

POTENTIAL CAREGIVING PRACTICES IN A CHRONIC SITUATION OF ALZHEIMER'S: SCENES OF THE CARE PROVIDED BY THE MALE SPOUSE

POTENCIAIS CUIDATIVOS NA SITUAÇÃO CRÔNICA DO ALZHEIMER: CENAS DO CUIDADO PELO HOMEM-ESPOSO

CUIDADOS POTENCIALES EN LA SITUACIÓN CRÓNICA DEL ALZHEIMER: ESCENAS DE CUIDADOS DEL HOMBRE-MARIDO

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ABSTRACT

This study presents the experience of an aged woman who has had Alzheimer's for 7 years and whose main caregiver is the husband. Based on the couple's life partnership and caregiving bonds, we tried to emphasize the importance of the attitudes, behaviors and feelings associated with caregiving. Thus, our aim was to observe the care provided by a male spouse to his aged woman with Alzheimer's, and to identify potential caregiving practices in such a relationship. This study used a comprehensive, life story approach. Data were collected through in-depth interviews and observation. The result of the analysis is presented in an analytical-descriptive diagram, which describes the husband's actions and attitudes in caring for his wife. This diagram enabled an understanding of the intense effort made by the husband to seek, provide and manage the care of his wife. It evidenced an affectionate and laborious organization for the maintenance of care "in and for" her life. This caring aspect in their marriage has been gradually built on the basis of mutual respect, reciprocity and commitment towards each other. Thus, we found that the potential care provided by the male spouse is particularized by the time and space of conjugal life and along the illness trajectory. This understanding allows us to highlight the fact that the family needs good healthcare services, especially by nurses. The latter should provide lasting care and engage in the family experience of caregiving, mobilizing resources to assist and support them with what they need.

Keywords: Caregivers; Alzheimer Disease; Family Relations; Aged.

RESUMO

Este estudo abarca a experiência de uma idosa que vivencia o adoecimento crônico por Alzheimer há sete anos, tendo como cuidador mais presente seu esposo. Diante da aliança de vida e cuidado do casal, buscou-se conferir relevo às atitudes, comportamentos e sentimentos que entremeiam o ato de cuidar. Assim, objetivou-se compreender o cuidado produzido pelo homem-esposo à idosa que vivencia adoecimento por Alzheimer, apreendendo os potenciais cuidativos nessa relação. Estudo de abordagem compreensiva conduzido pelo estudo de situação a partir da história de vida, operacionalizada por entrevista em profundidade e observação. A análise permitiu a construção de diagrama descritivo-analítico, remetendo aos atos e atitudes de cuidados do esposo à idosa. Nele foi possível apreender o intenso esforço despendido pelo esposo na busca, produção e gerenciamento do cuidado à esposa, mostrando tecitura afetiva e laboriosa para a manutenção do cuidado "na e para" sua vida. O cuidado foi sendo construído ao longo do matrimônio, tendo por base essa relação afetiva constituída pelo respeito mútuo, reciprocidade e compromisso de um para com o outro. Assim, permitiu compreender que os potenciais cuidativos do homem-esposo são circunstanciados no tempo-espaço da vida conjugal e ao longo da situação de adoecimento. Tal compreensão possibilitou dar relevo ao fato de que a família requer boas práticas profissionais em saúde, em especial por enfermeiros, e que estas "perdurem" no tempo e estejam implicadas na experiência familiar de cuidado, mobilizando recursos para auxiliá-la e apoiá-la com o substrato de que necessite.

Palavras-chave: Cuidadores; Doença de Alzheimer; Relações Familiares; Idoso.

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RESUMEN

El presente estudio se refiere a la experiencia de una señora mayor que sufría de Alzheimer desde hacía siete años y cuyo cuidador principal era el marido. El compromiso de vida y cuidado del matrimonio enfatizaba las actitudes, comportamientos y sentimientos del cuidar. El objetivo del estudio fue comprender el cuidado del hombre-marido hacia su mujer con Alzheimer, captando los cuidados potenciales de la relación. Estudio de enfoque comprensivo, conducido por un estudio de la situación a partir de la historia de vida y por medio de la entrevista en profundidad y de la observación. El análisis construyó un diagrama descriptivo-analítico remitiendo a los actos y actitudes de cuidados del marido a la mujer. Se captó el intenso esfuerzo del hombre en la búsqueda, producción y administración de los cuidados, mostrando tesitura afectiva y laboriosa para mantenerlos "en la vida y para su vida". El cuidado fue construido a lo largo del matrimonio en base a la relación afectiva de respeto mutuo, reciprocidad y compromiso de uno para con el otro. Los cuidados potenciales del hombre-marido son detallados en el tiempo-espacio de la vida conyugal y durante la situación de enfermedad. Tal comprensión destacó que la familia requiere buenas prácticas profesionales en salud, en especial por enfermeros, y que éstas "perduren" en el tiempo y estén implicadas en la experiencia familiar de cuidados, movilizandolos recursos para auxiliarla y apoyarla con lo que fuere preciso.

Palabras clave: Cuidadores; Enfermedad de Alzheimer; Relaciones Familiares; Anciano.

INTRODUCTION

Families serve as reference for life and care, and are the primary caregiving unit "in, of and for" life, throughout its history and in the context of its potentials.¹ Over time, it engenders efforts in the provision and management of daily care to each member in a highly personal way.¹

In the whole of life span, the family rearranges itself to deliver the best care possible, and, in the presence of illness, remodel their daily lives to fit new care needs. This responsibility belongs to all family members, not only to those who experience the illness or provide them care, but rather to all who are afflicted by the suffering of others.²

It can be understood that the care is produced based on the meanings and senses that are attributed to the needs of those who are cared for, always valuing the recognition and mutual respect between people.³ Thus, we sought to understand the family experience of care in the complexity of their daily lives, in accordance with its distinctions and enhancements in the face of many different events, including sickness, that are an integral part of the lives of each family member and of family itself.⁴ The experience of illness thus produces substantial changes in family life, changing its relationships and dynamics, which prove to be changeable in space and time.

When analyzing the suffering caused by illness, it can be said that "it establishes itself in life, not as mere interweaving of illness and life processes, but in relation to one another, forming a third party that is more than the sum of the previous two".⁵ It can be concluded that the family care is molded according to the circumstances imposed by the illness on daily life. It is changeable and dependent on the way the relationships between family members are established. This study corroborates the findings of other investigators⁶ that report that, when families are affected by illness, they rearrange their lives in order to provide the care and support needed to maintain the well-being of the ill person.

Thus, potential family caregiving depends on how each family member is affected by illness, as well as on the synergy

of the potentials of those who provide care.² In this study, caregiving potential is understood as the efforts made by family members to obtain the resources required to fulfill or meet the health needs of the ill family member.⁷

Among the ways of getting ill, those of different natures which are more perennial than others, therefore requiring continuous, prolonged and/or permanent care, are called chronic conditions,⁸ requiring the provision of care that exceeds the biological dimension and reaches psychological, social, economic, and cultural dimensions.⁹

However, in order to expand this definition to include those conditions that have some influence in coping with the illness and in people's need or will to provide care to others, the concept of "chronic situation" used in this paper was that of a situation that "[...] involves the illness and all the different kinds of care that must be provided, as well as the impact of the illness on people and the search for care in the lives of the person who is ill and his/her family".¹

Given the above, this paper covers the experience lived by Sara, a 70-year-old woman who has had Alzheimer's for 7 years, and Abraão, her 74-year-old husband and caregiver. The couple has been married for 41 years. Based on the couple's life partnership and caregiving bonds, we tried to emphasize the importance of the attitudes, behaviors and feelings associated with caregiving,¹⁰ as well as to identify the potential caregiving practices performed by the husband and the family in order to meet the care needs "of, in and for" Sara's life.

Thus, this study aimed to observe the care provided by a male spouse to his aged woman with Alzheimer's, a chronic condition, and to identify potential care practices in such a relationship.

The relevance of topic is highlighted in the intense effort made by the family to provide the best possible care, according to its care potentials, enabling health professionals to recognize the need to implement practices to support care in what, ethically and legally, is proper to them.

METHODOLOGICAL TRAJECTORY

This study used a comprehensive approach to identify subjective phenomena involved in the relationships, values, beliefs, perceptions and feelings,¹¹ such as those which are associated with family caregiving, thoroughly molded according to the experiences of life and illness. We conducted a "situation study", which allowed us make broader inferences from the micro reality of the family, given the acceptance of the illness and the provision of care.¹⁰ Thus, our aim was to report "how things come and go", based on a detailed description of people's experiences, without claiming to exhaust the multiple life dimensions and meanings. We seek a "broadening of thought, in order to seeks to understand in depth what constitutes the specificity of each situation, every experience, making them stand out from life's effervescence".⁴

Selection of the study participant family was mediated by a nurse who worked in one of the Family Health Units (FHU) from Cuiabá-MT. She reported the case of families who lived in the area covered by her FHU and were experiencing a situation of illness and care. Since we were interested in at-home family care cases, after receiving the consent of the group responsible for the main research project, we selected the family in whose life story the provision of care is done by the male spouse. This enabled us to broaden, reinforce and include other aspects of caregiving by males, which had already been discussed in the group.¹⁰

For data collection, we used a life story approach, developed through in-depth interviews¹² and observation. The interview was made based on the following guiding question "tell me about Sara's illness and care experience". The conversation was carried out based on the recollections of what the interviewee had experienced, with gradual deepening of narrative threads as the meetings proceeded.¹² With first met with Abraão, who seemed to be the main caregiver of this wife. All interviews with Abraão were audio recorded, because, according to other investigators,¹³ the unveiling of a life history allows us to describe the minutiae and peculiarities of the narration in their own modes of expression, entering in their own life contexts in order to better understand the choices and perceptions of the narrator.

Due to the advanced stage of the disease, Sara was not able to verbally express herself. However, she has been present in all meetings. Thus, the observational strategy used was of fundamental importance, because it made possible for us to provide the silent elements of Sara's and Abraão's relationship and describe how Abraão has been providing care to his wife, and how she receives and reacts to his care.

The thorough observation report also contains the description of all people, objects, places, events, activities and conversations observed by the researcher during the interviews.¹²

Between April and June, 2015, we had three meeting interviews with Abraão, who, in the presence of his wife, narrat-

ed his experience of illness and caregiving. The narrations were fully transcribed, together with the observations made. They were then placed in the research journal,¹² which totaled 125 typed pages of a *Microsoft Word* document.

In order to identify the dimensions of the caregiving experience that go beyond the narrated word, revealing itself as the "care in action",¹⁴ the first two meetings with Abraão were selected to compose the *corpus* of analysis of this study. This selection was made because the caregiving actions observed during these meetings were in a "natural" state, i.e., they were not previously prepared and "staged", but rather happened as we were there or had already happened in the daily lives of Abraão and Sara and we now could see their effects.

Based on the empirical data collected, we built a descriptive and analytical diagram, composed of narrations and observations related to the caregiving acts, attitudes, efforts and endeavors made by Abraão in order to provide daily care to Sara throughout her illness. From this diagram, we selected three major "caregiving scenes" that seemed emblematic of the careful and thorough care provided by Abraão in order to ensure the "best possible care"¹¹ to Sara. These scenes are, namely: "Caregiving actions and attitudes in Abraão's and Sara's everyday lives"; "Offering water to satisfy Sara's thirst; and "Providing intimate care to Sara".

This selection was made because we could see their importance in the couple's life, shown by the fact that, during these scenes or during situations when they were mentioned Abraão always tried to describe or explain them in detail. The descriptive and analytical diagram (Figure 1) will be explained on the next section, because it is part of the results presentation and discussion.

The main research project to which this study is linked was approved by the Ethics Committee on Human Research, protocol number 51.101/CEP-HUJM/2015 and complies with all ethical principles of Resolution 466/12 of the National Health Council. All participants of the family signed an informed consent form. Anonymity was guaranteed to all respondents, as well as to the institutions and health professionals mentioned by them.

RESULTS AND DISCUSSION

In order to understand the way in which the caring aspect has been part of their family life, it is important to get to know how Sara's and Abraão's relationship has been gradually built on the basis of mutual affection and complicity ever since their marriage.

Sara was born in a city 270km from Cuiabá, MT, Brazil, where she lived with her parents and sisters for several years before moving to Rondonópolis, also in the State of Mato Grosso. She met Abraão in this last city during a prayer congregation at an Evangelical Church. At the time, she was 29 and he was 34. Six months later they were married. They lived in Rondonópolis for 12 years and then moved to Cuiabá, their current city of residence.

Abraão was born in a town 608km from the capital of the State of Minas Gerais. He lived there with his parents and siblings until age 14, when they moved to the countryside of São Paulo. As a young boy and then as a man, he worked as a manual worker doing heavy work, but also delicate tasks. He worked in a farm in the countryside of São Paulo, growing crops of vegetables and fruits, and later as a mason laying ceramic tiles. Both activities involved delicate manual skills and required an eye for detail.

Their marriage relationship has always been built upon care, since Sara dedicated herself to the household and to her husband, while Abraão was the family provider and insisted that his wife not work outside the home. Abraão stresses that they were united in a religious home, by a relationship of affection, complicity and mutual care.

The couple has always been fervent evangelical practitioners. Abraão constantly preaches God's words and often claims "*It's so good to be a Cristian*". Nevertheless, he says that, due to his wife's condition, he is no longer able to attend church as often as before. Now he usually goes to church every 15 days, if another family member is available to take care of Sara in the meantime.

Sara showed the first symptoms of Alzheimer's disease at age 62: she had depression. Now she is in an advanced stage of the disease and has constant crying episodes, aggressive episodes, delusions of persecution, jealousy and behavioral changes. Sara was initially diagnosed with schizophrenia, but specific tests detected damage to the hippocampus, thus confirming the diagnosis of Alzheimer's disease. In 2012 the disease worsened considerably and Sara was no longer able to talk or coordinate her limbs, requiring full care by a caregiver.

Sara could always count on her caring husband. He is currently the person who usually performs the meticulous caregiving tasks for his wife, with the support of his niece and his wife's sisters. The latter offer Abraão support, helping especially with household chores and when the Abraão has to take Sara to a health institution. Their participation in care is promoted by the fact that Sara and Abraão live in conjugate houses next to Sara's sisters. Their houses are next to each other within the same ground.

Based on the understanding of this context of life and illness, we present some "caregiving scenes" (Figure 1), with the meaning of "scene" as a set of movements in space and time that can express important events that are repeated in everyday life. In this life story, these scenes show "care in action" (caregiving tasks) incorporated into the daily lives of Abraão and Sara. They have been intentionally selected and depicted as "two hands holding a rose." A rose is composed of petals and represents events that are not fixed but rather interconnected and in constant movement in the couple's lifetime. Thus, by unfolding itself towards the hands that hold it, the rose surren-

ders itself to the care, warmth and support that they so dearly provide. The following scenes have been selected:

- **scene 1** – "Caregiving actions and attitudes in Abraão's and Sara's everyday lives". Here we report in detail what the researchers could observe during the interviews and describe the home environment and context, as well as objects, gestures and the interaction between family members;
- **scene 2** – "Offering water to satisfy Sara's thirst". Here Abraão narrates the meticulous care provided by himself in order to keep his wife hydrated and to keep track of the amount of water that is being given to her, by measuring it in a jug and showing his accurate knowledge of this process;
- **scene 3** – "Providing intimate care to Sara". Narrated by Abraão, this scene evidences the relationship of trust and intimacy shared by the couple. This care aims at offering protection and attention to the needs of the female body.

In scene 1 (Figure 1) Sara was sleeping, resting on a wire chair, and Abraão used different materials resources, such as beams, bed sheets and towels, to keep her supported in the chair with something that looked like a "seat belt". This gave Sara physical support without restricting her movements.

This picture thus seemed very different than the one given by a Family Health professional who worked in the neighborhood and had said that "*Abraão ties Sara to a chair*", as if it were a sort of forced restraint. On the contrary, we noticed that Abraão tried to keep his wife as comfortable as possible and provide her protection and well-being. The care provided can thus be interpreted as a zealous attitude, and is rigorously checked by the spouse during the whole time that it is used, to see if it is working correctly.

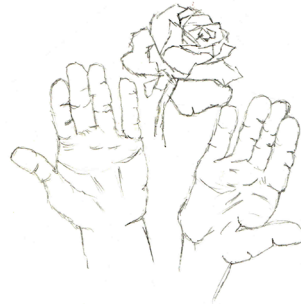
This loving and protective care that Abraão provides to Sara is also seen during some episodes of anxiety and agitation experienced by her due to disease progression. With the aggravation of the disease, Sara was prescribed drugs to calm her down:

It is a tranquilizer, you know... one of those tranquilizers that really calm you down [...] She kept screaming au au [making gestures with his mouth] started screaming, you know [...] He said [referring to the physician] you know what, I'll prescribe her a tranquilizer and this one will work, and that's that one there, you know [pointing to the medication that was on the hands of one of the researchers] (Abraão).

It is known that, among other things, Alzheimer's causes changes in cognitive functioning and often leads to behavioral changes, thus progressively limiting people's ability to perform activities of daily living and self-care.¹⁵ As Sara is in this stage of the disease and has episodes of intense agitation, she was prescribed tranquilizers that keep her sedated most of the day, which was evidenced during our meetings.

SCENE 3

My niece used to put on one of those panties that are like briefs that you wear, then I told her: "You know, these panties are no good... when she wears diapers she can spend the whole day without being wet... she can sleep for three hours in bed and she won't get wet"... but she did put the panties on her... "But these panties are easier to put on". I let her, you know... she laid down... then she got a little wet... but I put on one of these panties on her "what are these panties that you bought again?" If it were for you this... to sleep I put on diapers and put on these panties to sleep [...] but not the diaper... I put on a diaper on her and she spends all day... don't get wet... you know... but with these panties that she bought... she does get wet (Abraão – 1st meeting).



BELLATO, R. The blossoming of the rose, 2015.

SCENE 2

Sara... Sara... how're doing, sweetie? [Abraão talks to Sara] Want some water? What? Want some water? Lean back to drink some water [Abraão speaks softly, gets up and goes to the kitchen for some water]. Drink some water, will you sweetie? [Abraão comes back from the kitchen]... You can drink water now [Abraão puts some water in her mouth and Sara enfolds his hand in hers to drink] (Abraão – 1st meeting). We leave this glass here to see how much she is drinking [Abraão comes from the kitchen with a glass bottle of cold water] this one we... put some of the other water... you know... we leave it in the fridge for a while to cool it... and keep it... here so she drinks... I have another one... I drink from a different bottle... another bottle... this one is only hers [referring to the water bottle] (Abraão – 2nd meeting).

SCENE 1

"The chair was tied to one of the three support beams of the porch and the same bed sheet that was used to tie it was also braided around Sara's body, like the seat belt of a car. Nothing was too tight and it was clear that the intention was to keep her as comfortable as possible. There was a bed sheet on the chair seat, adding some padding to the seat, and a folded face towel under her neck – which tilted to the left -, to provide some support and prevent that the muscles of the area were fully extended. There was also a face towel on her lap, which Abraão used to ward off the flies that were flying around his wife's face (Observation report – 1st meeting)." "At some point, Sara started getting even more agitated, it looked like she was asking for water, because she was licking her hands, and the white residue around her mouth seemed to indicate that she had a dry mouth. Abraão noticed it and went get her some water. It was an aluminium glass, Abraão put it close to Sara's mouth and she, in a thirsty movement, wrapped her hands around Abraão's hands and drank all the water that he had brought her. (Observation report – 2nd meeting)."

Figure 1 - Caregiving scenes – the everyday life of Sara, who has Alzheimer's, 2015.

The attitude shown by the husband shows the essence of a way of being in which the person who provides care is not self-centered, but rather focuses on the other person and show great watchfulness and solicitude about her; this kind of care blooms when the existence of the person being cared is important to the person providing care, so that the caregiver feels involved with and effectively attached to the ill.¹⁶

Family care is this molded according to the way that each family member deals with the illness, and may change according to the relationship and interaction of each family member to and with the other members and with the person who is ill. Thus, the caregiving potentials of each family member are the result of a synergy of the individual potentials of each caregiver, being variable in time and space.²

We found that the care that Abraão provides to Sara is modeled according to the daily situations that are imposed on them, and that material resources become effective to enhance the caregiver's capabilities, providing thus a continuous and long-term care that meets her intensive needs. It is important to understand how the husband provides and manages the care in the context of Alzheimer's disease, highlighting

the potential caregiving actions that are undertaken. Caregivers are attached to the process of life and illness of their family members, having their lives managed in a particular way by the events that take place.

Changes in the daily routine of the couple clearly show the changes that happen in the course of the illness. One example of this is Sara's hospitalization due to dehydration, narrated as follows by Abraão:

We take her to the ECU [Emergency Care Unit] once, the first time, right... it was a lack of...what is it called? When the body is missing water... [...] dehydration... she's dehydrated, that's it, that's what it was... then she stayed, but we have to give her lots of water, right... the doctor said: "You have to give her lots of water, right, so she doesn't dehydrate, right"... So we give her lots of water... when she's awake I always give her water, right... (Abraão – 1st meeting).

The event reported seems to have made Abraão even more aware of the need of making Sara drink more water to

make sure that the dehydration episode does not repeat itself; he used this previous experience to support his explanation of how the best possible care should be provided to Sara from now on. Because Sara is incapable of verbally expressing her desire to drink water, Abraão is capable of recognizing it through her gesture of "licking her hand" (scene 1 – Figure 1). He also checks the temperature of the water and the amount of water that she drinks daily (scene 2 – Figure 1).

We can see that Abraão shows concern about Sara's hydration needs and he is capable of meeting these needs by means of a thorough and peculiar care (scene 1 – Figure 1). Therefore, it is important to have a sharp sensibility (Scene 2 – Figure 1) in order to recognize the characteristics of this need, which is shown by his wife through expressions and gestures, and that apparently have become their own communication code, requiring constant attention.

The relationship between caregiver and the person with Alzheimer's disease is so close and intimate that the caregiver ends up remodeling his own way of life in order to provide the best possible care to the person cared for. This relationship is often based on love and loyalty, so that the caregivers decide to devote their time and dedicate themselves to the ill family member.¹⁷ These were the feelings and attitudes that we could recognize in Abraão, who cares for Sara in a zealous and loving manner.

The caregiver-care receiver relationship may also be governed by reciprocity and reinforced by family ties, arising out of a sense of duty and making the person feel responsible for the provision of care.¹⁸ In the case of Abraão and Sara, these ties have been built throughout marriage life, and mediated by mutual care and complicity. These feelings now give the spouse the desire to take care of his ill wife, in a dedicated and comprehensive way.

This study corroborates that constant and continuous caregiving ends up modeling family relations, changing values and acquired knowledge to meet the needs of the care receiver, i.e., there is a straining between the previous way of life and the one experienced due to the illness.⁶

In the care relationship between Abraão and Sara, we could perceive a disinterested compassion, so that their relationship is sustained by love and constant caregiver availability. This intense emotional attachment provides Abraão with special accurate ways of recognizing Sara's multiple needs, using and modeling his own resources continuously, based on attentive and close observation of the results of each action and their adjustment to deliver the best possible care to her.

Thus, the affectivity of care is understood as a way of feeling the other and the world.¹⁹ In this relation, the caregiver let his feelings flow and wishes to express his/her love through care, concern, respect and solicitude, which makes care more effective, because it is affective.

The trajectory of disease, in its inexorable course, is what determines the care that has to be provided. In the face of ever new situations that present themselves, an attentive caregiver makes use of resources that will increase his/her potentials, culminating in constant rearrangements in care, outlined according to his/her experiences.

In everyday life, Abraão retired at age 65, he had to stop working as a mason because of Sara's increasingly demanding care needs, in order to dedicate himself entirely to the care of his wife. In addition, due to his advanced age, he was no longer able to perform jobs that required physical effort:

I've worked many years as a mason, I stopped working a while ago... I started taking care of my wife, right, and then I stopped working as a mason right [...]. Every now and then I work (as a mason), but I lack the time, you know, I have no time to work as a mason. My time is spent taking care of her [...]. I'm much older now, my body no longer endures the work of laying ceramic tiles (Abraão).

Staying home with Sara was of paramount importance for Abraão to be able to provide her a continuous and complex care that goes beyond the mere performance of a task, and are rather inclusive care acts and attitudes that are intimate, affectionate and constant.

A study about the experience of male spouses who care for women with dementia revealed how much they have, in the last years, directly engaged themselves in caregiving, remaining close to their wives for 10 to 24 hours a day, i.e., providing most of the care.²⁰ Some authors also highlight the special importance of marriage, since it is through marriage that people form a new family, imbued with love, and built a relationship of trust, commitment and intimacy.²¹

Other studies have shown that, in the intimacy of the family circle, men feel emotionally affected when a family member gets ill, suffering for him and therefore, building their own way of providing care.^{22,23} Moreover, among the reasons that led men to take the decision of being caregivers, the study highlights: the way they shared their lives before the illness, the love and passion with which they lived their relationship, the reciprocity or (social, moral or religious) duty, or to find redemption for the mistakes of the past.²⁰

In the lives of Sara and Abraão, reciprocity can be seen as the main motivation for Abraão's caregiving actions. Because she has always helped him and is currently ill, he now reciprocates, by providing her excellent and effective care to ensure her well-being and survival.

Another striking scene evidenced through Abraão's reports concerns Sara's intimate care provision (Scene 3 – diagram 1), particularly in relation to the diapers that she dai-

ly uses. We perceive Abraão's concern in providing Sara with quality diapers, in order to give her more comfort, and also because they last longer and she can wear them for a longer time, without having to change them constantly, this optimizes the time of use and the time available to provide care. Abraão explains the care provided in detail, showing that it requires accurate observation and assessment, not only of the use of physical resource such as the diaper, but also of what it brings to Sara in terms of efficacy and well-being.

We can infer that love and dedication are necessary when caring for a person with Alzheimer's. Nevertheless, financial resources are also important in order to acquire technologies needed to deliver care.¹⁸ In order to have access to simple resources such as high quality diapers, Abraão counts on the help of other family members who offer themselves to go and buy them, as Sara cannot be left alone:

[...] if it's not me, it's the girl [referring to the niece] when she's here, right, to help me out, right... but she doesn't like these panties [...] she avoids them, right, they get so wet, right [...] I buy, I give her money and she buys [...] my sister-in-law has been buying them at the drugstore, it's much cheaper in that drugstore, right [...] (Abraão – 1st meeting).

We could observe that the family constitutes a support network that may provide material help, guidance, information, among other things, to respond to the multivariate dimensions of care in illness. These networks are built by family members, according to the needs of the caregiver, and become stronger as they contribute to improve the management and provision of quality care to the person who is ill.⁵ In this perspective, it is important that the network that offers support to the aged caregiver is preserved by all family members, in order to deliver the care in a more dignified way, making the care receiver feel important, valued and loved.²⁴

We verified that Abraão provides intense and comprehensive care to his wife, and is also able to mobilize other family members to acquire the material resources necessary to improve the provision of care, making use of better adaptations of strategies and actions to face his wife's needs. Thus, observing Sara's daily needs, it was possible for us to better recognize Abraão's caregiving potentials, revealed during the caregiving scenes watched during the interviews or narrated by him.

The health needs mentioned here constitute what the ill person and his/her family experience as "lack" or "deficiency", whether of conditions, means or instruments to care for oneself or for someone under their responsibility.²⁵ As for caregiving potentials, these are a set of resources that, together with the effort made, the will to provide care, the restlessness and/

or the perceived lack in face of the experience of illness, make possible to boost new actions and confer new meanings to the experience, managing the possibilities of successfully providing the numerous care needed.²⁵

Thus, maintaining a positive attitude as a way of bring back new "normalcies" to life, the caregiving potentials tend to surmount the negative side of vulnerabilities and become a means facing and overcoming them, enabling changes and transformations in people's life situation.

Thus, it is necessary to value each and every one, as well as the magnitude of everyday aspects as the relational and affective site where one lives and where one's own way of life is created next to those with whom one lives and counts on to provide care, be they family and friends, or persons and institutions that may also help in the provision of care. It is important to highlight that the potential to provide care to a certain need always have to be referred to in a certain conjunction and permanence of these elements in space and time. Thus, these potentials always reveal themselves according to the "situation", depending on the phase of disease that is currently being experienced and the resources available to the family to provide care.

FINAL CONSIDERATIONS

This study evidenced the intense effort made by Abraão to seek, provide and manage the care of his wife, denoting an affective and laborious organization for the maintenance of care "in and for" her life.

The care provided by Abraão is based on the affective relationship that binds them, and is grounded on mutual respect, reciprocity and the commitment built throughout their married life. It is in this context of affection that it is possible to understand the kind of care that had to be gradually molded by Abraão, within his caregiving potentials, which are required in everyday situations to face the needs imposed on the family by Sara's illness.

From Abraão's narration of the types of care that are required by Sara and that are mainly provided by him, we selected a few and presented them as scenes in order to stage a small part of the couple's experiences in the situation of Alzheimer. It can be said, therefore, that the care provided is not a "male spouse-specific" care, but rather a highly personalized care, produced according to Abraão's way of life, because he is the guardian of the memories of Sara's "ways of being". The specificities and small changes that occurred in the course of the disease required perception and delicacy from this male spouse, in order to judge which was the best care to satisfy his wife's needs.

Moreover, by showing some scenes of the "care in action" that is part of the couple's everyday lives, we could see how people's lives are "allocated" and "immersed" in a highly relational space and time, as mutual affection and effort produce

the best care. Thus, the methodological approach used in this study proved to be consistent with the proposed objective, as it enabled the understanding of Abraão's caregiving potentials, which are used to produce and deliver a thorough, affectionate and effective care to his wife. A care that is woven in everyday life and lasts in time.

REFERENCES

- Bellato R, Araújo LFS, Dolina JV, Musquim CA, Corrêa GHLS. O cuidado familiar na situação crônica de adoecimento. In: Congresso Ibero-Americano em Investigação Qualitativa, 2015. Atas CIAIQ. Investigação Qualitativa em Saúde, volume 1. [cited 2015 Jan 15]. Available from: <http://proceedings.ciaiq.org/index.php/ciaiq2015/article/view/92>
- Almeida KB, Araújo LFS, Bellato R. Family caregiving in chronic illness: a young person's experience. *REME - Rev Min Enferm.* 2014[cited 2015 Jan 15]; 18(3):724-32. Available from: <http://www.reme.org.br/exportar-pdf/958/v18n3a16.pdf>
- Ayres JRCM. Cuidado: trabalho e integração nas práticas de saúde. Rio de Janeiro: CEPESC/UERJ-IMS/ABRASCO; 2011.
- Bellato R, Araújo LFS. Por uma abordagem compreensiva da experiência familiar de cuidado. *Ciênc Cuid Saúde.* 2015[cited 2015 Jan 15]; 14(3):1394-400. Available from: <http://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/26868>
- Bellato R, Araújo LFS, Mufato LF, Musquim CA. Mediação e mediadores nos itinerários terapêuticos de pessoas e famílias em Mato Grosso. In: Pinheiro R, Martins PH, organizadores. Usuários, redes sociais, mediações e integralidade em saúde. Rio de Janeiro: UERJ/IMS/LAPPIS; 2011. p. 177-83.
- Mufato LF, Araújo LFS, Bellato R, Nepomuceno MAS. (Re)organização no cotidiano familiar devido às repercussões da condição crônica por câncer. *Ciênc Cuid Saúde.* 2012[cited 2015 Jan 15]; 11:89-97. Available from: http://www.scielo.br/scielo.php?script=sci_nlinks&ref=000112&pid=S1413-8123201300090002200001&lng=pt
- Almeida KBB, Araújo LFS, Bellato R. Rural community participation in caregiving for a young person with chronic illness and his family. *J Nurs UFPE On Line.* 2015[cited 2015 Jan 15]; 9(6):8194-204. Available from: <http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/viewArticle/7114>
- Organização Mundial da Saúde. Cuidados inovadores para condições crônicas. Relatório Mundial. Doenças não transmissíveis e saúde mental. Brasília: TABLE; 2003.
- Souza IP, Bellato R, Araújo LFS, Almeida KBB, Nepomuceno MAS, Mufato LF. Direito à saúde no tribunal de justiça: demanda por medicações em oncologia. *Rev Rene.* 2012[cited 2015 Jan 15]; 13(4):919-28. Available from: <http://www.revistarene.ufc.br/revista/index.php/revista/article/view/70>
- Musquim CA. Experiência de cuidado pelo homem na vivência familiar de adoecimento crônico [dissertação]. Cuiabá (MT): Universidade Federal de Mato Grosso; 2013. 141f.
- Minayo MCS. O desafio do conhecimento. Pesquisa qualitativa em saúde. 12ª ed. São Paulo: Hucitec; 2010.
- Araújo LFS, Dolina JV, Petean E, Musquim CA, Bellato R, Lucietto GC. Diário de pesquisa e suas potencialidades na pesquisa qualitativa em saúde. *Rev Bras Pesq Saúde.* 2013 [cited 2015 Jan 15]; 15(3):53-61. Available from: <http://periodicos.ufes.br/RBPS/article/viewFile/6326/4660>
- Santos PRM, Brito ACC, Silva LS, Araújo LFS, Bellato R. O campo de observação em pesquisa compreensiva: a vivência de jovens pesquisadoras. In: IV Congresso de Investigação em Enfermagem Ibero-Americano e de Países de Língua Oficial Portuguesa - 2014. Coimbra: Escola Superior de Enfermagem de Coimbra; 2014.
- Schneider C L, Araújo LFS, Bellato R, Nepomuceno MAS, Petean E. Modeling of familiar care in a chronic condition by adrenoleukodystrophy. *Ciênc Cuid Saúde.* 2015[cited 2015 Jan 15]; 14(2):1130-8. Available from: <http://periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/23940>
- Inoué K, Pedrazzani ES, Pavarini SCI. Influência da doença de Alzheimer na percepção de qualidade de vida do idoso. *Rev Esc Enferm USP.* 2010[cited 2015 Jan 15]; 44(4):1093-9. Available from: <http://www.scielo.br/pdf/reeusp/v44n4/34.pdf>
- Boff L. O cuidado necessário: na vida, na saúde, na educação, na ecologia, na ética e na espiritualidade. Petrópolis-RJ: Vozes; 2012. 296 p.
- Seima DM, Leonardt MH, Caldas CP. Relação no cuidado entre o cuidador familiar e o idoso com Alzheimer. *Rev Bras Enferm.* 2014[cited 2015 Jan 15]; 67(2):233-40. Available from: <http://www.scielo.br/pdf/reben/v67n2/0034-7167-reben-67-02-0233.pdf>
- Petean E. Substância do cuidado na experiência familiar de adoecimento: subsídios para o cuidado familiar [dissertação]. Cuiabá (MT): Universidade Federal de Mato Grosso; 2013. 143f.
- Celich KLS, Batistella M. Ser cuidador familiar do portador de doença de Alzheimer: vivências e sentimentos desvelados. *Cogitare Enferm.* 2007[cited 2015 Jan 15]; 12(2):143-9. Available from: <http://revistas.ufpr.br/cogitare/article/viewArticle/9821>
- Melo G. A experiência vivida de homens (conjugues) que cuidam de mulheres com demência. *Rev Bras Geriatr Gerontol.* 2009 [cited 2015 Jan 15]; 12(3):319-30. Available from: http://www.crde-unati.uerj.br/img_tse/v12n3/pdf/art_1.pdf
- Oliveira AMN, Nitschke OR, Silva MRS, Calcagno G, Busanello J. Repensando as relações intrafamiliares sob um olhar foucaultiano. *Rev Rene.* 2009 [cited 2015 Jan 15]; 10(3):152-8. Available from: <http://www.revistarene.ufc.br/10.3/html/18.htm>
- Larrañaga PI, Valderrama PMJ, Martín RU, Begiristain AJM, Bacigalupe H, Arregi GB. Mujeres y hombres ante el cuidado informal: diferencias en los significados y las estrategias. *Rev Fac Nac Salud Pública.* 2009[cited 2015 Jan 15]; 27(1):50-5. Available from: https://www.google.com.br/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKewi5p6qey6XNAhVBESAKHVjTDPYQFggeMAA&url=https%3A%2F%2Fdiagonalnet.unirioja.es%2Fdescarga%2Farticulo%2F3986200.pdf&usq=AFQjCNHXZ6uGWS8ohtO9UrqW4VWVAcBSIQ&sig2=JjrqEOzLBUWRFHL7YfDF_A&cad=rja
- Wall K, Aboini S, Cunha V. A vida familiar no masculino: negociando velhas e novas masculinidades. Comissão para a igualdade no trabalho e no emprego. Lisboa: Editorial do Ministério da Educação; 2010. 533 p.
- Luzardo AR, Waldman BF. Atenção ao familiar cuidador de idoso com doença de Alzheimer. *Acta Scient Health Sci.* 2004[cited 2015 Jan 15]; 26(1):135-45. Available from: http://www.scielo.br/scielo.php?script=sci_nlinks&ref=000092&pid=S0104-0707201200030000800009&lng=en
- Bellato R, Araújo LFS, Faria APS, Costa ALRC, Maruyama SAT. Itinerários terapêuticos de famílias e redes para o cuidado na condição crônica: alguns pressupostos. In: Pinheiro R, Martins PH, organizadores. Avaliação em saúde na perspectiva do usuário: abordagem multicêntrica. Rio de Janeiro: CEPESC/IMS-UERJ; 2009. p.187-94.