

SATISFACTION IN CARING FOR OLDER ADULTS WITH ALZHEIMER'S: PERCEPTIONS OF THE FAMILY CAREGIVERS

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ABSTRACT: This study aimed to ascertain the conditions of satisfaction of family caregivers for older adults with Alzheimer's Disease in the municipality of Umuarama in the Brazilian state of Paraná (PR). It is a qualitative, descriptive and exploratory study, undertaken with eight family caregivers. The data were collected in the period July – September 2013, through semistructured interviews held in the caregivers' homes and later subjected to analysis, from which four categories emerged: The experience with the care allows the development of skills; The provision of well-being to the older adult affords satisfaction to the family caregiver; Religiosity promotes satisfaction in caring; and Demonstrating love and gratitude through the care promotes the satisfaction of the family caregiver. The results indicated that satisfaction also exists in the act of caring, demystifying the imaginary that this activity is permeated only by dissatisfaction and overload.

DESCRIPTORS: Alzheimer's Disease; Older adults; Caregiver; Personal satisfaction.

SATISFAÇÃO EM CUIDAR DE IDOSOS COM ALZHEIMER: PERCEPÇÕES DOS CUIDADORES FAMILIARES

RESUMO: O objetivo deste estudo foi apreender as condições de satisfação de cuidadores familiares de idosos com Doença de Alzheimer no município de Umuarama-PR. Trata-se de um estudo de natureza qualitativa, descritivo e exploratório, realizado com oito cuidadores familiares. Os dados foram coletados no período de julho a setembro de 2013, por meio de entrevistas semiestruturadas realizadas no domicílio e após, submetidas à análise, da qual emergiram quatro categorias: a vivência com o cuidado permite desenvolvimento de habilidades, o provimento de bem-estar ao idoso permite satisfação para o cuidador familiar, a religiosidade favorece a satisfação em cuidar e demonstrar amor e gratidão por meio do cuidado favorece a satisfação do cuidador familiar. Os resultados apontaram que também existe satisfação no ato de cuidar, desmitificando o imaginário de que essa atividade é permeada apenas por insatisfação e sobrecarga.

DESCRIPTORES: Doença de Alzheimer; Idoso; Cuidadores; Satisfação pessoal.

SATISFACCIÓN EN CUIDAR DE ANCIANOS CON ALZHEIMER: PERCEPCIONES DE LOS CUIDADORES FAMILIARES

RESUMEN: El objetivo de este estudio fue aprender las condiciones de satisfacción de cuidadores familiares de ancianos con Enfermedad de Alzheimer en el municipio de Umuarama, PR. Es un estudio de naturaleza cualitativa, descriptivo y exploratorio, realizado con ocho cuidadores familiares. Los datos fueron obtenidos en el periodo de julio a septiembre de 2013, por medio de entrevistas semiestructuradas realizadas en domicilio y, después, sometidas al análisis, del cual resultaron cuatro categorías: la vivencia con el cuidado posibilita desarrollo de habilidades, el proveimiento de bienestar al anciano, trae satisfacción para el cuidador familiar, la religiosidad favorece la satisfacción en cuidar y demostrar amor y gratitud por medio del cuidado posibilita la satisfacción del cuidador familiar. Los resultados apuntaron que también hay satisfacción en el hecho de cuidar, desmitificando el imaginario de que esa actividad es permeada solamente por insatisfacción y sobrecarga.

DESCRIPTORES: Enfermedad de Alzheimer; Anciano; Cuidadores; Satisfacción personal.

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INTRODUCTION

Aging is a dynamic, progressive, irreversible and universal process, characterized by the occurrence of biochemical, morphological, and psychological alterations which determine functional changes in the organism⁽¹⁾. The aging of the population which has taken place in recent decades has led to an increase in the prevalence of chronic and neurodegenerative diseases such as Alzheimer's Disease (AD). In 2010 alone, it was estimated that more than 35 million people were living with this type of disease⁽²⁾.

Responsible for approximately 50 – 70% of all the dementias, AD is a progressive neurodegenerative disease, with an insidious start which is commonly diagnosed in accordance with differential clinical criteria⁽³⁾.

There is a strong correlation between the stage of dementia and the ability to undertake activities of daily living and, even in the more moderate stage of the disease, the performance in these activities is compromised. In the more advanced stages, the decline of functional abilities also occurs, compromising the undertaking of activities of daily living, making the older adult dependent on care⁽²⁻³⁾.

Based on this assumption, the older adult with AD is increasingly dependent on care, requiring another person to take responsibility for the role of caregiver, whether this is a family member or not, who can offer assistance for meeting the needs caused by the functional incapacity, whether this is temporary or definitive⁽⁴⁾. When this role is taken on by the family, the person who takes responsibility for the care is termed the family caregiver.

It is known that the choice of the family caregiver for the dependent older adult, either through personal initiative or designation by the family, is linked to the degree of relatedness, to sex, and to physical and affective closeness. The activities undertaken by the caregiver – most of whom are spouses, children or other blood relatives – include assistance in undertaking personal care, communication, medication, mobilization and accompaniment to health services, with the aim of maintaining or recovering the quality of life of the person being cared for⁽⁵⁾.

The family is considered, therefore, a primary unit of care, made up of members who interact

and provide each other with mutual support in the presence of problems. The appearance of the disease in the family ambit, however, causes behavioral alterations in one of its members and the relationship between them is modified, with a tendency to the deepening, broadening, or breaking of affective bonds⁽⁶⁾.

In addition to this new family configuration, the person who takes on the role of caregiver is subject to the production of demands for care which affect her physical, mental and social dimensions. In particular, the psycho-functional dependency of the older adult with dementia, in modifying the routine, the dynamic, and the relationship of exchange between the members of the family, through the inversion of roles, places a series of new and unexpected demands on the family. The caregiver has to overcome many challenges to exercise her role with accuracy without, however, leaving to one side her emotional and social life⁽⁷⁾.

Coupled with this context, the family caregiver is generally concerned with the satisfactory performance of her functions. Without outside help, the family caregiver does not always understand that a good caregiver is one who observes and identifies what the person can do for himself, assesses the conditions, and helps to undertake activities. Caring is not doing things for the other person, but helping the other person when he needs help, and encouraging the person cared for to achieve autonomy, even if this should be in small activities; which requires patience and time⁽³⁾.

In the scenario of the families which experience the chronic character of the diseases with demands for care, such as in AD, it is expected that health professionals – among them the nurse – should have knowledge and should undertake specific interventions, besides effective work in monitoring and educating the families affected⁽⁶⁾. To this end, the professionals need to be alert to the aspect of the caregiver's biopsychosocial condition in providing care to the older adult with this disease, principally regarding the satisfaction of caring⁽⁸⁾.

In the light of the above, the study objective was defined as grasping the conditions of satisfaction in the act of caring, of family caregivers for older adults with AD, regarding the pleasure and contentment resulting from this practice.

METHODS

This is a qualitative, descriptive and exploratory study, undertaken in the municipality of Umuarama, located in the northeast region of the Brazilian state of Paraná (PR), which has a population of 100,676 inhabitants, of whom 12,700 are older adults⁽⁹⁾.

A total of eight family caregivers participated in the research. They met the following inclusion criteria: to have been a family caregiver for an older adult with Alzheimer's Disease for at least six months, to have the cognitive ability to answer the questionnaires, to have obtained a minimum score of 24 points in the cognitive evaluation of the Mini Mental State Examination (MMSE)⁽¹⁰⁾, to be aged 18 years old or over, and to live in the city of Umuarama, PR.

Intentional sampling was used, obtained based on the visit of one of the researchers to three Family Health Strategy (ESF) teams and one School Health Center (CSE) in the municipality. The Community Health Workers (ACS) collaborated in the selection of the participants, indicating the older adults with AD who were cared for by family members.

Of the 11 caregivers eligible, two were not found at home after three attempts, and one did not present the minimum score in the Mini Mental State Examination; as a result, eight older adults and their respective caregivers participated in the research.

Initial contact with the caregiver was made through a home visit (HV) by the researcher in the company of the Community Health Worker responsible for the area covered. The participants were informed regarding the study objectives, and where they agreed, interviews were scheduled in accordance with the availability of the researcher and interviewee.

The data were collected July – September 2013, using semistructured interviews with open questions and the application of two instruments: one for sociodemographic characterization, administered to the caregivers so as to obtain data related to age, sex, marital status, degree of relatedness with the family member, educational level and characteristics of the activity of caring; and the Barthel Scale⁽¹¹⁾ administered to the older adult who was the caregiver's object of care.

This scale was used to ascertain the older adults' level of dependency in the activities of

daily living, such as: eating, personal hygiene, use of toilets, taking a bath, dressing and undressing, sphincter control, walking, and ascending and descending stairs. The score of each scale varies from 0 to 100, in which 0 corresponds to maximum dependence and 100 is equivalent to total independence.

The interview's guiding question was as follows: "Tell me about how it is to be the caregiver for an older adult with AD, and about your perception of the positive and gratifying aspects in the act of caring for this older adult".

The mean duration of each interview was 40 minutes, all the content was recorded using an MP3 player and later transcribed in Microsoft Word 2010, and data related to the Barthel Scale were tabulated and analyzed on an Excel® spreadsheet, using the descriptive technique.

Following that, the accounts were transcribed in full and later subjected to content analysis, in the Thematic or Categorical mode⁽¹²⁾. The starting point for the analysis was the identification of the hypotheses established and the understanding of what was behind each content manifested⁽¹³⁾.

Following that, the researchers proceeded to the analysis and interpretation of the content obtained, resulting in the recognition of the theme and the unit of meaning, which decoded the communication's nuclei of meaning. The thematic analysis, therefore, made it possible to discover the presence or frequency of emergence of the theme related to the study's analytical objective⁽¹²⁾.

This research was approved by the Committee for Ethics in Research with Human Beings of the Universidade Paranaense (UNIPAR), under Opinion N. 335.501, in accordance with the requirements of Resolution 466/12 of the Brazilian National Health Council, and the participants signed the terms of consent, after receiving information about the study objectives. In order to ensure confidentiality and preserve the caregivers' identities, the accounts were identified by the letter 'C', for 'caregiver', followed by the number indicating the order of the interview (C1, C2, C3...C8).

RESULTS

Among the caregivers interviewed, all were female and aged at least 42 years old, emphasis being placed on two caregivers who were over

60 years old, evidencing the increasing tendency for older adults to be caring for other older adults. This is concerning, as the elderly caregiver also has conditions of weakness inherent to the aging process. The majority of the caregivers were daughters of the older adults with AD, were Roman Catholic, live with the older adults, have been providing the care for over 10 years, and had a mean of 7.5 years of education.

In relation to marital status, three were married, three were single, and two were divorced, constituting a heterogeneous group. All reported having access to the Unified Health System (SUS) through the health units in the neighborhoods where they lived.

All the older adults who participated in the research had AD and were aged over 60 years old. Regarding the results obtained with the Barthel scale, three older adults had total dependence, two had severe dependence, one had moderate dependence and two older adults had slight dependence, constituting a group needing constant assistance from the caregiver in their activities during the day whether this involved undertaking, assisting, or supervising.

Based on the identification of the record units, the themes were grouped in four categories presented below:

The experience with the care allows the development of skills

Aging with AD means an experience permeated by limitations and weaknesses, which require the caregivers to engage in continuous learning and the development of personal skills and technical competencies related to the acquisition of new knowledge and behaviors, as evidenced in the discourses below:

We learn a lot, I didn't know how to care, I learned when she was hospitalized, I paid attention to what the nurses did, and now I do it at home [...]. (C1)

I had a relative who helped, she cared for my father and taught me a lot, because before, I didn't know how to do very much [...].(C2)

[...] You have to learn a lot of things, I left my life to one side in order to live for the sake of hers. (C4)

I had to learn to care, I'm trying to do a daily routine of his basic activities, such as eating, having a bath and other things which I know to be necessary, like getting some sunshine and walking in the yard. I also read to him, in this way I believe that he feels more secure and less bored [...]. (C6)

The family caregiver's recognition of her role in coping with the disease promoted the development of technical competences and personal skills, as a form of learning in the provision of the care.

[...] First, I needed to learn a lot of things, I learned to be very patient, because you spend the whole day repeating yourself, you need to be resilient and you notice, therefore, that you have to keep calm, not to change your tone of voice, you try to keep your focus, because otherwise it gets very difficult, so you learn – above all – that people who are like this are not so because they want to be. So, you learn to be calm and to be patient [...]. (C3)

I had to learn a lot of things in order to be able to care well from my mother, doing dressings when she had lesions, doing massage to relieve the pain in her back, giving the right medication at the right time. (C5)

I grew a lot, I learned a lot, first to control my feelings, and later the specific care for his disease [...]. (C8)

The provision of well-being to the older adult affords satisfaction to the family caregiver

Knowing and recognizing the subjectivity of caring became essential in the process of the humanized care undertaken by the family caregiver, in both the instrumental and expressive dimensions. The expressive dimension of the care was characterized by its emotional nature, resulting in interactions which allowed the expressing of feelings related to the experience in

the health-illness process, including the intuition of the subjectivity. The caregivers reported pleasure in being able to provide well-being to the loved one, the focus of their care, emphasizing the bath as one of the care measures which gave them the most contentment.

Deep down I have a lot of pleasure, my greatest pleasure is when I have just given her a bath, I give the bath, get her changed and put talcum powder on, it's just like giving a baby a bath and having her smelling nice [...]. (C4)

[...] Although it is difficult, I like caring for her, it gives me a lot of satisfaction to know that she needs me and all the care which I do on a daily basis. It is so good when I finish giving her a bath, I like to leave her more comfortable and happy, as it reduces her irritation. (C5)

When I finish giving her a bath, she gives me a hug and a kiss every time, and says thank you very much to me. I notice that when she gets out of the bath she is happier, after the bath I have an afternoon coffee with her and we spend hours talking about the stories of when she was young [...]. (C7)

It is gratifying to know that today she is alive, and now it is me who can care for her, and give all the love, tenderness, attention and dedication that she once upon a time gave to me, and that she, with absolute certainty, deserves today. (C6)

Religiosity promotes satisfaction in caring

This disease often brings suffering, solitude and vulnerability, felt not only by the patients, but in particular by their caregivers, who seek refuge in their religious and spiritual experiences. The accounts below reflect this context:

It is an opportunity which we have to know that if God should give us the happiness of arriving at her age, what we are sowing today, for example, if we are loving today, with certainty we will be loved and respected in the future too. (C3)

There are many positive aspects to being able to care for my father who has Alzheimer's, firstly I

feel at ease when I do all the care, I like doing this, I like helping other people, I identify with this and because of this I feel very happy to be able to care for him, I want to care for him while God gives me health, as that way I can achieve my mission here on earth. I know that everybody has a mission, regardless of their faith, sometimes easier, sometimes harder, but everybody has one. I have already recognized mine, which is to care for my father who has this disease which leaves him weaker day by day. (C6)

Resilience strengthened by faith is a constant, felt in the life of the primary family caregivers of older adults with Alzheimer's Disease, principally in relation to the satisfaction of providing the care.

Demonstrating love and gratitude through the care promotes the satisfaction of the family caregiver

The disease goes beyond the biological event per se, as it is a sociocultural construction which has different meanings and interpretations depending on who experiences it, interfering in interpersonal relationships, principally within the family. In the family context, the person who takes on the role of caregiver is already – to certain extent – adapted to experiencing the life of another person. It is ascertained that it is not just the case that the patient becomes dependent on the caregiver, but that also a very close bond is established with the patient, that caring for him provides pleasure, well-being, satisfaction and contentment. The accounts below demonstrate all of the love and gratitude which exist in the act of caring in recognizing the importance and relevance that the family member cared for already had in the life of the caregiver.

[...] Sometimes I go into her room and I notice that it is me she is looking around for, she is in her chair here, and I am making lunch, she looks for me, she calls for me all the time, I wake up with her, and for me this is everything, it is very gratifying [...]. (C1)

I began to care for my mother because I wanted to, because she cared for my two children, she brought up my oldest daughter, she cared for my

son, thanks to her they didn't need to stay at the crèche – so in a way I am paying back. It is a way of recognizing that she is my mother [...]. (C2)

Being able to care for my father is very good, because he cared for me when I was little and now it is time for me to pay all that love back to him. It is a pleasure to be able to care for him, because he is my father, and he deserves the best of me. To care for him is to pay back what he did for me, it is my duty [...]. (C8)

Caring is a form of gratitude, expressed through feelings and actions, manifested in the accounts of the family caregivers of the older adults with AD. It is a matter of subjugating the 'I' itself in order to satisfy the wishes and needs of the other.

As she cared for me, I cared for my daughters, and now I care for her too [...]. (C4)

Caring for my father is marvelous, because he was always very good with everybody, if it had not been for him, I don't know how my life would have been. (C5)

My greatest satisfaction is knowing that I'm always close to my father, I know how he likes his food, how he likes to take a bath, how he likes to dress, I can care better for him, especially because I know his tastes. I love my father and he loves me. (C6)

DISCUSSION

The health problems resulting from AD require thorough and intense care from the caregivers, promoting the development of personal skills. Added to this, there are the health problems typical of aging which contribute both directly and indirectly to the older adult's weakness⁽¹⁴⁾.

The self-perception of the family in the exercising of the act of care, as well as providing well-being to the loved one, was able to develop distinct skills in coping with AD and bestows upon the nursing professional the important role of teaching this care. One of the characteristics performed by nurses, in this study, was to advise the family caregivers to understand the individuals

and their current condition, so that they would be able to perceive that the behaviors presented result from the disease, understanding the family as a unit which needs to be recognized as an extension of the nursing in the provision of the care and self-care⁽¹⁵⁾. It falls to nursing to be alert in identifying the caregiver's difficulties in undertaking her role, acting as an educator and as a multiplier and facilitator of the information on the health actions⁽¹⁶⁾.

The study evidenced that the process of aging, accompanied by debilitating disease such as AD causes functional harm to the older adults, making them increasingly dependent in undertaking activities such as getting dressed, eating, taking baths, administering medication and other tasks, which end up being undertaken by third parties, normally by informal caregivers represented by a family member⁽¹⁷⁻¹⁸⁾.

It is within the family that the moral and social values which serve as the basis for the process of socialization of the human being are transmitted, as well as the traditions and customs perpetuated over generations. In situations in which aging is accepted as success and as making the most of skills, the family caregiver tends to feel satisfaction in benefiting somebody who once lived for their sake⁽¹⁾.

The study indicates that the family caregiver recognizes that the older adult with AD – the object of her care – deserves attention, tenderness and love, manifested disinterestedly in recognition of the total abnegation and dedication which they once provided. The satisfaction from the care is in the retribution and gratitude for all the love received over a lifetime⁽¹⁷⁾.

The new reality in the routine of the family caregivers caring for older adults with AD brings a need for adaptive strategies, among which emphasis is placed on religion. This attitude is demonstrated through prayers and in the exercising of patience, attributing the expectation of improvement in their experiences to their beliefs⁽⁵⁾. For the caregiver, religiosity comes to represent an important source of emotional support, which has significant repercussions for their mental and physical health⁽¹⁹⁻²⁰⁾. Furthermore, the experience itself with the chronic disease and the condition of being a caregiver imposes reflection and, generally, re-signification of life through the experience, finding encouragement in religiosity.

Studies undertaken with caregivers of older adults with AD have evidenced distinct abilities with which the family members cope with the disease^(18,21). The perception of the respect for the autonomy and dignity of each person is an ethical imperative in the discourse of the caregivers in favor of what may or may not be done for one another, given the concern with meeting the needs of those close to them, in such a way that they feel happy in so doing⁽¹⁴⁾.

The self-perception of the impossibility of acting actively in curing the disease allows the caregivers the satisfaction of contributing in the process of mitigating their family members' suffering. It is noteworthy that this study's findings are in contrast to those of other studies, in which the caregivers' discourses expressed resignation, acceptance and suffering in having to live with a family member with AD^(7,14,18,21). One result specific to this study was the absence of feelings of anger, overload, and nonacceptance of the older adult's chronic disease, as although the participants were requested to indicate the positive and gratifying aspects of caring, they also had the opportunity to express themselves regarding what it means to be the family caregiver for an older adult with AD.

FINAL CONSIDERATIONS

In this study, it was observed that the context of the family caregivers was permeated by the satisfaction in guaranteeing the care necessary to achieve the mitigation of the suffering and balance amidst adversity, through belief and faith permeated by a perspective of hope. Caring for a family member with a chronic disease allowed the family caregivers to learn to develop personal skills and technical competences which culminated in the satisfaction of expressing love and tenderness in the form of care.

Individual interventions making available guidance and education in relation to how to undertake the care appropriately, allied with public policies which viabilize an appropriate social support network and support from primary healthcare, are of extreme relevance in recognizing the work performed by family caregivers, taking into account the reduction in the size of family nuclei and the lack of labor

qualified to meet the growing demand posed by dependent older adults, living in their own homes, and the probable growth in the number of children, grandchildren, and spouses made responsible for the home care.

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