

Perceptions of care for dependent older adults: a qualitative study

Percepções de cuidado ao idoso dependente: estudo qualitativo

Percepciones de cuidado a ancianos dependientes: estudio cualitativo

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ABSTRACT

Objective: to understand family caregivers' perceptions of care for dependent older adults. **Method:** this qualitative study was conducted, after research ethics committee approval, from the perspective of Symbolic Interactionism, by the interpretative movement of experiences of caring for very dependent older adults. Eight caregivers residing in Palmas, Tocantins, participated between January and July 2020. Data were collected through non-participant observation and semi-structured interview, and underwent content analysis. **Results:** the categories identified from the caregivers' statements were: "Repaying care from the past", "Wellbeing, gratefulness, and affection" and "Difficulties in care". The act of caring was expressed as an opportunity for retribution, enveloped in feelings of satisfaction, joy, and gratitude, but also sadness, grief, frustration, impotence, and fear of the older person's finitude. **Final considerations:** the act of caring for dependent older people is marked by affective experiences that lead to moments of joy and difficulties.

Descriptors: Health of the Elderly; Frail Elderly; Functional Status; Family; Caregivers.

RESUMO

Objetivo: compreender as percepções de cuidadores familiares sobre os cuidados aos idosos dependentes. **Método:** estudo qualitativo na perspectiva do Interacionismo Simbólico, conduzido pelo movimento interpretativo das experiências de cuidado de idosos acamados, após aprovação dos Comitês de Ética em Pesquisa das instituições envolvidas. Participaram oito cuidadores residentes em Palmas, TO, em janeiro a julho de 2020. Os dados foram coletados por meio da observação não participante e entrevista semiestruturada e utilizou-se a análise de conteúdo. **Resultados:** a partir das falas dos cuidadores, identificaram-se três categorias: "Retribuindo os cuidados de outrora", "Bem-estar, gratidão e afeto" e "Dificuldades no cuidado". O ato de cuidar foi expresso como oportunidade para retribuição, envolvido por sentimentos de satisfação, alegrias e gratidão, mas também, tristeza, mágoa, frustração, impotência e medo da finitude do idoso. **Considerações finais:** o ato de cuidar de idosos dependentes é marcado por experiências afetivas que provocam vivências de momentos de alegrias e de dificuldades.

Descritores: Saúde do Idoso; Idoso Fragilizado; Estado Funcional; Família; Cuidadores.

RESUMEN

Objetivo: comprender las percepciones de los cuidadores familiares sobre el cuidado de ancianos dependientes. **Método:** estudio cualitativo en la perspectiva del Interaccionismo Simbólico, realizado por el movimiento interpretativo de las experiencias de cuidado a ancianos encamados, tras la aprobación de los Comitês de Ética en Investigación de las instituciones involucradas. Participaron ocho cuidadores residentes en Palmas, TO, de enero a julio de 2020. Los datos fueron recolectados a través de observación no participante y se utilizó análisis de contenido. **Resultados:** a partir de las declaraciones de los cuidadores, fueron identificadas tres categorías: "Retribuyendo el cuidado del pasado", "Bienestar, gratitud y afecto" y "Dificultades en el cuidado". El acto de cuidar se expresó como una oportunidad de retribución, acompañado de sentimientos de satisfacción, alegría y gratitud, pero también de tristeza, pena, frustración, impotencia y miedo a la finitud del anciano. **Consideraciones finales:** el acto de cuidar a ancianos dependientes está marcado por experiencias afectivas que conducen a vivencias de momentos de alegría y dificultades.

Descriptorios: Salud del Anciano; Anciano Frágil; Estado Funcional; Familia; Cuidadores.

INTRODUCTION

Aging is characterized by biological, social and psychological changes that can increase the aging population's care demand¹. In Brazil, 30.1% of the population aged at least 60 years old requires help from someone to carry out activities of daily living, where aid person receives the name of "caregiver" and, in most cases, is a family member, generally women, daughters or spouses².

Care can be interpreted as a phenomenon wrapped in emotions and feelings, which can reinforce interpersonal affective bonds. It is a complex act involving affective relationships and symbolic dimensions, which reflect on the caregivers' perceptions and have direct implications on the effective execution of care and on coping with adverse situations³⁻⁵. In symbolic interaction, signification is a social product generated through human interactional processes⁶.

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The family is a system in which these direct and close interactions occur over the course of life and, when a family member becomes ill, the family reorganizes itself to provide due care. In highly dependent aged people, such as those who are bedridden, the continuous and uninterrupted care demand associated with dysfunctional family environments and an inefficient support network predispose caregivers to biopsychosocial wear out, which can trigger care burden.

Thus, considering the importance of family caregivers for comprehensive care of dependent aged people and the complexity of the act of caring, knowing these caregivers' perceptions is fundamental to properly incorporate them into a care plan that contemplates the older adult-caregiver binomial.

Studies that involve understanding of a given phenomenon make it possible to subsidize care and educational practices for health professionals, in addition to supporting the planning of interventions and systematized guidelines for caregivers, especially in Primary Health Care.

Symbolic Interactionism supports the meaning of social product; it is an indispensable element for understanding human behavior and social interactions^{6,7}. This framework was chosen because it offers theoretical support in the search for the symbolic dimensions that involve care and the meanings presented by the caregivers about their practice, in addition to the influence of social interaction.

Thus, the objective of this study was to understand family caregivers' perceptions about care for dependent aged people.

METHOD

Qualitative study carried out in the city of Palmas, Tocantins, Brazil, conducted from the perspective of the Symbolic Interactionism approach⁶.

The study population corresponded to caregivers of bedridden aged participants from the research study entitled "Caregivers of dependent aged people in the municipality of Palmas", approved by the Ethics and Research Committee of the institution involved. The sample was comprised by intentionality and closed by theoretical saturation. The inclusion criteria were as follows: being related to the aged person, being at least 18 years old, and having access to telephone devices for contact. Caregivers who received any financial remuneration for carrying out the care activity were excluded, for considering it an employment contract in which the relationship can be different from those who provide care without any remuneration.

Data collection took place between January and July 2020 through home visits and semi-structured interviews conducted via telephone contacts. The acculturation period that preceded data collection was supported by community agents to articulate contact between caregivers and researchers and provide non-participant observation, and two pilot interviews were carried out. The guiding questions of the study were the following: "Tell me about the meaning of caring for a dependent aged person" and "What feelings do you experience or have experienced in the care process". The interviews lasted approximately 20 to 30 minutes, and they were all recorded and fully transcribed.

After transcription and based on readings of the corpus of transcripts and field diary from the participant observations (POs), content analysis was performed. This technique allows data organization, as well as understanding the perceptions and exploring the meanings. The results describe some speech excerpts that were supported by the PO results. Thus, the data analysis process consisted of: pre-analysis, exploration of the material and treatment of the results, inference and interpretation⁸.

All caregivers signed the Free and Informed Consent Form and their anonymity was preserved through alphanumeric data coding. The statements were identified by the letter C, followed by a number from 1 to 8.

RESULTS

The final study sample consisted of eight participants, all of whom were children of the aged individuals; with six women among them, with a mean age of 43.2 years old, active for more than five years and all devoting most of their time to this activity, a mean of 17.7 hours a day.

Three categories emerged from data analysis: "Repaying the care of yesteryear", "Well-being, gratitude and affection" and "Difficulties in care".

Repaying the care of yesteryear

It was identified that care is expressed in the opportunity for retribution, that is, in the possibility of offering older adults actions previously received, especially related to zeal, attention and solicitude, as evidenced by the statements below:

It was like an exchange because she took care of me when I was a little girl, it didn't cost me anything to repay that, to take care of her when she needed me. (C1)

It's a really great privilege for me because I consider it a gift, also because having the privilege of taking care of him is like a way of repaying everything he did for me throughout my life. [...] when I think of giving back, it means giving back a little bit of what he did for me, I'd like to do much more. (C2)

Well-being, gratitude and affection

The care experience provided the interviewees with moments of well-being, often marked by affectionate feelings and gratitude, as shown in the reports below:

So it's very satisfying for me to take care of her, and kind of anyone else who needs my help. It's rewarding for me, I have nothing to complain about. (C4)

I'm happy to be able to take care of her, I feel that she needs me a lot, I have affection, attention, zeal, care, a lot of affection when I take care of her. (C6)

For me, the meaning of caring is love, when we have love then we take care, because you can't care without love; then, as I love my mother very much, I have to take care of her and I like to do it. (C7)

The act of caring is also represented by the feelings of satisfaction and joy experienced in the everyday achievements attained by the older adults, as indicated by the following statements:

[...] every day I try to see the bright side of things and I feel very successful for her achievements (C3)

The feeling I have is that I'm contributing for her to live more each year, more each day and live much longer. And I'm tireless. (C4)

[...] I give her all the freedom, she just doesn't have her sight, but she has her freedom. If you talk to her you'll see that she's not a downcast person, she's not a humiliated person, I try to do that for her. (C5)

It is noted that the caregivers feel co-participants and co-responsible for each evolution achieved by the older adults. These "victories" contribute to the act of caring making possible for the caregiver to experience moments of joy and a feeling of accomplishment.

Difficulties in care

It is observed that there are countless difficulties related to physical and mental burden involved in the care process, and that they make this experience marked by feelings of sadness, hurt and frustration, as indicated by the statements below:

[...] there are many sorrows that we feel, for example, when you worked all night and you want to get home and sleep and you can't do it, you have to take care of someone and that person depends on you, when you have to change a diaper, when you have to give a bath, do some things that you never had to do before. (C3)

Sometimes I get tired, stressed, but I go into my room and ask God for strength, I ask for strength, wisdom, patience because sometimes I run out of patience. (C4)

So, because it's not easy to take care of her when she's bedridden, only those who know, only those who feel the work it takes, are the ones that do it. It's not easy, it's hard. (C7)

It's not easy for me, taking good care and taking care properly is a lot of work, it takes a lot of time in my day and sometimes it's very tiring. (C8)

It is noted that the care process is also expressed in a feeling of impotence in the face of older adults' suffering, caused by the presence of comorbidities and fear of human finitude, as shown in the statements below:

There are days when I was in agony, disturbed, those days when she was moaning a lot. [...] I was in agony with her moaning so much and I couldn't do anything, she was moaning too much, there were days when it was too much. (C1)

The feeling that it's not easy we see what happens, my mother can't see. (C5)

I thank God so much for her existing and I'm terrified of her dying. [...] the fact that she's my mother and the love I feel for her, something will be missing in the house because she's already part of our daily routine, of our life, so there will be someone missing in the house. (C4)

I'm afraid of him dying. He's already old and I'm worried about him dying. He's my father and I like him, taking care of him, I don't want him to die. (C8)

Living with the older adults' suffering and physical limitations represents a complex challenge for caregivers and they are often unable to deal with the feelings arising from this experience. The other person's pain also causes them pain, as well as imposing emotional burden, frustration and consternation on them.

Self-denial as a care subject is also present in the interviewees' experiences since, in order to care for older adults, they frequently need to neglect their own demands and prioritize the other person's needs, as revealed in the statements below:

The feeling of being imprisoned. I suffer a lot when I'm taking care of someone that I stop living for myself and start doing so for someone else, much more debilitated than me, this is a general statement and I believe that any caregiver goes through this (C3)

[...] my time is only for her. I stopped living like that, the things I used to do I don't do them anymore, because my time for her while she's alive is for her, you know, the care is hers, I don't have that life I had of traveling, going out, having fun. It's very difficult. (C4)

I can't go out either because I can't take her, so I have to stay at home, I can't go out, we get stuck, both me and my husband, because she needs a lot of care and she can't stay alone. And it's not easy. (C7)

[...] there are days when I'm full of things to do and I have to take care of him, it takes a lot of time and I have to leave my tasks for later, then I end up accumulating things to do. (C8)

Caring for the other was also presented as an obligation imposed by life circumstances, as evidenced by the reports below:

[...] it's very complicated, it's more complicated than suddenly having a child for you to take care of. So it's very difficult and in my case it's like adopting an unwanted child. [...] the question of anger is like this, it's hurt, it's frustration, saying why am I doing this? Why do I have to be forced to do this and then I have to change the whole life context to be able to adapt to a person who needs it (C3)

[...] and knowing that I'm going to get old too and I do good for her, to receive good and, even so, taking care of my parents is my duty. (C5)

I take care out of love and out of obligation, because if it were someone else, I don't know if I'd take care of them the same way. (C7)

The act of caring is commonly imposed on caregivers, that is, they are not offered the possibility of refusing. Such a condition elicits feelings ranging from anger and frustration to love and compassion.

DISCUSSION

For caregiver of aged people, the meanings in the care process can be influenced by social interactions, experiences and culture³. The perceptions found in this study denote that relationships build and strengthen bonds, content that was evident mainly in the first two categories. Some studies corroborate these findings, as the interactions experienced throughout life are essential for care⁹⁻¹¹. In this sense, Symbolic Interactionism supports the understanding that it is from the interaction-bond process that human beings construct meanings and move in relation to people and things¹².

All the caregivers included in the sample lived with the older adults, contextualizing intergenerational care, that is, children taking care of their parents. This situation enhances the formation of family bonds, which in the present time emerged in the content related to the reports of attention, zeal, concern, responsibility and solicitude. Thus, it can be understood that care is a way of showing affection and has the ability to awaken trust and empathy, thus strengthening the emotional connection between caregivers and older adults. It is an act of reciprocity that is developed based on family values and personal experiences¹².

An international study validates this content, disbelieving that the role of a caregiver is not only attributed to routinely performed tasks. The understanding of care begins at the individual level from the perspective of the family caregiver, that is, this role is perceived in terms of meaning or purpose as the preservation of aged people's dignity and sense of identity¹³. Articulating with the theoretical framework, the dialectical interpretation of this content finds resonance in the concept that SI sustains the meaning of social product, and this assertion is fundamental in understanding the relationships⁶. As an implication for the clinical practice, it is understood that health devices need to know the relationships established between caregivers and the dependent aged people, so that intervention proposals make sense in the social role that each one plays in the care process.

The literature points out that the choice of becoming a caregiver can be natural or imposed. The commitment to care is seen by many people as an obligation and not as an option, influenced by sociocultural factors¹⁴. It is noted that, in addition to moral and sentimental obligation of family members applied to the care of aged parents, there is legal

responsibility, as described in Article 229 of the Federal Constitution, which establishes the following: *“that just as parents have the duty to take care of their children while they are minors, adult children must support their parents in their old age”*¹⁵. However, this legal responsibility does not guarantee that care will be carried out effectively. Therefore, looking at the quality of these relationships, object of the current study, is fundamental to broaden understanding of this phenomenon, which will be increasingly frequent in the face of the demographic transition underway in our country.

Regarding the gender discussion, women are the main care providers, with their identity attribute representing a cultural and social symbol³. Both historically and culturally, modes of identification between men and women were established, whose functions were differentiated in care, with social and family influence. Women were designated to play the role of caregivers, as they were seen as innate caregivers of the family and the home, while men had the role of financial providers¹⁶.

Love, freedom, peace and respect stand out with regard to the feelings perceived by the caregivers related to the act of caring¹⁷. Such feelings are essential for the development of affectivity, which is a crucial component in the constitution of harmonious interactive processes between people, based on the values of the subjects⁶.

Faced with these statements, the current study makes it clear that understanding the family caregivers' perceptions can provide important information for health professionals and devices to devise interventions that meet the needs of both. In this sense, knowing the family values and the relationships of affection that permeate this bond can support more accurate interventions, as SI highlights that perceptions influence social interactions and human behavior⁷. However, not only affective relationships emerged in the current study and, therefore, other bonds that need to be understood will be discussed.

The act of caring can change family dynamics¹⁸, as well as enable the expression of negative feelings, as identified in the content analyzed. Emotional wear out is one of the main difficulties reported by the caregivers of older adults¹⁸, being important to identify and value the feelings experienced by these social actors in the act of caring³. The interactive process between caregivers and aged people, even if involuntarily, can generate negative feelings such as hurt, fear, insecurity and worry¹⁹. Articulation with the theoretical framework is fundamental for understanding these statements since, when they encounter these emotions through relationships with other people, people change their perceptions and consequently initiate a mental process of interpretation of that reality⁷. As evidenced in the results of the “Difficulties in care” category, the experience and contact with adversities raises some types of distress through negative emotions, and this process can weaken the bond and care will suffer this impact.

There were also testimonies that represent a feeling of impotence in situations that cannot be solved by the caregivers. These events generate anguish, distress and fear about issues related to the finitude and functionality of the older adults cared for. In view of these negative feelings, nurses play an essential role in devising a care plan based on the understanding of these relationships and feelings. Nursing interventions should seek to minimize stressful situations through welcoming, qualified listening, guidelines and training of caregivers.

Significant changes in daily care appeared in the content analyzed; the data point to a transformation that exerts impacts on an overload generated by this care relationship. Caregivers feel the burden caused by the changes in their everyday lives and report renuncements in their personal life that are necessary to exercise this role^{4,20,21}. Faced with these situations, it is necessary to develop positive attitudes to face the physical and emotional/psychological burden related to the act of caring. It is noted that caregivers experience adversity differently, which evidences the individuals' resilience as an important indicator for sustainability of this relationship¹⁸. Nurses should have skills and competencies to assess these needs and act in the prevention of distress and in promotion of the mental health of the individuals involved. It is necessary to devise strategies that seek to improve protective mental health indicators, such as resilience, already mentioned in the study.

Thus, the family caregivers' perception regarding the act of caring for dependent aged people is fundamental to direct planning of the health actions that will guarantee support to caregivers. Starting from the assertion that the family should not bear the burden of caring for a dependent aged person alone, actions should favor sharing of demands between the family, the State and civil society.

The theoretical framework proved to be paramount in the discussion, as it provided theoretical support for the symbolic dimensions of care for dependent aged people from the caregivers' perspective. The perceptions emerged in the results through content analysis, and were interpreted in order to structure these representations and meanings. This process makes it possible to understand the importance of health professionals appropriating these perceptions, aiming at more accurate, systematized and effective care.

Study limitations

A limitation of this study consists in the fact that the interviews were conducted via telephone contacts due to the pandemic of the disease caused by the type 2 coronavirus (COVID-19), not allowing face-to-face contact with the caregivers or the opportunity to observe their face expressions during the reports. However, via telephone contacts, it was possible to retrieve feelings and perceptions about the act of caring, because of the previously established bond.

FINAL CONSIDERATIONS

The complexity involved in the act of caring is evident, marked by daily accomplishments, feelings of fulfillment of duty, joy, gratitude and well-being. These perceptions reinforce the sensation that the care experience is an opportunity to return the attention once received. However, it was noticed that, in some cases, this relationship is established as an imposition of circumstances. In these cases, the relationship is permeated by feelings of selflessness, sadness, frustration and impotence, in addition to the physical and emotional burden inherent in the act of caring. In other words, sometimes care promotes positive emotions/aspects in caregivers' life, but negative ones others.

Thus, it is revealed that the perceptions of caregivers of dependent aged people related to care are full of meanings, products of social interactions and expressed through symbolic dimensions. The care process and the experiences of this role are essential in establishing good quality bonds. The perceptions of care can reflect on quality of life, daily actions and social interactions. These findings make it possible to devise a therapeutic plan that meets the real needs of this relationship, with the objectives of strengthening the bond, accommodating needs and improving care.

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