DOI 10.18471/rbe.v31i1.20439
Original Article

EXPRESSION OF GRIEF IN WOMEN WITH CHRONIC WOUNDS IN LOWER LIMBS

EXPRESSÃO DO LUTO EM MULHERES COM FERIDAS CRÔNICAS DE MEMBROS INFERIORES

EXPRESIÓN DE DUELO EN MUJERES CON HERIDAS CRÓNICAS DE MIEMBROS INFERIORES

Anara da Luz Oliveira[1]
Evanilda Souza de Santana Carvalho[2]
Gilmara Ribeiro Santos Rodrigues[3]

Objective: to understand how women express grief when faced with a chronic wound in lower limbs. Method: this is a qualitative study developed in two health units of the state of Bahia, from March to June 2012. Thirteen women participated. Data was obtained through the application of the Designs-Stories Procedure with a theme and the In-depth Interview technique and was analyzed with the thematic content analysis technique. Results: when assuming a new body, marked by the presence of the wound and, therefore, considered incomplete, the participants experienced the loss of identity and the need to draw up a new reference for the female body. Conclusion: their grief was expressed by means of denial, anger, bargain, sadness and acceptance, where the stages of sadness and acceptance were more frequent.

Descriptors: Gender and Health; Wound Healing; Attitude to Death; Grief; Chronic Disease.

Objetivo: compreender como as mulheres expressam o luto diante da ferida crônica de membros inferiores. Método: estudo qualitativo desenvolvido em duas unidades de saúde do estado da Bahia, no período de março a junho de 2012. Participaram 13 mulheres. Os dados, obtidos pela aplicação do Procedimento de Desenhos-Estórias com tema e da Entrevista em Profundidade, foram analisados de acordo com o método da análise de conteúdo temática. Resultados: ao assumir um novo corpo, marcado pela presença da ferida e, portanto, considerado incompleto, as participantes vivenciaram a perda de identidade e a necessidade de elaboração de novo referencial de corpo feminino. Conclusão: o luto expressou-se por meio da negação, ira, barganha, tristeza e aceitação, sendo as fases de tristeza e aceitação mais frequentes.

Descritores: Gênero e saúde; Cicatrização; Atitude Frente à Morte; Luto; Doença Crônica.

Objetivo: comprender como las mujeres expresan el duelo frente a la herida crónica de miembros inferiores. Método: estudio cualitativo efectuado en dos centros sanitarios en el estado de Bahía, durante el período comprendido entre marzo y junio 2012. La investigación contó con la participación de 13 mujeres. Los datos, obtenidos por medio de la aplicación del Procedimiento de Dibujos-Historias con tema y de la Entrevista en Profundidad, fueron analizados con arreglo al método de análisis de contenido temático. Resultados: al asumir un nuevo cuerpo, marcado por la presencia de la herida y, por consiguiente, considerado incompleto, las participantes experimentaron la pérdida de

[1] Nurse. Former fellow PIBIC FAPESB, resident of the Instituto Nacional do Cancer José Alencar Gomes da Silva, Rio de Janeiro, RJ, Brazil. anaraluzoli@yahoo.com.br
[2] Nurse. PhD in Nursing. Adjunct Professor of the Undergraduate Nursing Course of the Universidade Estadual de Feira de Santana. Researcher at Núcleo Interdisciplinar de Estudos sobre Desigualdades em Saúde (NUDES). Feira de Santana, Bahia, Brazil. evasscarvalho@yahoo.com.br
[3] Nurse. PhD in Nursing. Adjunct Professor I and Coordinator of the Nursing Specialization Course in Cardiology and Hemodynamics of the Escola Baiana de Medicina e Saúde Pública. Salvador, Bahia, Brazil. jubaenfa@hotmail.com

identidad y la necesidad de desarrollar un nuevo referencial de cuerpo femenino. Conclusión: el duelo se expresó a través de la negación, rabia, ganga, tristeza y aceptación, donde las etapas de tristeza y aceptación fueron más frecuentes.

Descriptores: Género y Salud; Cicatrización de Heridas; Actitud Frente a la Muerte; Duelo; Enfermedad Crónica.

Introduction

The existence of chronic wounds awakens the individual to the acceptance of a new body image. This process involves the loss of an identity adapted to the social requirements and the need to construct a new identity to have a place in society. In this process, people who live with chronic wounds experience the event of death itself in life. The suffering resulting from this disease and the consequent loss is similar to a grieving process of the own body, the feeling of loss of oneself and of the meaning of life[1].

For people with chronic wounds, the presence of the injury represents the loss of the intact body, of the social role and, consequently, the breaking of bonds. This new situation also requires constant adaptation and building a new identity, which can result in a grieving process[1].

Despite the chronicity of the wound involve subjective aspects of the individual, health care in these cases are primarily focused on technical procedures directed to the wound, based on the biomedical model of healing[2]. The feelings that people with exposed wounds have are frequently underestimated by medical teams.

Grief can be defined as an event that involves the loss of meaningful structures for the individual and encompasses not only the loss of a loved one, but also other situations where the link is broken. This break can be the passage from one stage to another of vital development, the loss of a pet, q social and psychological loss without death and even a chronic illness, due to the loss of health[3-4]. In general, studies addressing the theme of mourning are directed toward the grief experienced at the loss of someone or something external. Mourning caused by the inherent loss of oneself is still an approach little explored by nursing.

The experience in the care provided to persons with chronic wounds and listening to reports of suffering of these people spurred the following question: how do women experience the process of chronicity of wounds and how does this process resemble the experience of grief? In order to answer this question, this study aims to understand how women express grief in the face chronic wounds in the lower limbs.

Method

This is a study with qualitative, descriptive and exploratory approach, part of a greater project funded by the National Council for Scientific and Technological Development (CNPq), Notice n. 020/2010, entitled "Body and Sexuality of Women with Chronic Wounds: Images and Social Representations". This project was approved by the Ethics Committee of the State University of Feira de Santana under Protocol n. 032/2011 (CAEE 0035.0.059.000-11). The recommendations of the Resolution n. 196/96 dealing with ethics in research involving human beings were adopted at all stages of the research. The participants were told about the objectives of the study and they signed the Informed Consent (IC). In order to preserve the confidentiality of identity of participants, and to signal the speeches, fictitious names chosen by participants were used.

The study included women who had chronic wounds in the lower limbs (leg ulcers of venous, arterial, mixed, traumatic or unknown nature) in several stages, who were admitted to two public health units located in two cities in the state of Bahia; one was an unit of reference to people

with hypertension and diabetes and the other was a specialized unit for people with wounds.

The inclusion criteria were: having chronic ulcers in the lower limbs for more than 30 days and being regularly assisted by one of the units elected as field of study. The occurrence of pain at the time of data collection represented the exclusion criterion.

Data collection occurred from March to June 2012, by applying the techniques: Design-Story with Theme (SD)[5] and in-depth interview individually conducted. At first, the SD technique was applied; paper and colored pencils were offered to participants and they were asked to draw something that represented the life of a woman after the appearance of a wound. Then, they were asked to look at their drawings, draw up a story and give it a title.

Interviews were conducted in a space restricted to the presence of the interviewer and the participant only. Interviews were developed based on the following question: How is it to live with a chronic wound? New questions were formulated during interview, seeking to deepen the issues raised by participants. Data collection was stopped when there was saturation of the content of speeches.

All statements, after authorization of the interviewees, were recorded on tape and afterwards played aloud for them to hear and change the contents if they wanted, or even to give up to participate. The interviews were transcribed in full length by the authors immediately after collection. Then, all statements and stories were submitted to thematic content analysis. This technique seeks to understand the content of communications, whether expressed or implied[6]. Speeches were interpreted in the light of the five stages of grief: denial, anger, bargaining, depression and acceptance[4].

Results

The study included 13 women between 23 and 59 years old. Of these, 5 were retired, 4 were housewives, 3 were cooks and 1 was a farmer. Regarding color, 5 women declared themselves black, 3 white and 5 brown. Among the participants, one had diabetic foot, 6 had ulcers of vascular nature and 6 of traumatic nature.

Women with wounds in the lower limbs experience lengthy treatment processes and a large number of them do not reach the cure. Faced with this situation, they develop various mechanisms to cope with the disease. The strategies adopted to experience the chronic illness translate the sense that the person attaches to her condition, which directs her to the preparation for mourning or experience of pathological mourning.

Experiencing Denial

This category shows that, for many women, it is difficult to accept the existence of the wound, since it represents abnormality, a deviation from aesthetic standards and a distortion of the female body. There is a strangeness of the self. They said that when they look themselves in the mirror, they think: "That's not me!" Before the new image, women do not recognize themselves. Thus, the denial it happens because the wound represents the loss of the healthy image and the perfect body, as evidenced in the lines:

> *Accepting this is very difficult, because you were used to a perfect body, without wound, no, nothing.* (Jessica, 53, wounded for 6 years).

> *[...] because I've handle with this here* [the wound] *for 28 years, but even so, I do not accept it, no, no, I do not accept, and every day I say, "God!" And the lots of medicine that I have to take too, I do not accept that either, no, I don't accept, every day I say to God: "Lord, I can't take all this medicine!"* (Victoria, 59, wounded for 28 years).

Starting from the idea that there is something strange, different in their body, women understand that the wound should be masked and forgotten, as if that had not happened in their lives. Thus, tactics are used to avoid the perception of their uncomfortable presence, such as making the dressing while everybody sleeps and clean the whole bathroom to avoid odors coming from the wound.

For these women, it's like the people around them always drive looks of discrimination,

prejudice and curiosity and as if people perceive them as dirty and disgusting bodies, calling them rotten legs. In face of perceived rejection, women stay away from the others. This removal culminates in self-isolation and social isolation.

That is why the participants reported that they could not wear skirts and dresses and gave preference to dark clothes to avoid unsightly images due to the possible dirt aspect of the wound. They said that, after the wound, their lives have become more restrained, discreet, lonely and with less socializing with other people.

Experiencing Anger

Realizing that there is a new reality that they cannot avoid and which they need to face, women step into the anger/wrath stage. At that stage, they express anger, envy, revolt and resentment. They used to say: "I get irritated with everything and everyone!"

Anger can be expressed against those who are close, such as children, partners and even health professionals, but can also be directed against oneself. This behavior is linked to the feeling of guilt, to the extent that the person reflects on her health habits and believes that the wound could have been avoided, as pointed out the participants:

> *I get very nervous. There are times when I give cry out indoors.* (Fernanda, 48, wounded for 18 years).

> *But there are times that I get annoyed, because it's something I did not have to face, because I blame myself [...]* (Amanda, 59, wounded for 10 years).

Experiencing Bargain

After the initial shock and numbness resulting from the diagnosis of a chronic condition, women begin to try new experiences, including routine of visiting health services in search of care. Before the impact of the difficulties brought about by the new reality to which they had to adapt, they express a bargaining feeling. They seek agreement with divine entities, in the attempt to solve their problem. They use different religious beliefs, nurturing faith and trust in the resolution of their health problems, cultivating the hope of achieving the healing.

Often, the search for hope overcame the difficulties of displacement, as expressed by the following speeches:

> *But when I can drag myself, I keep going* [referring to the visits to the church]*; because if I do the will of my foot, I will not walk anymore. So I prefer to go walking, it's close, I live in the half of the street and the church is at the corner.* (Michele, 57, wounded for 20 years).

At this stage, women seek support and assistance of the saints and entities of Christianity, as well as African religions, revealing the bargaining behavior. This mix of orientations and beliefs points out that the women seek all possible alternatives to get rid of the wound.

> *The wound? Mother said not to send back to her, no, she spoke to the "pai de santo" [male priest of Umbanda] to leave into God's hands, sent it to the Holy Spirit [...]* (Patricia, 23, wounded for 2 years).

> *I asked God to heal me and make me well, let me free of those pains, this suffering.* (Bruna, 57, wounded for 25 years).

In some situations, women even change religion when they experience the chronicity of the wound, because they believe that other forms of religiosity can be more effective in wound healing and relief of suffering. Thus, some women convert to protestant churches. This behavior denotes that suffering helps to strengthen faith in search of mercy:

> *I am a Jehovah's Witness. I used to be Catholic, but for 30 years or more, I am a Jehovah's Witness.* (Judith, 59, wounded for 38 years).

Experiencing Depression

The expression of depression, also known as the stage of sadness/hopelessness was very recurrent in the accounts of the participants. Anguish, grief, lack of peace, discomfort and unhappiness were some feelings expressed by the interviewed women.

The sadness is still associated to the manifestation of pain, which is a constant and stressful experience in the life of these

women, fostering consequent unhappiness, discouragement, lack of pleasure and despair.

The limitations imposed by the wounds entail various losses, like the loss of mobility and changes in the performance of small daily tasks that lead these women to the loss of freedom and autonomy and make them experience deep sadness, tending to depression.

> *At first, I would not even go out the door. But it was so. I did not go out at all. I did not speak to anyone when I discovered this horrible disease. That was it, I wouldn't do anything, I would stay at home, I lost my freedom, right?* (Michele, 57, wounded for 20 years).

Experiencing Acceptance

The statements made possible to see that women with chronic wounds can experience the stage of acceptance from the beginning of the wound or only after living many years with it, and after experiencing the difficulties for healing or even the inevitable and irreversible complications.

> *A person with a chronic wound is awful. A woman with a chronic wound, she was always very sad, nothing would give her joy, she lived isolated, crying in the corners, disgusted. Then she heard the advice of people, and she began to go out and have fun, and today she lives happy and smiling, and she leads her life.* (Andreia, 60, wounded for 28 years).

Acceptance may also arise when a woman with a chronic wound identifies in health services people who are worse off, with older wounds than hers, larger wounds, more exudative or more painful:

> *I resigned because I see a lot of people worse than me here, a lot really. There is a woman that has both legs injured. So I think that I would be very selfish, right?* (Amanda, 58, wounded for 10 years).

Moreover, the experience of mourning involves a change in the relationship with the lost object and with the very identity of the bereaved person, which allows the preparation before the loss.

> *We feel like this, like missing a piece of ourselves, but life goes on. Nothing is difficult and nothing is easy, but you can live, you know?* (Carine, 47, wounded for 5 months).

Thus, it is clear that after the experience of mourning and considering the chronicity of the wound, part of the women managed to keep their lives and incorporate the presence of wound in their day to day, adapting the wound care demands to their routine:

> *If I go, I go on the market. If I go to the market, I now only do market on Saturdays, because my son is at home and takes me in his car, because I cannot get any weight.* (Amanda, 58, wounded for 10 years).

Discussion

The experience of losses allowed the women with chronic wounds reworking their daily lives, re-signifying their identity, whether reaching or not the acceptance of their condition.

The grieving process does not happen only after the death of a person, but in every change that involves losses, such as marital separations, the departure of children from home, the loss of health, loss of cognitive skills, of employment, social status, relationships, among many others situations that require elaboration[7].

The function of mourning is to provide reconstruction of resources and allow adjustments to the transformations resulting from losses[8]. This fact brings two possible destinations before losses: the fall into melancholy or the reframing of identity with the development of loss[9]. Dealing well with mourning means being able to face the feelings evoked by the loss, the new imposed reality and also being able to have moments to avoid pain and get back to life[10].

Study on women and men with wounds corroborates the findings of this research when identified that there is a process of deterioration of the image, and people with chronic wounds display a behavior that is similar to the stages of grief found in people under finitude process, such as denial , anger, bargaining, depression and acceptance[4].

Another study on people with chronic wounds showed that the stage of denial is manifested especially when people start to enter the health services and raise questions about the life of a person under a specific health condition/ disease[1]. In the present study, however, the stage of denial was present both in women

with recent wounds, precisely three weeks, and women with wound for more than 1 year.

This stage of denial is temporary and necessary, now and then, in every patient. It is more frequent at the beginning of a serious illness, although it may never be expressed or persist throughout the therapeutic process[4]. Denial represents a healthy resource, since it leads the person to adopt behaviors considered abnormal in other period of his/her life, but ameliorated before the mourning, thereby preventing a collapse[11].

We identified that women experience anger. This stage is marked by extreme feelings of revolt and resentment, in which they ask: "Why me?" That anger is an emotion that is not always directed to the object that caused it and is expressed in different directions, many of which are even banal[3]. Thus, it is common to observe anger be directed to people who are close, living around, including health professionals that assist in the treatment, and there is usually no good reason to justify it[1]. Feelings of this nature were also found in reports of people with chronic kidney disease, leprosy and diabetes[12-13].

Women in this study made promises to God and the Saints in exchange for the cure. This bargaining behavior arises when the person makes promises for a prolongation of life or a few days without pain, or for the healing of physical ills[14]. In exchange for healing and salvation by superior forces, these women resorted to faith, which gave them strength to move forward in the face of so much suffering, believing in divine healing or miracle.

The reasons for the feeling of sadness of these women are various. They include psychological loss, recurrent pain, limitations imposed by the presence of the wound, impediment to perform domestic and work activities, and financial difficulties. The difficulties of the treatment and its long-term nature increase sadness that, along with other feelings, cause depression[14].

The acceptance, the last stage of grief is associated in the speeches of the women with the acceptance of the new body image and the need for continued treatment and care. This is influenced by *coping* by comparison, by the support network and even by the financial component[15]. Regarding *coping* by comparison, women seek to compare with others in health situations that resemble their status, but with signs of disadvantages that make them feel less impaired by the situation in which they are. This happens, for example, when they meet other people in health services who have fallen ill and who have even worse limitations.

This stage is intrinsically associated with hope, which is the only thing that usually persists at all stages[4]. For the sickened and their families, the fact that they hope in the healing and believe the wound is improving and that the pain and the constraints they face will end one day, may positively contribute to cope with the treatment[15]. Although in most situations, this is associated with obtaining the cure, hope should not have an exclusive focus on the desire of healing or in having more years of life. Other options to relief suffering can be focused, such as pain management[16].

There is no order to the occurrence of the grief stages, and the person in pain may experience these phases simultaneously, in the same period, or may even not experience some of them[14].

Persons with wounds face a complex reality that requires understanding by nursing professionals and family with respect to the feelings caused by the disease, helping them to rebuild their lives[17]. Working with people who experience a grieving process means helping them settle down to face the losses inherent to the chronic illness and aiming at the restoration of life[10].

By accepting a new body, marked by the presence of the wound and, therefore, considered incomplete, participants experience the loss of identity and the need for developing a new female body frame.

One limitation of this study is that the mourning of female patients and related to wounds in the lower limbs only was addressed. We suggest that further studies try also to understand how people with other types of chronic illness and

people with chronic wounds express grief, so that a comparison may be possible.

Conclusion

This study investigated the expression of grief by women with chronic wounds in the lower limbs and allowed understand that the process of evolution of the chronic disease is experienced with loss: loss of autonomy, freedom, social and sexual relations. These losses translate into suffering, decreased self-esteem, change of the self-image and identity, culminating in expressions of the stages of grief.

The identification of the stages of grief in these women helped to realize the need these women have to express their feelings and to be heard and embraced in their experiences. The experience of grief is expressed through denial, anger, bargaining, depression and acceptance.

The results of this research will help to reflect on professional training, seeking to invest in qualifying, particularly nurses, to meet the subjective aspects of the care to mourners. This way, it will be possible to help them experience losses and grief aiming at re-signification of the reality and of life.

Understanding the stages of grief in this study allows for a new look at the care offered to women with chronic illness, contributing to the comprehensive care, able to meet the specific needs of individuals. To the extent that the health professional recognizes and attaches importance to the subjectivity of these women in the context of chronic illness and their treatment, it is possible to qualify the therapeutic encounter, in order to provide an authentic health care.

Collaborations:

1. conception, design, analysis and interpretation of data:Anara da Luz Oliveira and Evanilda Souza de Santana Carvalho;

2. writing of the article relevant and critical review of the intellectual content:Anara da Luz Oliveira, Evanilda Souza de Santana Carvalho and Gilmara Ribeiro Santos Rodrigues;

3. final approval of the version to be published: Evanilda Souza de Santana Carvalho and Gilmara Ribeiro Santos Rodrigues.

References

1. Carvalho ESS. Viver a sexualidade com o corpo ferido: representações de mulheres e homens [tese]. Salvador: Escola de Enfermagem, Universidade Federal da Bahia; 2010.
2. Carvalho ESS, Sadigursky D, Vianna R. O significado da ferida para quem a vivencia. Rev Estima. 2006 abr-jun;4(2):26-32.
3. Parkes CM. Luto: estudo sobre perdas na vida adulta. São Paulo: Summus Editorial; 1998.
4. Kübler-Ross E. Sobre a morte: o que os doentes têm para ensinar a médicos, enfermeiros, religiosos e aos seus próprios parentes. 7a ed. São Paulo: Martins Fontes; 1996.
5. Coutinho MPL. Depressão infantil: uma abordagem psicossocial. João Pessoa: EdUFPB; 2001.
6. Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2012.
7. Melo AS, Costa AS, Cardarelli G, Moraes LSC. Elaboração de perdas por mulheres saudáveis. Interação psicol. 2004 jan-jun;8(1):129-40.
8. Gesteira SM, Barbosa VL, Endo PC. O luto no processo de aborto provocado. Acta paul enferm. 2006 out-dez;19(4):462-7.
9. Mendlowicz E. O luto e seus destinos. Ágora. 2000 jul-dez;3(2):87-96.
10. Bousso RS. Editorial. A complexidade e a simplicidade da experiência do luto. Acta paul enferm [internet]. 2011 [cited 2011 July 23];24(3):vii-viii. Available from: http://www.scielo.br/pdf/ape/v24n3/01.pdf
11. Oliveira TM. O psicanalista diante da morte: intervenção psicoterapêutica na preparação para a morte e elaboração do luto. São Paulo: Mackenzie; 2001.
12. Vieira C, Lopes MHBM, Shimo AKK. Sentimentos e experiências na vida das mulheres com câncer de mama. Rev Esc Enferm USP [internet]. 2007 [cited 2011 May 19];41(2):311-6. Available from: www.scielo.br/pdf/reeusp/v41n2/19.pdf
13. Péres DS, Franco LJ, Santos MA. Sentimentos de mulheres após diagnóstico de diabetes tipo 2. Rev Latino-Am Enfermagem [internet]. 2008 [cited 2012

Nov 15];16(1). Available from: http://www.scielo.br/pdf/rlae/v16n1/pt_15.pdf

14. Susaki TT, Silva MJP, Possari JF. Identificação das fases do processo de morrer pelos profissionais de enfermagem. Acta paul enferm. 2006 Apr/June;19(2):144-9.

15. Sousa FAMR. O "corpo" que não cura: vivências das pessoas com úlcera venosa crônica de perna [dissertação]. Porto: Instituto de Ciências Biomédicas de Abel Salazar, Universidade do Porto; 2009.

16. Balsanelli ACS, Grossi SAA, Herth K. Avaliação da esperança em pacientes com doença crônica e em familiares ou cuidadores. Acta paul enferm. 2011;24(3):354-8.

17. Salomé GM, Blandes L, Ferreira LM. Avaliação de sintomas depressivos em pessoas com diabetes mellitus e pé ulcerado. Rev Col Bras Cir. 2011;38(5):327-33.

Received: December 20, 2016

Approved: March 8, 2017