Suffering, enduring and rehabilitation: perspective of a woman who survived a burn

Sofrimento, tolerância e reabilitação: perspectiva de uma mulher sobrevivente de uma queimadura

El sufrimiento, la tolerancia y la rehabilitación: perspectiva de una mujer sobreviviente de una quemadura

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ABSTRACT

Purpose: To understand and analyze the meaning of rehabilitation from the perspective of a woman who was a victim of burns and multiple losses. **Methods:** We carried out semi structured interviews and direct observations at the participant's home. We asked her to tell us the trajectory after the burn and talk about the meaning of rehabilitation. **Results:** She described the pain and solitude during the hospitalization process and after the discharge. The narrative shows the suffering and insecurity due to the lack of financial resources, family support, the loss of her husband, who died during the same accident, and the threat of losing her children. In the course of the trajectory after the accident, her enduring and persistence to overcome the experience of suffering were identified, as well as the support resources used in this process; besides the meaning of feeling rehabilitated: recovering the ability to taking care of herself and her children and work. **Conclusions:** This report of a severe burn survivor shows the rupture experienced with intense suffering in a context of changes, involving the survivor's personal, social and professional life.

KEYWORDS: Stress, Psychological. Pain. Burns. Rehabilitation.

RESUMO

Objetivo: O objetivo deste estudo foi compreender e analisar o significado de reabilitação, a partir da perspectiva de uma mulher que sofreu queimaduras e múltiplas perdas. **Método:** Os dados foram coletados por meio de entrevista semiestruturada e observações diretas realizadas na casa da participante. Foi solicitado que ela narrasse a sua trajetória após a queimadura e falasse sobre o significado de reabilitação. **Resultados:** Ela descreveu a dor e a solidão durante o processo de hospitalização e após a alta. A narrativa mostra o sofrimento e a insegurança em razão da falta de recursos financeiros, de apoio dos familiares, da perda do marido, que faleceu no mesmo acidente, e da ameaça de perder os filhos. Ao longo da trajetória após o acidente, identificaram-se sua tolerância e persistência para superar a vivência do sofrimento, e os recursos de apoio utilizados nesse processo; além do significado de se sentir reabilitada: recuperar a capacidade de cuidar de si e dos filhos e o trabalho. **Conclusões:** A queimadura grave provoca uma ruptura, vivenciada com intenso sofrimento, sendo que essa experiência ocorre em um contexto de mudanças envolvendo todo o contexto de vida da pessoa: pessoal, social e profissional, como relatado neste estudo de caso.

DESCRITORES: Estresse Psicológico. Dor. Queimaduras. Reabilitação.

RESUMEN

Objetivo: El objetivo de este estudio fue conocer y analizar el significado de la rehabilitación, desde la perspectiva de una mujer que sufrió quemaduras y múltiples pérdidas. **Método:** Los datos fueron recolectados através de entrevistas semiestructuradas y observaciones directas en el domicilio del participante. Se solicitó que narrase su trayectoria después de la quemadura y relatase el significado de su rehabilitación. **Resultados:** Se describen el dolor y la soledad durante el proceso de hospitalización y después del alta. La narración muestra el sufrimiento y la inseguridad debido a la falta de recursos financeiros, el apoyo familiar, la pérdida de su marido, que murió en el mismo accidente, y la amenaza de perder a sus hijos. En el curso de la trayectoria después del accidente fueron identificados tolerancia y perseverancia para superar la experiencia del sufrimiento, y los recursos de apoyo utilizado en este proceso; además del significado de sentirse rehabilitado: recuperar la capacidad de cuidar de sí mismos y de sus hijos y el trabajo. **Conclusiones:** Este informe de un sobreviviente quemadura grave muestra la ruptura experimentado con intenso sufrimiento en un contexto de cambios, que implica la vida personal, social y profesional de la sobreviviente.

PALAVRAS-CLAVE: Estrés Psicológico. Dolor. Quemaduras. Reabilitación.

INTRODUCTION

Care for burns victims implies the consideration of the trauma experience as the person and relatives experienced it. The burn experience gains different meanings for the trauma victim, for the relatives and professionals; permeated by different expectations and objectives, which entail implications for the way they experience the burn and for decision making on the treatment. The severe burn entails serious consequences for the individual and relatives. It is mainly characterized as an abrupt event that interrupts the course of life of a person and the family group, often causing an irreparable rupture in the course of life[1].

For the majority of burn victims, the hospitalization phase is represented as a moment permeated by suffering, associated with physiological changes, painful procedures, separation from the family and loved ones and from the activities that are sources of pleasure. Each day, the severe burn victim discovers that (s)he will have to overcome many challenges to survive and is confronted with changes that happen in his/her body and life. In that context, each surgical procedure can signify the hope of recovery. The hospital discharge marks the passage to a new phase of daily coping; the experience of the end of a challenge – survival and the recovery from injuries (during hospitalization) – to cope with the external world[2,3].

After the discharge, the burn victim and relatives take the long course of the adaptation process. In this case report, the meaning of this experience is described from the perspective of a 46-year-old female health professional who was a victim of severe burns.

Morse & Carter[4] described a Model of Suffering, analyzing a similar case, of a woman who was a burn victim and had to cope with multiple losses. In that Model, the authors distinguished between enduring and suffering. Enduring, an emotional condition, refers to the present, to the moment experienced. This emotional condition can comprise three distinct moments: enduring to survive (bearing an impacting physical threat); enduring to live (a psychological reaction in response to a significant threat) and enduring in view of death (perseverance to complete the selected tasks instead of surrendering to death). Suffering is an emotional status, in which the person acknowledges the reality of the events, assessing the impact of the event on his/her past, present and future[4,5].

Although these constructs (enduring and suffering) are discussed as separate stages, in practice, they are interrelated[6]. Between enduring and suffering, the authors include uncertainty. The moment when the person recognizes what (s)he wants to achieve but does not know how to do it. The suffering present in this phase is associated with the perceived lack of capacity to overcome the situation. In the process of tolerating the present, the possible overcoming is not perceived as a possible choice. The acknowledgement of the trauma, disease or loss and its circumstances as something oppressive, crushing and the perceived change this situation will provoke in the future makes the suffering unbearable. It is in the process of suffering, of the past experience (event) and the perception of the present (intense emotion of suffering) that the person starts to perceive the hope in the future. A future in which one cannot continue based on the recovery of the past condition[7], but only adapt to the change.

The description of the reality that involves bearing and enduring in view of the pain, the misery and the suffering is more than the report of reality; it includes a moral message that is shared by all people who are close[7]; by those people who in close contact contribute to legitimize the social standards of behavior. Thus, the suffering is experienced, expecting survival and losing the hope of returning to the previous condition (without the physical and visceral marks) day by day, as these will modify the individual forever[7].

Hence, the reconstruction of new perceived possibility, i.e. of the hope for a new life occurs in the experience of intense pain and suffering independently of being strong, optimistic or resilient (in the magical sense)[7]. The suffering becomes a reparation process[6]. The acknowledgement of the effect of the trauma in the person's life, provoking irreparable damage, and of the effects on the future, in an experience of intense suffering, can result in a flexible and more realistic planning of the future[6].

This process is social and culturally determined and, to understand it, the aspects involved in the disease or trauma, adaptation and rehabilitation need to be considered in the context of the sociocultural relation, besides taking into account those aspects related to the domain of the natural sciences. With its sociocultural particularities, each group presents different forms of attributing meaning to the experience of being or feeling ill or suffering. The representation of the disease or trauma is related to the role performance or to the social use of the body, that is, to the experience, which informs and is guided by the representations, at the interlink between action and representation[8].

We based this analysis on the interpretative perspective of the health and disease phenomenon, theoretically aligned with the hermeneutical paradigm. According to Geertz, the main representative of this perspective, the culture, "networks of meanings" woven by man and which tie him down, constitutes the context in which humans guide their actions and grant meanings to the world[9].

Focused on the analysis of the structures of meaning that guide the actions and representations of a human group, and in line with the theoretical premises of hermeneutics, interpretive studies adopt the understanding as a fundamental category of knowledge (although they also include explanation), which aims to interpret the meanings of human conducts. For these studies, the ethnographic method is used[9], which implies personal contact with the research subjects, emphasizing the qualitative research techniques, mainly participant observation and interviews. The emphasis on the understanding of the cultural context in which the different explanatory models of the disease are constructed represents the core of the interpretive approach, interested in apprehending the meanings socially attributed to health and disease.

The acknowledgement of the models' heterogeneity is in accordance with the proposal for an analytic distinction between the disease, which refers to the abnormality of the biological process according to the medical understanding, and the illness,

corresponding to the subjective experience of the disease, and the cultural expression of the disease (sickness)[10,11].

The objectives of this ethnographic case study are to describe and understand the suffering process based on the narrative of a female burn victim. This narrative is analyzed in the light of the models by Morse & Carter[4] and Kleinman[12], which are focused on the experience of suffering and disease/trauma, respectively. This analysis shows the emotion the patient experiences as part of the process and some comforting care strategies in the process of suffering that help the individual to cope with it[4].

METHODS

Qualitative ethnographic case report that analyzes the meaning of rehabilitation based on the perspective of a female burn victim attended at the Burns Unit of the Ribeirão Preto Medical School Hospital das Clínicas. This study is part of a broader study that received approval from the Hospital's Ethics Committee. To preserve the participant's anonymity, despite the consent granted for the dissemination of this experience, information like the place of residence and the profession were omitted.

We collected the data by consulting the medical and nursing records in the patients' histories, besides semistructured interviews and direct observations at the hospital and at the participant's home after the discharge. We asked the participant to tell her story. We visited her home twice that also served as the scenario for this study. In this context, the following we observed the following aspects: housing conditions, relationships among residents, behaviors and interactions, work and leisure activities, and also how the patient and relatives manifested when discussing the trauma and the current condition, and the support resources used when coping with the situation.

We recorded the data on tape and in a field diary. The narrative was reconstructed based on the analysis process. In the data analysis, the set of information was considered, organizing initial categories that were interpreted in view of all the information collected.

RESULTS

Sociodemographic and clinical characteristics

Forty-six year-old woman, widowed, health professional from a city in the region of Ribeirão Preto, state of São Paulo, Brazil, where she lives with her two children, aged 11 and 18 years. At the time of the accident, she indicated a monthly income of U$ 8.775 with a higher education level. The total body surface area burned corresponded to 30%, with second and third-degree burns on the upper and lower left limbs, due to the explosion of a gas cylinder after technical problems with a stove. As a result of the explosion, the house was damaged. Initial care was provided at another private hospital, where she was hospitalized for four months.

Her husband, who suffered burns during the same accident, died during the week of the accident as a consequence of the trauma. Next, she was hospitalized for 26 days at a Burns Unit in the interior of the State of São Paulo. Nothing happened to the children, as they were in the bedrooms of the house when the explosion happened. Next, this woman's narrative is presented in chronological order.

A narrative of suffering and mourning and tolerance/persistence to survive

Since the start of the conversations, the participant was available and remained focused on the interview. She remembered the possibility of losing the children during the accident and her emotional and physical frailty; she talked about how she perceived her changed appearance after the burn.

"My first perception after the accident was that I was mutilated (...) I did not look at my burned skin; I only looked at my skin afterwards, at the Burns Unit (...) I felt very lonely, very lonely."

She talked about the perception of death and mourning because of the losses she experienced, of her husband, her appearance and her house. She smiled when talking about her relationship with her children and husband. She cried when talking about her frustration about the initial treatment at a private hospital, highlighting her humiliation because of the financial difficulties to pay for the treatment and because she did not perceive improvement during the initial treatment.

"After my whole house exploded, after I lost my skin, I lost my husband, my everything, the possibility of everything… I closed down… I felt in raw flesh… But it was good… I needed that… I started thinking of the desire to get cured."

After the discharge, the first visit to the participant took place, while the children were in school, at a home to which she had moved temporarily after leaving her mother's house. At that house, few reminders of the couple and the nuclear family's joint life were observed in the domestic environment, such as pictures or other objects that could favor the memories of the relation with the husband/father (field diary). According to the participant, his family of origin took many personal objects after the expertise and vacation of the house damaged by the explosion.

"After the accident, my husband's relatives removed all of the things from the house and took everything. They delivered the rest of the stuff for friends to keep. I felt… burned, dumped in the garbage."

A plant was left for the participant, which the couple had grown before the burn. A friend of the couple, who kept of the family's belonging at the time of the accident, rescued the plant, which survived the explosion.

Her reports are permeated by resentment, felt when she perceived the family members' resistance to receive her, shown in the complaints of her mother when she spent some time at her parents' house. She reported that the house did not possess the facilities needed for her physical sequelae.

"I felt like a nuisance... (...) I couldn't stay at my mother's house at all. Nobody was concerned about me. My brother went to see me just once and disappeared (...). I didn't get support from my mother.

That routine of washing the children's clothes, of lunch, her saying it was bothering... (...). Now, (reminding) the relation with my mother is what hurts most. I didn't get the extent of that relationship (...) I felt very lonely, very lonely."

__(During the hospitalization):

"...there was great distancing from my family. (...) ...there was a couple and they did not have children and wanted to adopt mine. There was this uproar… They thought I wouldn't recover; they (couple) were thinking of adopting the two (her children). The children told me that this couple said I had suffered a third-degree burn and that I had died. (...) It was abusive... (...) ...it was during the psychotherapy that I perceived, when I was the weakest, what family I had… The psychologist helped me a lot, I remember all therapy sessions..."

Assuming the mothering role and getting back to work:

When she discussed the resumption of the course of her life, she emphasized her insecurity and conflict between the desire and the fear of getting back to the city where she used to live and to work. She mentioned the difficulties she felt in her life with and care for her children, because of her husband's absence to support her in her mothering role:

"Soon after I got out of hospital (...) in one month... I started looking for an apartment… I asked the children to come and live with me, soon during the first week… It was very difficult for me to organize the meals; at first, we went hungry... (...) I remember that the psychologist helped me a lot when she talked about the targets and I was trying to follow that. It was as if it were a light at the end of the tunnel, because I could not see the children. I started seeing them not so long ago. I was aware of my responsibilities, but I was only thinking of taking care of myself. And that was good, how was I going to take care of them if I wasn't well? I was concerned with feeding myself, feeding the children, sleeping a lot."

The return to work appears as an important element in the perception of normality:

"It was very difficult to return to work, I was very reluctant until then. I knew that I'd have to return one day... (...) ...I even considered not returning anymore, but I have my children… I still do not feel able to take care of others, to listen to (the report of) my patients' suffering, their solidarity with regard to my recovery still touches me and, at the same time, their piety concerning what happened to me and my family. I tried to return; I was obliged to return and now I cannot ask the psychiatrist for a leave anymore."

When she got back to work, she manifested the need to maintain the bond with the multidisciplinary team for the sake of physical and emotional strengthening, as she did not feel rehabilitated in view of the evidence of conflicts and challenges that had to be overcome. When she returned to work, she started to contribute to the family income with her salary, adding up to the husband's pension (hers and each of her children's), received after his loss.

"Now, there is nothing better than having my home and having returned to my job. First, I didn't know that they (colleagues) would welcome me the way they did. I was not expecting that I think I invented too much about what they were going to say: "that problematic employee"; "the trauma victim is back"! "thepost-trauma is back"; "what is she (I) going to do her? ...because I'm one of the latest to enter the team. They (colleagues) waited for me!... So, when I had to come back, the team itself protected me in that sense... Despite having sequelae, despite my lack of mental conditions to attend I wanted to stay there. I felt insecure but, at the same time, I said to myself that I wouldn't give up. I was very sincere and it was agreed that I would return little by little. I said "I don't know if I'll stay here again… I don't know where I'll go..." After two months of coming and going the team welcomed me (...)."

The participant acknowledges that she may have had mistaken impressions of the welcoming she'd receive in her job, but also reports on the concrete losses that were interpreted as problems with her head:

"Of course, I had problems with the head... Ah! First, I lost my room. My things were all lost… the table was something I fought for… I pursued it… something else was when my head came into my group, while she (head) did not enter any other group… it seemed as if she wanted to check if I could handle it."

Besides the loss of physical space, she mentioned her perception of being persecuted, supervised and having no autonomy to do the work:

"I feel that my head is persecuting me, they're pressuring me... (...) ...there were days when I didn't want to go to work. There were days when I was very sad and thought that I wouldn't handle talking to the patients anymore. When I got there (work), I forgot everything, my problems, my life. I say that, if it weren't for this job, which was something I was able to construct, I wouldn't survive... I don't lose that (my work, myself), the burn does not take that away from me. The house can go away... that (the accident) may happen again... but what I am... that is inside of me and nobody takes that away. Here I am, still persecutory: "do they (colleagues) want me to leave...?."

She reported on the support she received from her children and friends and neighbors:

"...There was a school I trusted to leave the children. They granted me full support. That was one problem less. They (children) went to school with friends (ride with parents of other children) ...There was a neighbor who helped me a lot. This first apartment was a second hospital to me, I'll suffer a lot when I leave (she was moving to a new house within the next few days). It makes me feel safe. My entire recovery happened here."

The meaning of Rehabilitation: *I learned what the burn was and how to take care of myself*

The second meeting with the participant took place at her new house in the city where she lived, after moving with her children and after having worked for some months at the sector where she had already been active, with some differences in her function.

The participants showed the rooms of the house and expressed her satisfaction with the conquest process after the sale of the pre-

vious house, where the explosion had happened. She described in detail how she has been trying to organize and conclude the reform of the house. While talking, her son watched television, her daughter was in the shower and there was a maid cleaning the house. While she made lunch, she talked informally about how gastronomy please and relaxed her and discussed her doubts about a new job offer to work in the municipal government's occupational safety team (Source: field diary).

When the family joined to have lunch, the participant spontaneously talked about her rehabilitation experience and about the conquests at work (Source: field diary):

"Even this week, I summarized everything and felt extremely happy. I got my (work) agenda and saw the whole record of the process... ...of course, now in the beginning I did more lectures, a more cognitive work. There are times when, like now, I sat down and talked about me, I spent time alone and got scared. …I love my job. No matter how many problems I have, I grab onto my work, that's why I got mad when my things were out of place."

She talked about relatives, sometimes highlighting negative and sometimes positive aspects, with pauses, while keeping up her organization routine of the house, divided with her aid. She showed the cupboards with her husband's objects and went to the balcony, where she informally talked about her gardening hobby. On that balcony, there was a plant, the same as she rescued after the explosion. The plant was stronger and more colored. During this second meeting with the participant, her enthusiasm about her rehabilitation could me noted, as well as her efforts to overcome the conflicts (Source: field diary).

"I gradually understood what a burn was and how to take care of it. Everything they taught me, I did faithfully. I started taking care of the wound, doing the dressing and continued the therapy with the psychologist. The wound gradually dried, I got better. I started using the net, started to walk, I stood up. That was when I started to see my recovery… I started taking care of myself..."

DISCUSSION

The narrative presented in this ethnographic case study is very similar to other narratives published[6,8,13] or known through the experience of professionals working at Burns Units.

At the start of the narrative, at the same time as she reported on her struggle to survive, she talked about the losses (of her skin, her husband and the house) and the threats of losing her children and the interruption of the treatment due to a lack of resources. In this context of suffering and pain, she mentions her attachment to her children and to what was left of her house, a plant that survived the explosion but that, like her, was weakened. She was unable to envisage the past and the future[13]. At first, she concentrated on the pain and suffering: *"I lost my skin, I lost my husband, my everything (...) I felt like a nuisance, burned and dumped in the garbage"*.

Over time, the suffering obliged her to reflect on what had happened, on the reactions of loved ones, relatives, friends and the treatment received. This process is similar to a vicious circle, in which the reflection process, which is inherent in suffering, makes people relive the trauma experience repeatedly and, by contextualizing the horror, reassess and find strength to endure[13], to understand the present and think about the future. This process is enhanced, incorporating present and past situations: *"the relation with my mother is what hurts must. I didn't get the extent of that relation, I relived it again"*. In that situation, the support of family members and loved ones is fundamental. Pre-existing conflicts can be exacerbated at these moments though, when the relations are already fragile and conflicting. Perceiving health professionals and relatives' empathy can also be harmful at that moment[6]. Therefore, appropriate strategies need to be used, proposing targets and showing routes to achieve them, as the participant affirmed, *"... I was trying to follow that (...) a light at the end of the tunnel"*.

According to Kleinman[12], the disease or trauma can be located in the tissue of a single individual, but the disease experience will incorporate the entire social circle, family, friends, loved ones and work. The feelings of fear and demoralization are rarely restricted to the client. The welcoming is important, but the expression of emotion and suffering the family and team present can provoke a collapse instead of helping the individual[6].

In her reports, the participant shows the financial difficulty and the fact of having paid for care that did not seem to offer results according to her. She discussed the importance of the team's welcoming at the hospital and at work, but also the difficulties, at first, in private care, centered on the recovery of the injuries, from the pathological viewpoint, when her disease experience and expectation of results were completely ignored. Depending on the public and private, generalized and specialized health care spaces, other conflicts can be generated, imposing even greater suffering on the patient. Often, besides the institution, the distribution of power in the traditional relation between the professional who cures and the person who should receive care is unequal, involving people with different capacities: "one knows, the other feels; one prescribes, the other obeys; one is paid or the other pays"[14]. The treatment offered frequently focuses on the cure and, thus, in the case of burns, on the healing, and not on care. The traditional role of the "patient", hence, takes the form of passiveness and suffering[14].

Suffering seems to resist to the "methods of science"; refers to something that cannot be studied in a laboratory. It is not a gross piece of information or a phenomenon that can be classified and measured, but a condition we externalize or hide from the social world[14]. This can also explain the difficulties the health professionals may experience to cope with the suffering, although they should be prepared for that. Similarly, the relatives suffer together with the burn victim and are not prepared to experience this kind of abrupt situation or even death, mainly because of the unexpected nature of the event. This moment is very stressful to the victim though, who frequently cannot engage in practical matters, which the family should solve, such as the cost of treatment, resources and support to guarantee the continuity of the children's routine.

The return to work and the recovery of the capacity for self-care and care for the children are mentioned as central targets of the rehabilitation. Several authors have indicated that burn victims go through a process of rupture, financial difficulties, due to the interruption of the work, early retirement or functional changes due to difficulties to adapt to the previous job[1,15,16].

CONCLUSIONS

This ethnographic case study presents the experience of a single female victim of burns and multiple losses. Although limited to a specific care, in the narrative of this experience, the concepts of the Model of suffering were identified, described by Morse & Carter[4]. In the course of the trajectory after the accident, enduring to survive was identified in the experience of the suffering, as well as the support resources used in this process; besides the meaning of feeling rehabilitated: recovering the capacity to take care of oneself and of the children and work.

Like other types of accidents, severe burns provoke a rupture, experienced with intense suffering. The experience of this rupture takes place in a context of changes, beyond the physical body, involving the entire personal, social and professional context, as reported in this case study.

The health professionals who take care of burn or trauma victims should be trained to recognize and deal with the process of suffering. The burn victims need support from the health team, relatives and loved ones to find appropriate strategies to achieve the targets set together, and thus to cope with the suffering.

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