de seis categorias temáticas. Desse modo, foi possível desvelar algumas facetas do fenômeno amputação, à luz do referencial fenomenológico, além de compreender a pessoa amputada em sua situcionalidade, tal como ela se mostra em si mesma, em sua essência.

DESCRITORES: amputação; enfermagem; reabilitação

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INTRODUCTION

As a nursing undergraduate and scientific initiation student, I became concerned with amputations, their implications and feelings aroused in the people who experience them, a concern generated by personal experiences. To obtain further knowledge about the theme, I carried out a bibliographic survey, which allowed me to get to know amputation from an anatomic-physio-pathological focus, as well as nursing production about the subject. Thus, in theoretical-practical activities, I started to have contact with people who experienced this phenomenon.

Amputation is the eldest of all surgical procedures and, for a long time, it represented the only surgical possibility for man. In surgery, the term designates the removal of an organ or part of it, located at an extremity. However, when used isolatedly, it is considered to be the amputation of limbs. Its current concept refers to a reconstructive surgery instead of simple ablation and should be the first step for the patient's return to a normal and productive place in society[1]. The surgery should be considered as yet another phase in treatment. The mutilation only affects the limb and not the patients' soul[2].

Upper and lower limb amputations can be carried out at different levels and derive from: peripheral vascular diseases (most common cause among the elderly), congenital malformations, tumors, traumas (predominant cause among young people) and infections[1,3-5].

There are no exact statistics about the number of existing amputees or the number of amputations carried out each year. However, about 85% are lower limb amputations[1]. These are common in diabetics with lower limb ulcers[6]. Diabetes patients with larger amputations also present a reduced quality of life[7]. However, disabled persons can have a good quality of life when they overcome limits and achieve a balance between mind, body and spirit[8].

Nurses have stood out as educators for diabetes patients, and their integration into the multidisciplinary team becomes increasingly important, with a view to contributing to educational strategies and minimizing health problems[9]. However, there is a lack of nursing publications about the subject, which makes it important to carry out and publish studies about the theme[10].

Despite the literature review, something still remained hidden to me, because I hadn't managed to answer my concern and, thus, understand the emotions and feelings, that is, the experience of human beings submitted to amputation. Hence, I carried out this study to unveil some facets of the amputation phenomenon from the perspective of the people who experience it.

THE METHODOLOGICAL COURSE

Phenomenology is a descriptive, rigorous science that is concerned with the essence of experiences[11]. It calls upon us to take up the qualitative course of existence again, to rediscover the global meaning of existing[12]. The phenomenological method seeks what transcends the empirical particularities of the phenomenon, with a view to understanding it[13].

Starting from the philosophical premises of phenomenology, I saw the possibility to understand the phenomenon "experiencing an amputation situation" in the way it appears in itself, which is the goal of this study.

The study was previously submitted to the Research Ethics Committee and carried out at the University of São Paulo at Ribeirão Preto Medical School *Hospital das Clínicas* (HCFMRP–USP)-Campus, more specifically the vascular and orthopedic surgery clinics, due to the fact that these offer the highest possibility of finding people who are going through an amputation situation.

To collect the amputated patients' testimonies, I carried out individual interviews from January to May 2005, when I accompanied the hospitalization period of 13 adult patients, who were hospitalized for the surgery, from the preoperative stage until discharge. This care is in line with the proposal of phenomenology, which looks for the meaning attributed by people going through a certain situation. Meetings were held on alternate weekdays, totaling 52 meetings with these patients. The collection of statements was terminated when, through the reading and interpretation of the 52 testimonies, I perceived the invariant, i.e. what continues and appoints what the phenomenon is, in its essence. All of these interviews were used for analysis.

Nine patients were men and four women; ages ranged from 44 to 80 years; seven underwent suprapatellar amputations, five infrapatellar and one hand amputation, all of them resulting from chronic

diseases. I got access to the patients through the daily observation of the surgical scale, to verify if some amputation would take place the next day, and by talking with the nurses at the clinics.

During the first meeting with the patients who would undergo the amputation, I requested their collaboration in the study by providing their testimonies. If they expressed the desire to collaborate with the project and signed the Free and Informed Consent Term, the collection of testimonies started, in line with the following schedule:

- Whenever possible, the first interview was held on the eve of the day programmed for the amputation. For this interview, I proposed the following guiding question to the patient: *How do you see tomorrow's surgery?*
- Subsequent interviews were held from the first postoperative day until hospital discharge. The guiding question the description of the phenomenon was based on was: *What does this amputation mean to you? Describe it to me.*

Most of the interviews were recorded, with the patients' permission, and later transcribed. When the recorder was not used, I transcribed the reports immediately after the interview, with a view to maximum reliability. In line with my methodological proposal, no determination of patients occurred in terms of gender, color, civil status, socioeconomic level, age, hospitalization motive or disease that led to the amputation.

THE CONSTRUCTION OF THE RESULTS

While reading the 52 testimonies obtained through the interviews, initially, I attempted to become familiar with the experiences. Next, I identified the units of meaning and the meanings they contained. Finally, these units were synthesized to arrive at the essence of the phenomenon. This synthesis took the form of the construction of thematic categories[14].

Merleau-Ponty's philosophical thinking was used to support discourse analysis, as he is the philosopher of existence, of the body, and the phenomenologist of perception. I perceive and I am perceived through my body, as it is my vehicle of being-in-the-world and, this way, I do not have a body, but I am a body. The "own body" or the "lived body" is the one that, through the sensitive, exercises vital communication with the world, which is what I live and not what I think. The body is our means of having the world and it is through the body that one relates with others, with things, with the world itself, experiencing my own body[15].

In an amputated person, this relation between the body and the world is changed, as a part is questioned in the body which no longer exists and is silenced. Thus, the research subjects perceived the amputation as follows:

Living the preoperative period in an attempt to keep up appearances

During the preoperative period, the patient experiences ambiguous feelings, as this moment in life at which the person is about to assume a new way of being-in-the-world arouses an infinite range of feelings, which are expressed or not.

Although the patients affirmed their agreement with the surgery, they displayed feelings of discouragement, pain, anguish, fear, sadness and crying and remained downcast. At all times, their gestures communicated the difficulty to live with the imminence of a mutilating surgery.

*They could cut it today. Get it over with (intense crying). Affection - I1**

Losing a body part means having one's entire existence altered, it means living an incompleteness that entails a series of changes in one's existence. It means having to adapt/readapt, learning to live again, now assuming another perspective on the world for oneself, for the others, for objects. Preoperative patients try to get distant from what they consider painful, affirming that they feel well despite the circumstances. This effort is a mere attempt, as the body expresses everything that words do not say and, in this case, verbal and non-verbal expressions diverge.

In spite of the suffering experienced because of the imminent loss, the patients see their family as a reason to try and hide the pain they suffer. Protecting their relatives from the suffering they experience seems to be a primordial issue. In a way, their concern with their family reveals to be something determinant

* To maintain anonymity and preserve identities, the people who participated in this study are identified through fictitious names, which express the feelings they left after the realization of this study. The abbreviation I(No) indicates the interview the citation was extracted from.. All markings in bold were made by the authors.

to try and keep up appearance and for their continuous effort no to let their pain come to the surface.

... everybody stayed there, at home, crying. I don't cry, things will get solved. I make the decision. Strength - I1

The surgical experience shows its possibilities to the patient, as it makes possible a different existence. We can see the perspective of an incomplete existence, as a body part is lost, or simply the perspective of standing open to new experiences, free from the pain, from the deformed part, from the organic part that also causes suffering and that often modifies the movement of the being-in-the-world.

Experience permeated by a dualism: the logical and the experience

Experiencing an amputation implies an experience marked by bio-socio-psycho-spiritual and cultural changes, loaded with stigmas, deriving from the installed disability and from different converging and diverging feelings, which interweave and join, constituting a whole. This experience consists of feelings that are mixed up and permeated by reason on the one hand, which visualizes the surgery as necessary, and emotion on the other, which does not accept the loss.

In looking at the amputation as a phenomenon, I noticed that it can be good and bad, pleasant and sad, happy and unhappy, easy and difficult, in the eyes of the people who experience it. Opposite but mutually united feelings and sensations coexist in one and the same scenario. How, then, can one consider a surgery that is mutilating and leads to such important changes in the lives of the human being and his relatives as good? This experience becomes more pleasant to the extent that the amputated persons perceive it as a source of hope to return to life, to keep on living, as being-there-in-the world, with a singular will and desires.

In the case of patients affected by vascular problems, the definitive relief of their pain reveals to be a priority. Pain is discouraging, unbearable, sad and limiting and, at this moment, any attempt to relieve/eliminate the pain is considered positively, even if this demands the loss of a body part. Amputation starts to be seen as a necessary evil.

... not sleeping for six months is hard... it hurt when I lay down, when I stood up, it's hard, it's sad, I suffered so much, so much, so much. Now, if I had to do it again, I'd do it again, because all of the suffering ends... Strength - I2

Besides an alternative for pain relief, amputation is a possibility to maintain life, mainly for patients with tumors. It is seen as a procedure that must be done, despite all of its physical and psychological consequences, provided that it allows for a prolonged existence. The hope to save the whole body is an essential factor in making the decision and choosing the surgery. Death is the finitude that must be avoided, and the sacrifice of losing a body part is valued.

... if I didn't I could die. As I was saying: I'm between the devil and the deep blue see. You'd better guess right. So, let's move ahead. I told him: Dr., do whatever it takes... Force - I2

Dependence as a possibility of an existence marked by daily suffering

Dependence showed to be a source of concern for amputated persons. Becoming dependent is frightening, a source of unhappiness, of insecurity, of fear. Not performing daily activities or doing them with help causes feelings of inferiority, low self-esteem and concern in the patients.

It bothers you, you know. Perhaps the person helps you now, then you call him again. Perhaps he comes to help you with the same good will as the first time, but you don't think like that in your head. I think like, I'm causing too much trouble... It gets difficult (pause)... but what can you do? (silence). Overcoming - I1

Being dependent is extremely painful and discouraging and, in some cases, the patients even prefer death to being a source of pity, compassion or even work/effort for their relatives.

... I want to live, but provided that it does not cause trouble to my family. If I cause trouble, I prefer to leave. I don't want to leave (die). Force - I1

Amputated patients are concerned with their dependence and display difficulties to visualize what they can do. Mainly the elderly show dependence to perform activities of daily living. It is important for health professionals to stimulate patients towards self-care, acceptance of limits and return to activities[16].

In a phenomenological perspective, I consider that there is a need for a multi and interdisciplinary look, which helps the people to redimension their existence, opening up to new life projects and contemplating them in this new way of being-in-the-world. Receiving individualized and planned care is essential for the rehabilitation process to take place as adequately as possible and to achieve the proposed objectives.

Rehabilitation must be considered as yet another treatment step, as it allows patients to keep on throwing themselves into the world and living new experiences. The return to activities entails a feeling of fullness, in which possibilities become real and move from a desired world to an experienced one.

The difficulty to live in the hospital world

Patients see the hospitalization as frightening and inhuman. They start to live in a world that is different from theirs, permeated by tense and sad feelings, equally inhabited by unknown persons, with whom they will interact in a way, sharing experiences. Life in this world creates anguish and apprehension.

Lack of information is present not only in the most severe situations, permeating the entire hospitalization period and taking the form of imprecise dates, test results that are done and redone, unconfirmed diagnoses, promises that are not kept, realization of procedures and administration of unknown drugs or medication they are not informed about, among others. In this sense, we can observe the statement:

(Hospital) Sometimes I think it's good, sometimes I think it's bad. I think it's bad because they put fantasies into our heads: you're going to do the test that day and then they cancel it. We keep on waiting... Strength - I3

Hospitalized patients are weakened and submitted to health professionals' desires, mainly the physician, who possesses scientific knowledge. The relation between physicians and patients is impersonal, as the former are treated as masters, but always in plural, anonymously. There is neither humanitarian positioning of getting closer to the patient, nor the establishment of emotional and affective bonding in the relation. The patient's subjectivity and existence is not considered at any time.

The sick people's hospitalization time is primarily occupied with the expectation of their improvement and consequent hospital discharge. For man, time is the time lived, instead of the chronological time that disappears among the days and cannot be recovered.

And I don't like anything. I don't want to. They screwed up. They broke the deal. A deal is a deal. They cut off my leg and they won't let me leave now. They have to allow me, even if just for three days, I have to go. Perseverance - I5

Hospital discharge ends up being seen as the "passport" to life and to the return to activities. The patients affirm that, outside the hospital, they will do everything they were used to before the surgery, often denying the limitations imposed by the surgical procedure, as well as their new condition in the world.

... What is concerning me most right now is that I want to go home. That's what's concerning me most. I'm tired, I'm sick of it. There's no place like home. At home there's my chair, I can go out onto the street... I go everywhere, I go to church. Hope - I9

Mainly long hospitalizations give rise to an infinite range of feelings that demand the patients' efforts to achieve a balance and overcome any crises ahead. In this sense, humanitarian contact with health professionals becomes important in order to minimize the negative effects of hospitalization.

The phantom limb as the extension of one's own body

As a way of maintaining the body's expression and language, the phantom limb is present to a greater or lesser extent. The absent limb takes forms and continues living in the amputee's world, as the project that guarantee the human being's integrity are possible if their bodies are complete and, in amputees, this is possible by the unquestionable presence of the phantom limb. The feelings are so intense and true that the patients are able to describe their sensations in detail.

The arch of the foot hurts. It pounds. It pricks. But it's like that, in the arch of my foot... Will - I1

The phantom limb is a way of being-in-the-world, staying complete, open to actions in the world, fully, and to the possibilities of one's becoming, of one's existential projects. In the attempt to describe the belief in the phantom member and the refusal of the mutilation, the idea of an organic thinking is constituted, through which the relation between the mental and the physical could be conceived. The phantom members allows for neither a physiological, nor a psychological or mixed explanation, although it can be related to the two series of conditions. In the physiological explanation, the phenomenon appears as the simple persistence of interoceptive stimulations while, in the psychological explanation, the phantom members becomes a recollection, a perception[15].

Starting from these objective and mechanistic, physiological and/or psychological explanations, and looking at these only, we would highly reduce the existential dimension of the phantom limb phenomenon and its importance for amputated patients. Connecting and relating the physiological with

the psychological is possible when they are both integrated into one's existence.

It is. It is part of my life (amputated leg). You feel it, undoubtedly. The functioning of the rest of your body also belongs to it (amputated leg). Hope - I9

Hence, what we find behind the substitution phenomenon is the movement of being-in-the-world. The phantom limb is not a simple effect of objective causality. The patients seem to ignore the mutilation and consider their phantom as an actual limb[15].

... I saw that I didn't have the leg. It itched, my foot itched. I looked for this other one to scratch my foot that was itching. I asked the boy to bring the leg, the amputated leg so that I could scratch, but he didn't know where it was, I asked the nurse: I had to scratch the amputated leg and he said he would try and find it around, but he didn't. It's funny that you feel it. Right now I was feeling pins and needles in my foot... (short silence). Hope - E1

The phantom limb, as a part of one's own body, maintains the amputee fully in the world, trying to complete the void left by the body part through the substitution.

The prosthesis as a way of fully continuing in the world

It is believed that the prosthesis makes it possible to perform any activity, improving self-esteem and, thus, minimizing the negative effects that result from the amputation. Although they are adequate to any amputation level, those performed at more distal levels provide for a more efficient rehabilitation. Hence, rehabilitation has been considered increasingly important as, if the process occurs adequately, the patients will practically have a normal life and can do any activities they want or need to.

Prostheses are normally expensive, turning into a source of concern for the amputee, as it is a dream that often will not come true, impeding their movement towards the world.

... now, the two... It's difficult for poor people. It's faster if you have money; I'm not able to buy a prosthesis, it's expensive, the cheapest one costs eight thousand reais. It takes time at the hospital, there are a lot of people. Overcoming - I1

Purchasing the prosthesis seems to be an unquestionable dream; any amputee wants it as early as the preoperative period. In communicating the need for the surgery, the medical team itself already addresses rehabilitation with the help of a prosthesis, perhaps in the attempt to mitigate the suffering caused by the amputation.

...the doctor said that it's fast. Three months of treatment here, I put on the prosthesis and I can walk fine...Strength - E1

Although the prosthesis is considered extremely important for people who have already undergone the amputation, sometimes, it is seen as a source of difficulties, suffering, which demands adaptation, starting and starting over. The patients acknowledge that the organic part of their body is no longer there.

For the amputee, the prosthesis becomes something that moves further, as it is not only a facilitating object, but also something that will be a part of one's own body. It represents a horizon of possibilities. It will become a fundamental part of the body, allowing for the full and complete perception of a form similar to the phantom limb.

REFLECTIONS ABOUT THE REVELATIONS

This study made it possible to unveil some facets of the amputation phenomenon, at a moment of transition in the patient's life, from the possibility of becoming to the concreteness of this possibility, through the realization of the surgery. An infinite range of feelings is involved in the change process of the body and, thus, of the entire existence, as the body is of vital importance as a means of being inserted in and relating with the world, through perception.

Amputation is loaded with ambiguous feelings that mutually interact and remain united, permeating existence in the preoperative period, during hospitalization and possibly after discharge. Losing a part of one's body is painful and imposes a new way of life, of being-in-the-world and relating with it, which requires a redimensioning, as the body and, consequently, the perception of the world and things was affected. No matter how difficult or painful it is to be an amputated person, the patients surrender to the limit/limiting situation they are in, in the chronic disease, and chooses to do the surgery, hoping to put an end to the physical pain or to stay in the world, distancing the idea of a close death.

In the relation with the world, in questioning a body part that no longer exists, there will be a real and no longer ideal or habitual answer. This new reality creates fear, pain, anguish, as having to readapt to a new way of existing and overcoming barriers towards actual possibilities is, at first, something complex and difficult.

While the patients do not clearly visualize the possibilities that appear, which demand redimensioning, they suffer due to the lack of perspective and dependence expands through experience. The amputee starts to be concerned about dependence, seeing it as a future marked by suffering. Thus, the importance of harmonically developing the rehabilitation process becomes evident, as rehabilitating a patient does not only mean returning him/her to society as an independent person, despite the impairment. Rehabilitation should be capable of granting the patient perspectives of ideal daily activities, of a modified existence that allows him/her to stay open to the world and to things.

The patients showed that experiencing an amputation is sad, difficult and painful. However, despite all of these difficulties and suffering, they do not lose courage. The expectation of a new life is a reason for happiness and for the desire to want to keep on living. The surgery is incorporated into the existence and, as a part of it, it is accepted but not wanted.

Understanding this moment is essential for a more effective and complete performance of health professionals' activities. Looking at amputated persons from their perspective permits care delivery directed at these persons' singularity and at the particularity of their experience. Nursing needs to awake to what goes beyond the biological dimension, as the objective of the profession is care, which should be delivered in a way that expands through experience. In opening up to the private world of experience, the profession opens up to the human being who is there, providing him/her with complete and humanitarian care.

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