

THE EXPERIENCE OF BEING CHRONICALLY SICK BY ALZHEIMER AND THE ARBORESCENCE OF FAMILY CARE¹

Ítala Paris de Souza*
Laura Filomena Santos de Araújo**
Roseney Bellato***

ABSTRACT

Alzheimer's disease is part of the chronic-degenerative diseases, standing out as the most common cause of senile dementia, representing around 60 to 80% of them. We aimed to understand the arborescence structure of care in the family life through the illness caused by Alzheimer's, which generated and maintained over time, must meet diverse needs. The study conformed as a situational study, through the comprehensive approach, grounded in the elderly's life story, sickened for seven years ago, being operationalized by an in-depth interview and observation that made up the research diary. An allegorical design has highlighted the arborescent myriad of care in the family life. Such care reverberates in time through an amalgamated past based on the texture of the affective-loving relationship between the elderly and the family who, in turn, is attached, stronger, drives, mobilizes, and nurtures family life, modeling ways to take care in the present. We consider it important to design professional practices that consider the family's unique way of being, highlighting the context of their lives and supporting the care that they produce over time.

Keywords: Family relations. Health of the Elderly. Alzheimer's disease.

INTRODUCTION

Alzheimer's disease is part of the list of chronic-degenerative diseases, standing out as the most common cause of senile dementia, representing around 60 to 80% of them⁽¹⁾. It has insidious onset, is progressive and irreversible, affecting about 10% of people over 65 years⁽¹⁾. Given the importance of that disease, we direct our attention to the daily experience of the chronic situation due to Alzheimer's disease and, in it, the complexity and specificity that surround the family care.

In the family context, care for their different entities is generated and maintained over time, and needs to meet the diversified needs⁽²⁾. The family articulates diverse elements in their care, trying to provide well-being, since they care in life, of life and for life, not "of or in" disease. However, in the situation of sickness, a multiplicity of affections intends the familiar daily life, adding other care that greatly extend those already created.

Family relations, constituted by closer and

more intimate relationships, are built based on affectivity⁽³⁾ and, referring to Maffesoli, refer to what is 'affectionate', that is, done in the tension of the feelings of various orders, in the same relation.

Considering the verb "affect", it has multiple senses: to affect oneself, "to be interested in", "to provoke certain feeling", "to move", "to impress". Therefore, when referring to the relationship with the other, especially the family relationship, the sense of "affect" and "affect oneself" can only be understood in the bulge of "the idea of completeness in the other-self"⁽⁴⁾.

Thus, the suffering of the family throughout the experience of sickness conjugates the affected one by its various entities, being experienced in the relationship between the other and expressing itself, therefore, in the plural, since it occurs in the game of possible encounters and mismatches, in the 'being-staying' together with the family. Illness, as it were, affects everyone around them, promoting substantial changes in the various dimensions of family life, which reverberates and enhances the role of caregiving⁽⁵⁾.

¹Manuscript originated from the master's dissertation "Modeling of family daily care in the chronic situation by Alzheimer's", developed under the matrix study "Subsidies for the modeling of care of families in situations of vulnerability", institutional register 131/CAP/2014, under the responsibility of the Research Group for Nursing, Health and Citizenship (GPESC) of the Nursing College of the Federal University of Mato Grosso (FAEN/UFMT). Section to which the text is intended: Research Article.

*Nurse. MSc in Nursing. Member of the Research Group for Nursing, Health and Citizenship (GPESC). CAPES FAEN/UFMT Fellowship. Cuiabá - Mato Grosso, Brazil. E-mail: italaparis@hotmail.com.

**Nurse. Doctor in Nursing, professor at the FAEN/UFMT, leader of the GPESC. Cuiabá - Mato Grosso, Brazil. E-mail: laurafil1@yahoo.com.br.

***Nurse. Doctor in Nursing, professor retired from the FAEN/UFMT, member of the GPESC. Cuiabá - Mato Grosso, Brazil. E-mail: roseneybellato@gmail.com.

This study deals with the family experience of caring for Sara, an elderly woman with chronic Alzheimer's condition for seven years. In this experience, we drew our attention to the relationship of companionship and care with the husband with whom she has been married for 42 years and with the family, which has encouraged us to reflect on the care that transcends time and the myriad of acts and attitudes⁽⁶⁾ that trees and fruits the family's daily life.

Based on such conjectures, we aimed to understand care as arborescence in the family experience of Alzheimer's disease. We believe that the situation presented here can support essential reflections in the health field on the way the family lives and engenders a myriad of personal care, continuous and extended in time, seeking to respond, singularly, to the intense needs of the sick person. In this way, it will be possible to organize good professional practices that will last and become effective in the time, supporting the family in their care.

METHODOLOGY

This is a qualitative study that, under the comprehensive view⁽⁷⁾, allowed understanding the meanings emerged in the 'situation study'⁽⁸⁾. The members of the studied family are Sara, 70 years old, who has had a chronic Alzheimer's condition for seven years; and Abraham, a 74-year-old man, who had joined her in marriage for 41 years. The couple are flanked by close people - Sara's sisters and nieces - who collaborate in the provision of daily care.

The choice of Sara's family was due to the chronic condition of the elderly woman with Alzheimer's disease cared for by relatives in the context of her home; that peculiar situation, manifested as advanced dementia, total dependence on care, encompassing family experience of care mediated by affective bonds fed by long care relationship.

We used the Life History in order to ascertain the meanings of the family experience, through the narratives people report over time, revealing through their reminiscences what is significant to count as experiencing⁽⁹⁾. In order to do so, we used the In-Depth Interview, of the open type, which allows people to talk freely about their experience, being the researcher's questions

oriented in order to deepen certain narrative threads derived from the Life History⁽¹⁰⁾. We also used the Observation, for allowing us to apprehend the peculiar contexts of life and care, in the modes of expressions of that living⁽¹⁰⁾.

The interview collection took place from April to October 2015 through four meetings with Sara and her family, all at her house, with the participation of: in the first two meetings, Abraham and Sara, and he was the deponent. In the third meeting, besides them, Sara's sisters - Deborah, Samara, Mara and her niece, Lydia; and, in the fourth meeting, the sisters Marta, Susana and her nieces, Lídia and Talita.

The transcription of the In-Depth Interview, in its entirety, as well as the observation records and all the theoretical-methodological work of the study were compiled in the Research Journal⁽¹⁰⁾, which consisted of our corpus of analysis - compiled of 229 pages, typed in Microsoft Word Document (docx) feature, Times New Roman font, size 12.

The understanding effort of the Life History occurred from the beginning of the search for the family and lasted in and out of the meetings. Such extended immersion allowed a gradual and intensive diving, revealing elements that resulted in understanding the ways of family life and care. In a pragmatic way, we have repeated a careful reading of the corpus, and in the movement of reading and reflection we have been 'reviving' certain meanings. They were highlighted in colored 'tones', being arranged and rearranged, in a gradual process that allowed highlighting, among others, the axes here dealt with more details: a) Attitudes and acts for care: Sara's way of being and staying in the world and in the family, prior to his illness; B) care myriad for Sara's life for her family. Those two axes are depicted in the drawing entitled "Arborescence of Family Care in Sara's Life" (Figure 1), presented as results of this study.

This study is part of the matrix research, approved by the Research Ethics Committee of the Júlio Müller University Hospital under No. 951.101/CEP-HUJM/2015, and complies with the ethical principles required by Resolution No. 466/12 of the National Health Council. All ethical care was observed among the interviewees, as well as the institutions and health professionals referred to by them.

RESULTS AND DISCUSSION

Arborescence of Family Care in Sara's Life

The story told to us is marked by the intense meaning that the family attributes to the past that sustains the personal care in the present, shaped and provisioned throughout the illness of the elderly, showing us an affective, near, prosperous and shining life of care in the sinuosities of their relationships. In order to better present that configuration of the family care experience, we present, illustratively, the "care tree" (Figure 1), figured in the tree image. For clarity, the allegorical meanings of the tree will be explained and, then, their interpretation.

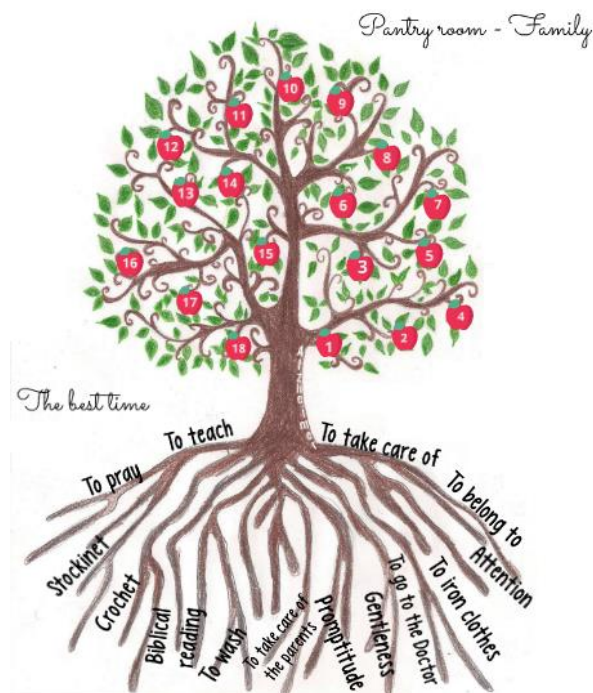


Figure 1. Arborescence of Family Care in Sara's Life. 2016.

The root, the nurturing base of the tree, refers, in the history of this family, to the rooting of the care that, in a past time, was able to guide the ways of caring; and, in the present, it gives fruits. Those fruits, scattered by the canopy of the tree, sprout and open in a way that alludes to the future, symbolizing the powers of and for the care. In the trunk of the tree, a singular, strong and compact portion, small channels of attachment are inscribed, from the roots to the crown and vice versa, through which flows intense nourishing flow

of the tree as a whole; it symbolizes the family itself in its attribute of essential caregiver and nurturer of goods of the living.

In an illustrative way, some cares were arranged as fruits in the tree canopy (Figure 1), enumerated from one to 18. Describing the intentionality of the allegory of the arborescence of care, we now bring the family experience, drawing lines of analogy with the tree drawing.

Sara made up this family, 70 years old, who was born and raised in a city that is 340 km away from Cuiabá-MT, with her parents and her seven sisters, and, later, living in Rondonópolis-MT. When she was 29 years old, she met Abraham, 34 years old, and, six months later, they got married. The initial period of marriage based on a trajectory of work and care, being lived by Abraham as the 'best time' (Figure 1) that he had alongside his wife-companion "and she is good, thanks... it was the best time we had" (Abraão).

Married life has been shaped by long years of dedication and complicity with each other, as well as sharing love, caring and attention (Figure 1 - root) with all family members - nieces, sisters and fathers; weaving, in their routine, intense affective ties in the warp of a life of care.

The roots of the tree (Figure 1) thus allude to the life dedicated to Sara's care of her family and spouse over time. The rooting of care, through its presence in the world, sustains, at the same time that nourishes, strong bonds, happening to mean the 'best time' according to her family. That rooting can be signified in action verbs, such as - 'belonging' (for their mission of 'touching each other', 'becoming a part', 'relating' and 'building bonds'); 'caring' (for her mission of care raised by the affection and availability of Sara to the next); 'teaching' (which included everything from the teaching of reading and writing, to sharing the art of crochet and knitting in a warm, gentle and respectful way); 'praying' (she guided her life and teachings through the prayers and preaching of the word of God).

That readiness of Sara produces attitudes and acts of care in family life - which "has been daily accomplished" - imaginatively presented by the secondary roots, which branch out in profusion in her living.

This family provides care in a wide way, both to thriving in life as in illness, highlighting the chronic situation of Alzheimer's that insidiously

establishes, affecting them and each one of its members. Little by little, it changes Sara herself, who passes from a great caregiver to the one receiving care by the family.

Sara's illness in family life is imbricated in the image of the tree trunk, which, in turn, supports and nourishes the crown, an imaginary place of the care tree (Figure 1). Sara began the first manifestations of Alzheimer's when she was 63, in the form of depression, constant crying, feelings that made her nervous, delusions of persecution, jealousy, with a clear change in her behavior.

In the search for professional assistance (Figure 1 - No. 1), she was initially diagnosed and treated for schizophrenia (Figure 1 - No. 2); after submitting to specific imaging tests, a diagnosis of Alzheimer's disease was confirmed.

Since the family recognized that Sara was ill, a vast supply of care (Figure 1 - No. 3) began to be undertaken, gradually expanding to each new need she presented. Exemplarily, Sarah and Abraham, who until then resided in a peripheral district of the city of Cuiabá-MT, moved in close to her sisters (Figure 1 - No. 4) so that they could provide, more intensely, the support to Abraham in the Sara's daily care.

While living with the illness, her husband has been the most present in the daily care (Figure 1 - No. 5): "*Abraão stays with Sara 24 hours, he does not stay for only two hours, he stays 24 hours with her, sleeps with her, lives with her, and stays with her during the day and when the morning comes*" (Abraão - husband). Nevertheless, the support from other family members becomes essential to maintain Sara's wellbeing, given the number of uninterrupted care, diverse and difficult for a single person to maintain. Sara's nieces and sisters help the couple (Figure 1 - No. 6), who collaborate, especially, to the "means-care" tasks, such as doing the laundry (Figure 1 - No. 7), clear the house (Figure 1 - No. 8), doing the lunch (Figure 1 - No. 9). Moreover, the help of her niece Lídia is essential during the visits to health institutions (Figure 1 - No. 10): "*my niece [referring to Lídia] always went there with us... [to the doctor] and took her and... watched her...*" (Abraão - husband).

The knowledge on the disease and how it manifests in Sara has led the family to personally promote a daily "means-care" ritual, such as bathing (Figure 1 - No. 11), drug preparation and

administration (Figure 1 - No. 12) and food (Figure 1 - No. 13), aiming at her comfort.

For better organization of care, the family undertakes a range of 'care-providence' to reorder the family routine; for this, they organize themselves in a cooperative and harmonious way (Figure 1 - No. 14), in order to offer the best possible condition so that they can be with Sara and care for her.

In the interview meetings, we had the opportunity to observe acts and attitudes of care in movement in the daily life of Sara and Abraão, which evidenced her many dependencies and intense need for care, resulting from the aggravation of the disease. Thus, from the situations of care we witnessed in their own happening, we could see the existence of voluminous arborescence of 'care-means' and 'care-providence' that allowed enhancing the achievement of 'end-care': to offer her the best for her many and renewed needs, providing comfort and well-being.

In Sara's life, the care provision movement has assumed its own contours, such as vigilant and protective care (Figure 1 - No. 15) that protects her, in common situations, from harming her health. Exemplarily, the family shaped an artifact, in the form of a "safety belt" (Figure 1 - No. 16), to protect Sara from falls from the cord chair where she sits a part of the day, providing her with physical security, while it does not restrict her movements (Figure 1 - No. 17).

The care, in its arborescence, is still the scene of the circulation of vivifying affects of the relationships that, in the life movement, far exceed the one restricted to health. It is, above all, inclusive; and the difficulties, overcome by persevering patience, give way to loving coexistence, affectionate companionship, the vivacity and joy of being with the other. In everyday life, for example, Sara is no longer able to recognize, in words only, the acts and attitudes of care, as well as not verbally expressing her needs. Nevertheless, Sara and her family give them meanings and recognize them in other ways: Lídia sat beside her on the armrest of the armchair - and Sara, quite confidently, held her left hand on Lídia's right arm, as if she was protecting her (Observation Notes).

Touch-mediated contact, trust, auditory sensitivity, caress, and warmth make the presence

vivifying when consciousness is no longer awakened to intellectual explanation. Therefore, Abraão, her nieces and sisters struggle to nest the space so that Sara feels as comfortable and protected as possible. (Figure 1 - No. 18).

The allegory of the tree exposes that there are "means-cares" that articulate and/or expedite and/or connect one or more actions for "end-care" to happen. There is also "caregiving" that seeks, collects, and aggregates conditions, people, family and/or professional and/or others, as well as material resources of various orders, so that "care-end" can be set in motion.

Arborescence of family care: senses of the experience of chronic illness by Alzheimer

In daily dimension, the family is the primary caregiver of its members, from which they emanate, throughout their lives, innumerable peculiar forms of care⁽⁹⁾. It also conforms to mutual, plural support and, in the collective, embraces and assumes diversity in the individual's ways of being⁽¹¹⁾.

Since it structures social life, the family solidifies human values, feelings and bonds, becoming, over time, a place of protection and acceptance, above all, in the manifestation of some illness. In that circumstance, they perform and orchestrate the most diverse ways and places of care, "either as self-care within the family, or through networks that sustain and support it, seeking to guarantee the 'best in health' for each one of its members"^(9:393).

We understand that, for presenting a diverse range of needs, the person suffering from chronic illness, specifically Alzheimer's at its advanced stage, lacks many of the care involved in the totality of life, mainly produced by the family's own movements. Such movement requires from the family 'increasingly sophisticated and sensitive acts and attitudes of care that embrace the uniqueness of such needs'⁽¹²⁾.

That support is necessary and indispensable to those who are sick and are, as a rule, through family relationships, made up of bonds, affections and affectations over time. Thus, in that place, the first relationships happen and most people find an answer to their needs, whether of affective or material origin; thus, it becomes a place of security, permanence and

trust (13).

The bond of affectation that permeates the family relationship causes, at the onset of the illness in one of its entities, everyone to feel, to some extent, responsible for his/her care. Such accountability affects actions and rearrangements for the care to succeed, whether or not supported by health professionals in that care⁽⁹⁾. However, it is extremely important to highlight the peculiar way of life and the context in which those entities, in close relation, are inserted.

Furthermore, the family takes care of its member depending on its possibilities and potentialities. Sometimes, situations of vulnerability exhaust those potentials to the extent that they "prolong and/or affect considerably their concrete possibilities of caring"^(9: 394). That impact stands out in the family and the sick person's life when health services and professionals do not support them in that process.

In the history of Sara and her family, there is an intense exchange that has solidified the affective links over time, permeating the life of a relationship productive and nurturing of care. Thus, the care in its primordial relational dimension, built from the ways of Sara being in the world and relating to the people and things around her, stands out. In that aspect, the long-term friendliness of the couple, and of them with the family, gains strength, as it is a powerful dynamo for a careful, courteous and protective care of the life and health of the elderly. In particular, the relationship perpetuated by the companionship and sharing in and between the couple, constituted in the 42 years of marriage, modeling peculiar forms of care, stands out; and, at present, Abraão remains indispensable in the care of his wife.

With regard to the conviviality of marriage that sometimes runs through a large part of a life, it is of the utmost importance to consider marriage as an important link in the formation of a new family, whenever it is flanked by values based on love, a relationship of trust, commitment and intimacy⁽¹⁴⁾. In the family life, the man, when experiencing a situation of illness, feels emotionally affected, suffering for those who fall ill, being responsible for their care based on the woven relations⁽¹⁵⁾. Thus,

depending on how he interacts in the family environment, he tends to constitute proper forms of caring along the coexistence, proving to be potentially participatory in care⁽¹⁶⁾.

A study dealing with men who care for a wife with dementia describes the many reasons that led them to perform the care, especially: the wife's dedication to caring for the family; the love and complicity that permeated the relationship; feelings of obligation/reciprocity, whether social, moral or religious⁽¹⁷⁾. Emotional involvement, the quality of experiences and memories of married life are also important elements to return the care. It also points out that few qualitative studies deal with husband-wife care, and it draws attention, above all, to health professionals, who consider them in their entirety, since they significantly shape family care experiences.

Care is a practice revealed in the dimension of human history, of which women have always been present⁽¹⁸⁾, being even attributed and concerning the feminine nature. However, studies have also discerned how men have been responsible for caring, and may constitute important sources of care for those who become ill^(15,17,19).

In the study, the care provided by the husband, in addition to the efforts of sisters and nieces, becomes something that the family designs - a sensitive and flexible project, taking responsibility for its existence. In the bosom of the family, care is shaped as a precious commodity that is exchanged, while also being shared with the members in daily life. Care, then, arises as a good that reinforces bonds and relationships, perpetuating itself over time, between generations.

We agree with authors⁽²⁰⁾ that care for the family is constructed and developed from the meanings it attributes to its being in the world, in the reflections and interpretations that arise in the process of interaction and in the understanding of certain situation. The production of care for Sara was shaped by the synergy of caring for several people who made efforts to meet the required needs, each one in a unique way. A study⁽²¹⁾, in turn, emphasizes that chronic illness affects the whole life of the person and his/her family, making them to develop personal ways of dealing with and living

with the disease, wrapped in a multiplicity of constantly updated events, whether structural, Symbolic, contextual, biographical and the course of the disease itself.

Regarding the course of the disease, the situation of Alzheimer's disease presents marked characteristics, expressed in time by its permanence and progression, generating multiple dependencies. The sick person and his/her family face intensely symptomatic behaviors, with gradual and progressive increase of disability⁽¹⁾. Faced with the progression of illness and disability, the required care become, daily, very differentiated and intensified. Thus, family members routinely shape their own ways of providing it. That "provision is made in a continuous process of modeling, according to its potencies and possibilities, in which the family is able to construct care 'with', not only 'for', the family entity, seeking to meet its own care needs"^(5:4739).

In Sara's life, there are many ways of caring, even respecting her time; and this is what the family models: the organization of the routine and the spaces, providing the security of the house and the external environments, also protecting her in times of agitation and anxiety; the care with the bath, hygiene, clothing, hydration, besides the constant attention to the standard of sleep, rest and an attentive and continuous perception of her reactions that can demonstrate approval, or not, to all of that.

Caring, in this context, trees in a myriad of care, which, incorporated into daily life, set the rhythms of living in the family. By 'myriad' we mean the many ways of expressing cares, "generally barely visible, for they are subtle, diverse and multiple, far exceeding what is rationalized as such by the health field"^(9: 394). In this provision, there is the intense movement in the form of readiness, acts and attitudes of care by the family members, involving Sara in a nest of protection and coziness. Abraão, being the great articulator of the care of Sara, drives the movement and is supported by his wife's sisters who also promote that caring movement.

All of those caring actions are designed to achieve what the family considers the "end-care" - the best living of Sara, that is, caring for life, of life and in life that, beyond the body, gives rise to tenderness, attention, gentleness, and love,

which, in turn, nourish the soul, relationships and affections, indispensable to life. That propulsive movement of inclusive care by the family stimulates the power of and for care, and reveals, among others, a relationship that produces affections and effects, based on affectations and mutual accountability of those family members. In this affecting oneself, and seeking for the well-being of Sara, the care is being modeled and provisioned throughout the life. Thus, people learn and teach, develop and appropriate different care potentials in the very movement of experiencing situations of life and illness.

FINAL CONSIDERATIONS

The wealth brought by the life story of Sara and her family gains special relevance in the daily dimension of care, leading us to some pertinent reflections in the health area. The allegory of the tree reveals the minutiae of care that tree in myriad. Such cares resonate in time, through a past amalgamated by the texture of an affective-amorous relationship of Sara with the family; which, in turn, links, strengthens, promotes, mobilizes and nourishes the family experience, teaching ways of caring in the present. Thus, the

routine projects as the stage of human relationships in which the bonds of affection delineate the living in harmony with care.

We were able to show the donation of the man-husband who mobilizes a composition of care of several orders, always in a very personal way and pertinent to the needs of his companion. That care closely articulates with the family, through the acts and attitudes of its various entities. We consider important to think about care that includes the family experience in its unique way of being, highlighting the context of daily life, surrounding them. In that family complexity, we consider relevant the production of new studies that cover care in the chronic situation of Alzheimer's disease and the its innumerable repercussions on the living of the sick person and his/her relatives, since they are still very scarce in the literature.

The health professional is important as well, who considers the broad needs that arise from living with Alzheimer's, seeking to know the affections and effects that it produces in the lives of the sick people and their families, so that he/she can produce pertinent and supportive practices, becoming more effective in the possibilities of also positively affecting the lives of those people.

EXPERIÊNCIA DO ADOECER CRÔNICO POR ALZHEIMER E A ARBORESCÊNCIA DO CUIDADO FAMILIAR

RESUMO

A doença de Alzheimer integra o rol dos agravos crônico-degenerativos, sobressaindo-se como causa mais comum das demências senis, representando cerca de 60 a 80% destas. Objetivamos compreender a arborescência do cuidado na vivência familiar de adoecimento por Alzheimer que, gerado e mantido ao longo do tempo, precisa atender necessidades diversificadas. Conformou-se como estudo de situação, por meio da abordagem compreensiva, embasado na história de vida de idosa, adoecida há sete anos, sendo operacionalizada pela entrevista em profundidade e observação que compuseram o diário de pesquisa. Desenho alegórico permitiu evidenciar a miríade de cuidados que arboresce na vida em família. Tais cuidados reverberam no tempo, através de um passado amalgamado pela tecitura da relação afetivo-amorosa da idosa para com a família que, por sua vez, vincula, fortalece, impulsiona, mobiliza e nutre a vivência familiar, modelando maneiras de cuidar no presente. Ponderamos ser importante conceber práticas profissionais que abarquem a família em seu modo singular de ser, com destaque ao seu contexto de vida, amparando, ao longo do tempo, o cuidado por ela produzido.

Palavras-chave: Relações familiares. Saúde do idoso. Doença de Alzheimer.

LA EXPERIENCIA DEL ENFERMAR CRÓNICO POR ALZHEIMER Y LA ARBORESCENCIA DEL CUIDADO FAMILIAR

RESUMEN

La enfermedad de Alzheimer integra la lista de los agravios crónico-degenerativos, destacándose como causa más común de las demencias seniles, representando cerca de 60 a 80% de estas. El objetivo fue comprender la arborescencia del cuidado en la experiencia familiar del enfermar por Alzheimer que, generado y mantenido a lo largo del tiempo, necesita atender demandas diversificadas. Se configuró como estudio de situación, por medio del abordaje comprensivo, basado en la historia de vida de anciana, enferma hace siete años, utilizando entrevista en profundidad y observación que compusieron el diario de investigación. El diseño alegórico permitió evidenciar la pluralidad de cuidados que arborece en

la vida en familia. Tales cuidados resuenan en el tiempo, a través de un pasado amalgamado por la coyuntura de la relación afectivo-amorosa de la anciana con la familia que, a la vez, vincula, fortalece, impulsa, moviliza y nutre la vivencia familiar, moldeando maneras de cuidar en el presente. Ponderamos ser importante elaborar prácticas profesionales que abarquen a la familia en su modo singular de ser, con destaque a su contexto de vida, amparando, a lo largo del tiempo, el cuidado por ella producido.

Palabras clave: Relaciones familiares. Salud del anciano. Enfermedad de Alzheimer.

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Corresponding author: Ítala Paris de Souza. Endereço: Av. Fernando Corrêa da Costa, nº 2367 - Bairro Boa Esperança. Cuiabá - MT Brasil, telefone: (65)36158805.

Submitted: 24/11/2015

Accepted: 28/11/2016