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Experiences of family caregivers of hospitalized elderlies and the experience of intercorporeality*

Vivências de familiares cuidadores de pessoas idosas hospitalizadas e a experiência de intercorporeidade

Vivencias de familiares cuidadores de personas ancianas hospitalizadas y la experiencia de intercorporeidad

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Abstract

Objective: To reveal experiences of family caregivers of hospitalized elderly individuals, having Merleau Ponty's phenomenology and the notion of intercorporeality as theoretical-philosophical reference. **Methods:** A phenomenological study was conducted with five accompanying family members of hospitalized elderly at a public hospital in the state of Bahia, Northeastern Brazil, in March 2014. The experiences were produced by two rounds of conversation, recorded and submitted to the technique of analytics of ambiguity. **Results:** By understanding the descriptions of experiences, the category arose: The experience of the *other myself* in the relationships of care between family members and hospitalized elderly. **Conclusion:** We understand that care, as it is subjective and dynamic, allows the experience of ambiguities, resulting in transcendence, both for accompanying family members and hospitalized elderly individuals. Thus, the hospitalization context provides opportunities of intercorporeality that can lead to new meanings of life and relationships.

Keywords: Aged; Hospitalization; Caregivers; Family relations.

Resumo

Objetivo: Desvelar vivências de familiares cuidadores de pessoas idosas hospitalizadas, tendo como referencial teórico-filosófico a fenomenologia de Merleau-Ponty e a noção de intercorporeidade. **Métodos:** Estudo fenomenológico, realizado com cinco familiares acompanhantes de pessoas idosas hospitalizadas, no mês de março de 2014, em um hospital público no interior da Bahia, Brasil. As vivências foram produzidas por meio de dois encontros de rodas de conversa, gravadas e submetidas à técnica analítica da ambiguidade. **Resultados:** Na compreensão das descrições vivenciais emergiu a categoria: experiência do *outro eu mesmo* nas relações de cuidado entre familiares e pessoas idosas hospitalizadas. **Conclusão:** Compreendemos que o cuidado, por ser intersubjetivo e dinâmico, permite a vivência de ambiguidades que resultam na experiência de transcendência, tanto para o familiar acompanhante como para a pessoa idosa hospitalizada. Assim, o contexto da hospitalização proporciona oportunidades de intercorporeidade, que podem convergir para ressignificações de vidas e relações.

Palavras-chave: Idoso; Hospitalização; Cuidadores; Relações familiares.

Resumen

Objetivo: Desvelar vivencias de familiares cuidadores de personas ancianas hospitalizadas, teniendo como referencial teórico-filosófico la fenomenología de Merleau-Ponty y la noción de intercorporeidad. **Métodos:** Estudio fenomenológico, efectuado con cinco familiares acompañantes de personas ancianas hospitalizadas, en el mes de marzo de 2014, en un hospital público en el interior de Bahía, Brasil. Las vivencias fueron producidas a través de dos encuentros de ruedas de conversación, grabadas y sometidas a la técnica analítica de la ambigüedad. **Resultados:** En la comprensión de las descripciones vivenciales ha emergido la categoría: la experiencia del otro yo mismo en las relaciones de cuidado entre familiares y personas ancianas hospitalizadas. **Conclusión:** Comprendemos que el cuidado, por el hecho de ser subjetivo y dinámico, permite la vivencia de ambigüedades que resultan en la experiencia de trascendencia, tanto para el familiar acompañante como para la persona anciana hospitalizada. Así, el contexto de la hospitalización proporciona oportunidades de intercorporeidad, que pueden converger hacia resignificaciones de vidas y relaciones.

Palabras clave: Anciano; Hospitalización; Cuidadores; Relaciones familiares.

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Submitted on 11/09/2015.
Accepted on 04/20/2016.

DOI: 10.5935/1414-8145.20160070

INTRODUCTION

Population aging is currently a common characteristic in demographic trends in the majority of countries worldwide[1]. Developing countries are expected to become home for more than one billion elderly individuals by 2040, including Brazil, whose figure surpassed three million in 1960 and slightly over 20 million in 2010, an increase of approximately 700%[2].

More conservative predictions indicate that by 2020 Brazil will rank sixth in the world in number of elderly individuals, totaling over 30 million[1]. However, the majority of this population experience or will experience chronic diseases and/or functional impairments that, not rarely, cause decompensations, functional dependency, frequent hospitalizations and higher mortality[3].

Due to these characteristics, there has been a steady increase in the elderly individuals' demand for hospital beds, accounting for 23% of all hospitalizations occurring in Brazil. Additionally, their length of stay in health care services of seven days on average stands out, as it is 25% higher than the period of hospitalization of the remaining age groups[4].

The pathological process that leads the elderly to being hospitalized usually requires intensive and permanent care, due to the greater vulnerability and reduced capacity to respond to different types of stress usually found in this age group[5]. This situation forces families to be responsible for organizing themselves due to the care required by the sick elderly member, as someone needs to continually accompany them during the hospitalization process.

The importance of the presence of a family member accompanying the hospitalized elderly individual is acknowledged by researchers in this area and by the Brazilian Ministry of Health. Decree 280 was issued on April 7th 1999 to guarantee the full-time stay of someone accompanying hospitalized elderly individuals and the financial resources needed for their accommodation[6].

However, looking back on the figure of the accompanying family member, we realize how strong it is the belief that caring for a vulnerable and dependent elderly individual, especially during hospitalizations, is an experience that causes conflict in the life of caregivers, with physical, emotional and social impacts[7,8].

Despite the judgment of the value of experiences of care, Merleau-Ponty's phenomenology enables us to understand that the prejudice arising from such experiences can be steadily overcome. This occurs because all experiences are ambiguous, which includes the phenomenon of caring and, in this sense, a negative or positive value cannot be attributed to it[9].

This perception of care discussed in a phenomenological perspective represents a gap in the state of knowledge of the area investigated. The need to resume debates on this theme with a new theoretical-philosophical approach was observed, as the information produced could converge towards the deconstruction of absolute truths rooted in society and towards a new way of thinking and perceiving experiences of care.

Thus, the results and discussion of the present study can enable the development of new care strategies for elderly individuals and their accompanying family members in the hospital environment.

In view of this situation, the following question arose: what are the experiences of family caregivers of hospitalized elderly individuals? Therefore, the present study aimed to show the experiences of family caregivers of hospitalized elderly individuals.

METHODS

A qualitative study was performed, originated from situations experienced. Among the several theoretical approaches comprising the field of qualitative methodology, we decided to base this study on Maurice Merleau-Ponty's phenomenology.

Aiming to achieve the proposed objective, we sought to establish a connection among the descriptions of experiences provided, studies on human aging and the theoretical approach to Merleau-Ponty's intercorporeality based on the notion of one's own body. According to this philosopher, intercorporeality alludes to the intertwining between human beings and other living beings, resulting from the dynamics of perceptive experience, which functions through the set of senses connected to the world[10,11].

The location selected for this study was a large public hospital in the countryside of the state of Bahia, in Northeastern Brazil. It has more than 200 beds and it is a model hospital for over 30 cities in Southeastern Bahia. It provides high-complexity services (neurosurgeries, orthopedic surgeries and traumatology, nutritional therapy, type 2 intensive therapy, cardiovascular surgeries), 24-hour urgency and emergency care, and hospitalization in specialties such as medical clinic, surgical clinic, neurological clinic, pediatric clinic and blood bank. The present study was performed in the medical and neurological clinics, where a significant number of hospitalized elderly individuals were found. Currently, the medical clinic includes 30 beds, subdivided into male and female wards with 13 and 17 beds respectively. The neurological clinic has 11 beds, of which six are for men and five for women.

A total of 22 accompanying family members were invited to participate in this study, as they met the inclusion criteria: to be a family caregiver of an elderly individual who had been hospitalized for at least seven days. Only five accompanying family members participated in this study, as others showed interest in doing so, but were not present for this, and the remaining ones did not want to participate.

However, as this was a phenomenological study, the number of individuals included was not the most relevant aspect, but rather the depth of the analysis and the discussion about the testimonies obtained, enabling generalizations to be made, among other things. The reason for this is that phenomenological research is concentrated in the description of what is revealed from the sensitive nature, the world of feelings, which is potentially experienced by all and enables humanity to have something in common. All participants signed two copies of an informed consent form, one of which was given to participants and the other to researchers.

For the production of descriptions of experiences (data collection), rounds of conversation were the technique used, a methodological resource that prioritizes discussions about a predefined theme and considers interpersonal relationships as rich research material[12]. Thus, it is possible for participants to interact and, through shared thinking, they can understand and give a new meaning to their experiences. This possibility of dialogue and influences characterize inter-subjectivity, inherent in phenomenological studies[13].

There were two rounds of conversation conducted in March 2014, lasting one hour and thirty minutes each on average. A reserved and well-ventilated room close to the beds of hospitalized elderly individuals was selected for the meetings, which developed in four stages: 1. Welcoming and interaction among participants, with an introduction dynamics; 2. Exhibition of a video for reflection; 3. Opening of the rounds of conversation, following previously prepared guidelines; and 4. Closing and evaluation of the activity developed. The experiences described were recorded, transcribed and submitted to analytics of ambiguity, a technique that does not seek to analyze or interpret such experiences, but rather to perceive ambiguities that are revealed in the inter-subjective experience established between researcher and participants in this study[14].

The analytics of ambiguity was developed based on the ontology of Maurice Merleau-Ponty's experience and the following implementation steps are recommended: transcription and organization of the material produced, thorough reading of texts, perceptive exercise of the descriptions according to a figure-background perspective and organization in categories[14].

The perceptive exercise following this perspective was performed in the present study from the understanding that the descriptions of experiences revealed were figures that brought with them a background. Thus, every time we stopped focusing on one thing, we would discover new ones, corroborating the ambiguity which is characteristic of human perception and its inability to establish concepts and definitions.

Following this logic, the descriptions of experiences were essentially discussed based on Merleau-Ponty's theoretical foundations, regarding the approach to the perception of one's *own body*, specifically in the dimension of the *other's body*. The present study followed the norms for human research in accordance with Resolution 466/12 from the National Health Council and it was approved by UESB's Research Ethics Committee through protocol Nº 518.994/14. Participants selected a pseudonym associated with feelings experienced in recent days to maintain their anonymity: Nostalgia, Love, Sadness, Anxiety and Concern.

RESULTS AND DISCUSSION

All participants were females, aged between 33 and 57 years, and daughters of the elderly individuals they were accompanying. These data corroborate other studies that discuss about the predominance of women as caregivers[15]. Regarding marital status, four of them were married and one was single. The accompanying time varied from eight to 60 days and only two women affirmed taking turns with another family member to care for the elderly individual.

In the inter-subjective experience with the reading of descriptions of experiences, our perception decided to categorize them as follows: the experience of the *other myself* in the relationships of care between family members and hospitalized elderly individuals. Although this was organized as a category, we understand that every attempt to turn the experiences reported into something more objective will never be sufficient to fully express their meaning.

The experience of the *other myself* in the relationships of care between family members and hospitalized elderly individuals

Care is part of the essence of every human being, it is the foundation that enables human existence to be considered as human. Additionally, it represents an attitude of action, concern, responsibility and emotional involvement with the other[16]. In a phenomenological perspective, caring functions on the inter-subjective level, which implies a field experience and, consequently, the reversibility of perceptions involved and continuous movement of opening oneself to the other[17]. In this sense, caring consists in the intercorporeality and guidance towards transcendence, which refers to the experience of the *other myself* in the perspective of Merleau-Ponty's phenomenology.

In the beginning of the first round of conversation, participants were asked about their history with the respective elderly individuals who had been hospitalized. One of the study participants, whose code name was Love, reported as follows:

> *[...] my mother used to beat me and my sisters would say, 'She is hard on you because she loves you!' So I'd say, 'She loves me, but she has to stop being so hard, because I need to be free!' This is how I felt [...] But, now, I don't feel like this anymore, because I see the situation she is in and I'm the only one she has to support her. My choices are not my focus now! [...] I always tell her, "Mom, you should really thank God, because you'd be alone if you depended on your other daughters!' (Love).*

This participant's speech enables us to observe that her body reflects her past life of physical violence, injustices and the resulting emotional needs. Despite her having been mistreated by her mother during her childhood and adolescence, the future now emerges with her elderly mother's hospitalization, allowing her the opportunity to show gratitude, acknowledgement, affection and love, thus enabling the caregiver to look to this future through constant and dedicated care. Consequently, care is manifested according to a temporal perspective, which encompasses the past and the future in the present[18].

These reflections allow us to understand that experiences of care in the hospital context are characterized by the existence of ambiguities: at the same time that there is a more personal

approach (socio-anthropological dimension comprised of one's being), which shifts the focus from oneself to the other who requires care, a more impersonal approach (sensitive dimension) that enables new meaning to be given to the other (similar being) and their personality.

The *experience of the other* is always a replica of myself and it is the result of the action of using one's body (perception) to explore and establish a relationship with the world, which results in a "short distance between myself and the being who had the right to a different perception of the same being"(14:223). The same caregiver guided us towards deepening our understanding of the care phenomenon:

> *[...] I feel I've succeeded because it's my mother, which means I have to do whatever I can so she'll be proud of me [...] I married two times and came back home. Marriage never works for me, I always returned to her home, I had nowhere else to go [...] Once, I had a boyfriend and he was concerned, because my sister travelled and I didn't. So I said, 'I'm not going! I'll leave and let my mom feel pain? No!'. Then, he said, 'Your sister doesn't like your mom, she doesn't care for her like you do!' [...] and I replied, 'I'm the only one she (her mother) can count on! My sisters don't care for her like I do!' (Love).*

The speech reveals that, throughout her life, this caregiver probably has experienced or is experiencing a situation of loss of social rank and, as a result, she unreflectively expresses the need to be valued and recognized. When she is willing to care for her hospitalized mother, she begins to have a social visibility that she did not have before. Feelings of pleasure and recognition are aspects that enable caregivers to raise their self-esteem. "Nostalgia" was a participant who showed support to "Love" after her testimony and revealed a similar situation:

> *[...] My mother was never caring towards me. If she caressed me today, she'd beat me tomorrow. She'd beat me for anything and she'd beat it hard, very hard! To the point that, when I was almost 13, I asked God to let me die or get married [...] I couldn't stand it anymore! [...] Sometimes, I'd give her a bath and she'd say, 'Thank God I have my daughter! [...] She'd say, 'I'll ask you something and you got to be honest [...] Who's your mom? Then, I'd say, 'You're my mom!' and she'd reply, 'Oh, if only I had a daughter like you!' (Nostalgia)*

The experiences enabled new knowledge and abilities to arise from caregivers[17], so that conflicts found in interpersonal relationships could be resolved and/or reduced. When asked about whether another family member could care for the hospitalized elderly member as they did, they all said no in unison.

Thus, we could observe that Love and Nostalgia experienced transcendence in the context of caring for their hospitalized mothers and a continuous "investment" in caring for the other occurs so that somehow they can also care for themselves. Caregivers probably do not have the perception of value and care for oneself, as their experience involves not knowing the way they feel about the other and themselves. In this context, they corroborate the notion of caring for oneself unreflectively[18].

In his writings, Merleau-Ponty does not approach care directly, as did phenomenologist Martin Heidegger. However, the essence of his thinking enabled the development of the notions of unreflective and reflective care, the latter being associated with conscious and planned acts and the former, intuitive acts[18]. When introducing herself to the group, Anxiety's speech revealed a description of unreflective care for oneself:

> *[...] I'm from São Paulo, Campinas! I rushed to come and care for her. I came because if I'd stayed home, I'd think, 'Oh, God, what if something happens? I can't see what's happening, I'm not around' [...] And I would've felt anxious and things would've been worse there. I have to be close to her and see how she is doing. (Anxiety)*

This experience helps us understand that, although the caregiver tries to explain the reason for her action, i.e. leaving the state of São Paulo and her home to care for her mother in the state of Bahia, she will never be able to fully explain this. She decided to stay with her mother, because if she had stayed far from her, she would have felt distressed and suffered and could even have blamed herself if something serious had happened. Consequently, she immediately decided to go to Bahia to care for her mother and to care for herself as well, although in an unreflectively way. Thus, although the hospitalization seems to represent a phenomenon of pain, anxiety and uncertainties, somehow it contributes to "different cures" of family caregivers.

Accompanying one's hospitalized elderly mother or father enabled study participants to experience ambiguities and unique emotions. Therefore, the *other myself* who appears in the testimonies will be different if the health-disease process of elderly individuals is experienced in other contexts, such as their home. Experiences of care are thus always new and creative, constantly leading to transcendence.

According to Merleau-Ponty's perspective, *intercorporeality* allows us to understand that the experience of the *other* is not a phenomenon restricted to the accompanying family member, known as caregiver. This is because care, as it is not static, but rather dynamic and inter-subjective, also enables those cared for to experience ambiguities and openness towards the *other*, identified in isolated extracts from the following testimonies:

> *[...] I lost my dad early and she (mother) really mistreated me! And now I'm the only one who cares for her [...] But she's already thanked me a lot for this! She says, 'If it wasn't for you, I don't know where I'd be [...] because if I depended on the others' [...] Sometimes she thanks me. (Love)*

[...] At my home, the one who was here today (sister) was the apple of his eye. He got sick and, whatever he needed, he'd only ask for her! And we got jealous! He'd ask why my sister hadn't come for him [...] I felt he didn't like me and this made me sad. I'd sit down and wonder, 'Does my dad like me for staying here? But not now [...] Now, when we leave, he thanks us, it's a joy! He says, 'Look how my kids care for me! There are no more choices. He realized that everybody does the same thing and cares as much! I used to feel rejected, but not anymore. (Sadness)

The experiences show that the new meaning given to the relationship between mother/father and daughters occurs spontaneously through the intercorporeality of the experience of care. The *experience of the other* is perceptible when elderly individuals begin to acknowledge and value their daughters more after receiving care during hospitalization.

All of us, in some way, feel connected to each other, forming a single organic whole, diverse and inclusive. This whole reminds us of a link that supports everything and enables it to be dynamic. Thus, we construct the world from emotional bonds and this causes individuals and situations to be valuable. We worry and spend time to dedicate ourselves to them; we feel responsible for the bond formed between us and the others[16]. In this perspective, past relationships between mother/father and daughters, regardless of how they developed, created emotional bonds throughout the years and caring is something that enables one to receive this whole way of being, thus strengthening bonds.

In this sense, we are constantly transcending something in each experience. This is because the world which we are a part of is being continually formed and always seen in different perspectives, including the remaining perspectives, without us having to develop them[18]. This means to say that our environment always allows us to grasp something and this perception implies that something is significantly more than what is revealed[19].

Through the understanding of the dynamics of perception, we can add the idea that beliefs, traditions and principles acquired in a socio-cultural dimension are not static either, but rather susceptible to transformation and adaptation, according to what reality imposes; an aspect that also characterizes transcendence. At a certain point during the discussion, when talking about her hospitalized elderly father, "Concern" revealed the changes that occur to family members based on the reality experienced:

When you're young, we control you! He (father) said. Now, our children control us! They say that, after we grow old, they are the ones in charge! (Concern).

After Concern's speech, Sadness showed her support to this testimony and complemented the idea:

[...] caring for my mom is easy, but what about my dad, who is ashamed of us? He says, 'Oh, my daughter, I've never been naked in front of you!' [...] But now [...] he needs us. So I say, 'Oh, dad, don't worry! We never see our parents naked. Now, we need to bathe you, help you to pee, change your diapers and so on! Oh, dad, don't feel embarrassed! Everybody looks after their parents! Because boys have more freedom, but girls don't, right? (Sadness).

It is extremely common to see daughters taking care of hospitalized parents in the routine of health institutions, partly because women are historically viewed as "great caregivers", who have the established moral duty of caring for the whole family[20]. However, for those involved with care, dealing with the exposure of vulnerabilities and nudity, especially when this involves fathers and daughters, requires breaking away from cultural traditions incorporated throughout their lives. These breaks from tradition represent the experience of the *other myself*. We imagine that, for a man who depends on care from others, this experience is more difficult and includes ambiguous feelings and inner conflicts.

Despite women's several social achievements in recent years, we still live in a predominantly patriarchal society, where men have a hegemonic presence, ruled by supremacy and feminine submission, in a context that defines them as "heads of household", responsible for supporting their home, children and wife[21]. Thus, elderly men becoming dependent on and exposing their nudity to their daughters in the context of hospitalization represent a break from the male-centered view ingrained in their being. It is *the other myself* that renounces the impotence of masculinity and accept the fragility of the human being, the vulnerability experienced and the need to be cared for, thus experiencing transcendence.

Based on the experiences and feelings revealed, it is important that the entire health team, especially nursing professionals, have the sensibility of perceiving meanings, ideas, concepts and values that caregivers attribute to care[22]. This will enable the development of strategies to implement humanized care that can reach not only hospitalized elderly individuals, but also their family caregivers.

CONCLUSION

When we understand that the experience of perception according to Merleau-Ponty's phenomenology is seen as a continuous opportunity of becoming *the other*, we can no longer accept the assumption that caring for a hospitalized elderly individual is an experience that causes the caregiver "to be sick" and to suffer. This assumption, founded on the socio-cultural world in which we live and reinforced by many in the scientific production on gerontology, cannot be defended as the only truth.

The experiences described, discussed in the perspective of intercorporeality and experience of the *other myself*, enable us to achieve a new perspective on the condition of being a caregiver. Situations in which the experience of caring for one's hospitalized elderly father/mother was revealed allowed caregivers to obtain the respect to dignity, affection, love for others and social inclusion.

We realized that ambiguous feelings expressed during care will guide the relationships established and they are directed by an intention which is often hidden: caregivers do not perceive that caring for the other means to care for oneself as well. Although at times care involves a mere moral obligation, at other times it is also a way of caring for ourselves, whether to overcome resentment, anxiety or fears, for example.

Additionally, we see that hospitalized elderly individuals, receivers of care, also experiment the possibility of new meaning being given to their life and relationships, becoming the *other* in the context of fragility experienced. The hospital environment is a collective space that offers the opportunity of unique intercorporeal experiences, which usually converge to that of transcendence.

Studies of such nature, which enable family members of users of public health services to be heard are relevant to redirect the policies, planning and implementation of more humanized care practices that not only see the health of those undergoing treatment, but also of their family members who accompany them and help with their recovery process.

As limitations to this study, we should emphasize the participation of a small number of family caregivers in the rounds of conversation promoted. This probably occurred due to the fear of being away from their hospitalized elderly parents for a longer period of time.

Thus, being aware of the insufficient knowledge acquired, we concluded that there is still much to be revealed about experiences in the hospital context.

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* Article extracted from the Master's Thesis: "Experiences of Family Caregivers of Hospitalized Elderly Patients: A Phenomenological Look" (2014).