CONTRIBUTIONS OF A GROUP ABOUT THE ALZHEIMER’S DISEASE FOR FAMILY MEMBERS / CAREGIVERS, PROFESSORS AND STUDENTS FROM THE HEALTHCARE FIELD

CONTRIBUIÇÕES DE UM GRUPO ACERCA DO ALZHEIMER PARA FAMILIARES/CUIDADORES, DOCENTES E DISCENTES DA ÁREA DA SAÚDE

GRUPO SOBRE LO ALZHEIMER: CONTRIBUCIONES A FAMILIARES / CUIDADORES, PROFESORES Y ESTUDIANTES DE LA SALUD

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ABSTRACT

Objective: to identify the contribution of the group “Multiprofessional and Integrated Care for Caregivers of Alzheimer’s Disease Bearers” in the daily lives of family members/caregivers of Alzheimer’s patients, professors and students from the healthcare field. Method: it is a qualitative, exploratory and descriptive study, with six family members/caregivers, five professors and five students from the health-related courses, through a semi-structured and self-administered questionnaire. The data were analyzed according to the content analysis technique. The research project was approved by the Local Ethics Research Committee (Opinion no 039.2009.2). Results: we have identified two categories: (re) organization of the daily family life with basis on the certainties and uncertainties, and (re) constructing meaningful skills towards the professors and students, through the articulation between the scientific knowledge and the experiences of family members/caregivers. Conclusion: the family members/caregivers have expressed that the coexistence, relationships and interactions in the group eased the (re) organization process of the daily life. Descriptors: Alzheimer’s Disease; Family; Caregivers; Healthcare Professionals.

RESUMO

Objetivo: identificar a contribuição do grupo “Avaliação Multidisciplinar Integrada aos Cuidadores dos Portadores de Alzheimer” no cotidiano de familiares/cuidadores de pessoas com Alzheimer, docentes e discentes da área da saúde. Método: estudo qualitativo, do tipo exploratório-descritivo, realizado com seis familiares/cuidadores, cinco docentes e cinco discentes dos cursos da área da saúde, mediante um questionário semiestruturado e autoaplicável. Os dados foram analisados conforme a técnica de análise de conteúdo. O projeto de pesquisa obteve parecer favorável do Comitê de Ética e Pesquisa local (Parecer no 039.2009.2). Resultados: identificamos duas categorias: (re) organização do cotidiano familiar a partir das certezas e incertezas; e (re) construindo habilidades significativas aos docentes e discentes pela articulação do conhecimento científico e as vivências dos familiares/cuidadores. Conclusão: os familiares/cuidadores manifestaram que a convivência, as relações e interações no grupo facilitaram o processo de (re) organização do cotidiano. Descriptors: Doença de Alzheimer; Família; Cuidadores; Profissionais de Saúde.

RESUMEN

Objetivo: identificar la contribución del grupo “Atención Integrada Multidisciplinar para cuidadores de pacientes con Alzheimer” en el diario de la familia / cuidadores de pacientes de Alzheimer, profesores y estudiantes en el campo de la salud. Método: estudio cualitativo, exploratorio y descriptivo. La recolección de datos se realizó con seis familiares / cinco docentes, profesores y estudiantes de los cursos de la área de la salud, todos miembros del grupo, a través de cuestionario semiestructurado y autoadministrados. Los datos fueron analizados de acuerdo con la técnica de análisis de contenido. El proyecto de investigación fue aprobado por el Comité de Ética e Investigación Local (Informe N° 039.2009.2). Resultados: se identificaron dos categorías: (re) organización de la vida diaria de la familia de las certezas e incertidumbres, (re) construcción de conocimientos significativos para los profesores y estudiantes a través de la articulación de los conocimientos científicos y las experiencias de los familiares / cuidadores. Conclusión: la familia / cuidadores expresaron que la vida, las relaciones y las interacciones dentro del grupo facilitó el proceso de (re) organización de la vida diaria. Descriptores: Enfermedad de Alzheimer; Familiares, Cuidadores, Profesionales de la Salud.

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INTRODUCTION

Alzheimer's disease (AD) is characterized by a neurodegenerative dementia, whose incidence has increased to the extent as the life expectancy increases in the population, and might be considered an epidemic, due to affecting 10% of people over 65 years. It is estimated that there are currently around 25 million AD bearers across the world, 60% of these are located in developing countries. It is noteworthy that this disease has not yet a precise diagnosis. The AD generates a progressive decline of cognitive functions linked to perception, learning and psychomotor functioning, and might present severe manifestations. It also has four stages, which might be mild, moderate and severe. At the initial stages, the first clinical manifestations are deficits in memory with regard to events, language difficulties, loss of recognition towards the family members, as well as the loss of sphincter control, which leads to the need for daily care.

Accordingly, personality changes range from apathy and social isolation to disinhibition and irritability. As to the later stages, it should be cited the substantial impairment of memory with regard to events, language difficulties, loss of recognition towards the family members, as well as the various events and movements that assure the everyday vitality.

The illness process, accompanied by important and gradual vital changes, starts to generate major disorders for the family members/caregivers, who, often, begin to take care of the AD bearer. The disorders experienced by family members/caregivers might influence with the work, professional life, family life, social life, as well as with the various events and movements that assure the everyday vitality.

Hence, the pathology affects not only the bearer, but also the family members/caregivers, who end up assuming, gradually, an important role in the care process. According to German statistics, about a million people with dementia are treated by their family members.

It should be highlighted that, in the Brazilian context, most families take care of the AD carrier in its own household, usually, devoid of specific training, as well as of human, material, structural and social resources, by generating, therefore, physical and emotional burden, as well as feelings of uncertainty and family disorder before the pathology. This reality requires that the family members/caregivers (re) organize their healthcare strategies in the face of this new reality.

These data reinforce that the AD requires attention from the healthcare professionals and government agencies in a general way, because, under these conditions, being relative/caregiver of a patient with AD encourages the development of human-interactive skills, which are able to understand the AD bearer as a complex and multidimensional human being. Moreover, it implies the development of relational processes differentiated and adapted to live/coexist with this disease, which causes, occasionally, feelings of disorder, fear, insecurity and gradual losses.

It is noteworthy to mention the activities carried out in aid groups directed to family members/caregivers of patients with AD. From this perspective, it should be cited the group that is held at Franciscan University Center (UNIFRA), which is characterized as an extension project with sights to address this need. The project is called: Multiprofessional and Integrated Care for Caregivers of Alzheimer’s Disease Bearers (AMICA), whose focus is precisely assisting relatives/caregivers of AD bearers in the understanding process of this disease, as well as improving the life quality of everyone (patients and family members/caregivers).

Likewise, it should be emphasized the relevance of this experience for the professors and students as future healthcare professionals, who should be prepared to work in several sectors and activities that address the health of individuals/families and community. Thus, it emerges the need for further researches, in order to help with the discussions and the development of a proper body of knowledge about family healthcare, as well as enabling possible new interactive and managerial tools, capable to assist in the systematic care and in the understanding of the social support network.

Based on the above mentioned, we have formulated the following question: What are the contributions of the AMICA group for the family members/caregivers, professors and students from the healthcare field? In an attempt to answer to the explained question and, with the expectation of enabling interactive and committed gazes with human being inserted in its actual context, we aimed at identifying the contribution of the group “Multiprofessional and Integrated Care for Caregivers of Alzheimer’s Disease Bearers” in the daily lives of family members/caregivers of Alzheimer’s patients, professors and students from the healthcare field.
It is a qualitative, exploratory and descriptive study. This type of study aims at providing an overview of a particular situation and might be considered as the first step in a broader research, since, as a consequence of their results, strategic action plans might be organized and, consequently, the research might contribute to the changing of the surveyed reality.\textsuperscript{10}

The study was performed at the UNIFRA, with family members/caregivers of AD bearers, professors and students from the healthcare area, as well as AMICA extension project participants. Ten family members/caregivers have regularly participated in this project, however, there is no specific number because of the non-stable staying of many relatives, i.e., some people attend the meetings, withdrawal from the group during a certain time, due to various reasons, and, subsequently, come back to it.

It should be emphasized that this project has the participation of at least one professor and one teaching assistant from each of the seven courses that comprise the health sciences field at the UNIFRA, namely: Biomedicine, Nursing, Pharmacy, Physiotherapy, Nutrition, Dentistry and Occupational Therapy. The project at stake still has the support of professors and students from the Psychology Course and one member from the Brazilian Association for Alzheimer's (ABRAZ).

As inclusion criteria, we have established: being relative/caregiver of elderly with AD, professor or student from the above mentioned courses and being participating in the AMICA meetings. As to the exclusion criteria, they were: subjects that only participated in some meetings and withdrew from the group for another period, people in attestation time, vacation or that were not present on the day of the data collection.

The total number of participants was six family members/caregivers, five professors and five students. The data were collected between the months of April and May 2010, through a semi-structured and self-administered questionnaire. The questionnaires were answered by family members/caregivers, professors and students throughout the group meetings, at times previously scheduled.

The results were analyzed and categorized according to the Bardin's\textsuperscript{11} content analysis method, from a pre-analysis (organizing the collected material and systematizing the ideas obtained throughout the interview. Next, we performed the categorization of the recording units, which has resulted in two categories: (re) organization of the daily family life with basis on the certainties and uncertainties, and (re) constructing meaningful skills towards the professors and students, through the articulation between the scientific knowledge and the experiences of family members/caregivers.

We have considered the ethical and legal issues that involve researches with human beings, in accordance with the Resolution 196/96 of the Brazilian Ministry of Health.\textsuperscript{12} Thus, we have previously distributed the Free and Informed Consent Form to the research participants, being that it was confectioned in two copies: one held by the participant and the other held by the researcher. We kept the participants’ anonymity and they were identified by the letters “FC”, “P”, “E”, referring to the terms “family member/caregiver”, “professional” and “student”, respectively, followed by one numeric digit (FC1, FC2…FC6; P1, P2…P5; E1, E2,…E5).

The research has obtained the permission of the extension project’s coordinator and approval by the Ethics Research Committee from the Franciscan University Center, under the CAAE Nº 039.2009.2.

\section*{RESULTS}

From the analysis, two categories have emerged: (re) organization of the daily family life with basis on the certainties and uncertainties, and (re) constructing meaningful skills towards the professors and students, through the articulation between the scientific knowledge and the experiences of family members/caregivers.

\begin{itemize}
\item (Re) organization of the daily family life with basis on the certainties and uncertainties
\end{itemize}

The contribution from the AMICA group in the daily lives of family members/caregivers of AD bearers is experienced and lived in a peculiar and complex way by each component thereof. Nonetheless, there are common features, such as the disorder that might be both individually or collectively manifested, which are observed upon after the relative/caregiver reaches the group; there is often a confrontation with the unknown, lack of preparation and emotional instability from this family member/caregiver, as well as the feeling of powerlessness before the pathology.
The illness process of the Alzheimer’s patient, even initially monitored by an intense process of disorder and conflicts, also assumes new meanings, which are enabled by a (re) organization of the daily life. Such a (re) organization is based on the ability to adapt to a new existential context, which is supported and enhanced by the group activities. The speeches, below, partially reflect on the certainties and uncertainties of “attending” and “being” part of a contradictory process, but at the same time liable to face a (re) organization of the daily family life empowered by group relationships and interactions, even providing a better life quality.

Formerly, it was all very uncertain. Through the help of professors and students, I feel safer and oriented. The group helps me in daily routine, in the life quality. (FC3)

[…] The students have helped me to organize myself and improve my life quality through clear guidelines that are easy to assimilate. (FC1)

In the group, I live together with people in the same situation as me and I learn to organize myself for the future life with the bearer, by taking care of my health and life quality too. (FC5)

[…] The students and teachers have helped me to understand how the patient behaves and how to care and understand him, because he acts like that, because it’s all very uncertain. (FC2)

The feelings of certainty and uncertainty gradually become part of the daily family life, by generating new ways of thinking, moving, communicating and living and coexisting in society. The answers have emphasized the positive participation of professors and students in the (re) organizational process, by facilitating the adaptive processes of individuals.

The answers also show the appreciation of “being together”, caring, dialoguing, i.e., the simple fact of being part of a group of people who experience similar realities. The group is formed by stories marked by the daily news, the acceptance of different situations or people, the apparent failure and the need to individually or together (re) organize its own reality to keep a new organization which ends up installing itself.

In this perspective, it should be mentioned the different wires that weave themselves and need to be woven into the daily life of a family member/caregiver of a patient with AD, which guarantee the vitalism and the dynamism of an integral and integrator care. This care type keeps the energy before the losses, security before the uncertainties/instabilities and assures the feeling of unity before the life’s contradictions.

♦ (Re) constructing meaningful skills towards the professors and students, through the articulation between the scientific knowledge and the experiences of family members/caregivers

It should be observed that both the professors and the students recognize the group as an important ally in the teaching process, since the exchanges of experiences between students, professors and relatives/caregivers provide a therapeutic and didactic environment. The coexistence and the reports of caregivers might result in new skills, often different from those constructed in the university. This environment of (re) construction of knowledge through experience offers personal and professional growth to professors and students. Accordingly, the following lines might be analyzed:

[…] The students have the opportunity to talk to people who go through a situation of Alzheimer’s disease and, together, they can build and consolidate cognitive skills. (P1)

[…] I believe that they can transmit their knowledge about the disease and learn from the caregivers’ experiences. (P2)

 […] The students have the opportunity to experience real situations and act on their context, while in that they guide, discuss with other students, professionals and relatives/caregivers. (P3)

It is a daily reconstruction of knowledge, which is very important for my career, experiences and to understand more about the disease […]. (E1)

[…] The group contributes to a better training, by combining theory with practice […]. (E4)

 […] In the group, I get more knowledge about the disease and the coexistence with people […] (E5)

Thinking about the relative/caregiver, bearer of a chronic and degenerative disease, which is presented in a condition of vulnerability to a group of professors and students from the healthcare field, requires levels of understanding, welcoming, qualified listening and intersubjective bonds of trust, sustained in the light of references that conceive the multiple interrelationships and interconnections that involve the health/disease process. Furthermore, it demands that the professors and students rethink about the “new”, “broaden their horizons", be open to new experiences, new knowledge and new ways of learning and
teaching to (re) construct.

It should be realized, through the speeches, the importance of this experience for the students from the health courses, since they report to learn a lot from the knowledge of family members/caregivers. Hence, it should be perceived that the articulation of different skills (scientific and common sense) provides a singular gaze in the training process of future healthcare professionals.

It is important that the students, who are AMICA group members, dialogue and (re) design new skills along with the family members/caregivers who experience the daily life of the bearer of AD, in order to understand the uniqueness of each individual (relative/caregiver) and the family institution as a unit.

**DISCUSSION**

To understand the complexity of the family member/caregiver of an Alzheimer's bearer, it is necessary to extend the focus to a boundary beyond the disease and to enter into new paradigms, in order to seize the meaning of the illness process in a multidimensional way.

One previously performed study showed that the confirmation of the Alzheimer's diagnosis, generates a state of shock in many families, followed by feelings of doubt, uncertainty and fears. The relatives are faced with a new and unexpected role - being a caregiver. They need to make decisions about the future of the AD bearer, deal with all sorts of contradictions and face a new daily routine to which they find no answer and support, in addition to, often, suffer emotional pressure, lose their close relationships and see their health/care of family members/caregivers and for the relatives/family members/caregivers who experience the daily life of the bearer of AD, in order to understand the uniqueness of each individual (relative/caregiver) and the family institution as a unit.

In the interviewees' speeches, it has become clear that the (re) organization of the daily family life is enabled by the negotiations of the care actions. This new way of being and coexist with the illness process is expressed in the reports, and in the union with the other group members. These actions are enhanced by continuous and integral care, both for the family members/caregivers and for the healthcare professionals. Moreover, they promote dialogue between the whole and the part; between the unique and the multiple, to which the complex thought leads us back.6

It is noteworthy to highlight that by means of the guidelines held in the group, a new order of complexity emerges, because the group members are open for negotiation. The existence and maintenance of diversities are inseparable from the interrelationships of those involved (students, family members/caregivers and professors) with the environment through which they experience everyday situations. In this environment, the caregiver/family member becomes, concomitantly, autonomous and dependent.8

Thus, it becomes necessary that professors and students consider the subjects, in this case, family members/caregivers of AD bearers, as protagonists and authors of their stories; in other words, someone who is exposed to all sorts of conflicts, uncertainties, instabilities and chaos, but able to continuously (re) organize itself, from the multiple interactions, as well as from the family and social relationships.13

The student, after reaching a level of complex reasoning, will have subsidies to understand the complexity, which in turn is antagonistic and complementary; contradictory and ambivalent; singular and multiple; sustained by an interdependent, interactive and interretroactive weaving.14 Therefore, professors and students when experiencing/sharing/producing knowledge together with the group, enable creative and (re) organizational possibilities, i.e., expand and start to value the adaptive family interactions of living and coexisting with the health/disease process.

In this respect, the family members/caregivers, professors and students extend new networks of friendship through the supportive group.14 This interactive process finds adherence in the definition of what complexity is, which is understood as a woven fabric formed by different wires that have turned into a network. That is to say, where all the wires intersect and intertwine themselves to compose the unit of complexity.13

It is important that future professionals from the healthcare field, during their training process, coexist with the reality reported by those who daily coexist with this disorder, by considering the tensions, conflicts and instabilities that permeate the daily lives of relatives/caregivers of patients with AD. It is necessary to consider, above all, that they are able to (re) organize their everyday lives, by adapting and adjusting themselves to the imaginable and unimaginable new requirements, mainly if they have a network of social/professional support.

In this perspective, due to its managerial and interrelational profile, it should be evidenced the AMICA group as a strong ally in the teaching process of future healthcare professionals, and also for the relatives/
Conclusions about the Alzheimer’s…

The results showed that being relative/caregiver of an Alzheimer’s patient is a singular and adaptive process, which requires sensitivity, solidarity, persistence and boldness to face any kind of adversity. It is a process that involves gradual losses and the possibility of (re) organization by the expansion of interactions, relationships and associations.

Much more than bringing answers or unquestionable truths, the study aimed at instigating new possibilities of dialoguing with the already constructed knowledge about the certainties and uncertainties of being relative/caregiver of an Alzheimer’s patient and analyzing the contribution of this extension project for those family members/caregivers, professors and students.

The understanding of the (re) organizational process of family members/caregivers was constituted as whole, not as a linear process in which only the disease is the focus; but, as a circular, dynamic and gradual process, which involves the conflict of instability before the AD, as well as before the ability to (re) organization of the daily family life and the possibility of extending the interactions in the search for the “new”, the “different” and the “random”.

The results allow us to conclude, in short, that each family member/caregiver is a single, complex and multidimensional being. But that the uncertainty permeates the lives of everyone, even if it is experienced in a different way. The family members/caregivers have expressed that the coexistence, relationships and interactions with professors, students and other family members/caregivers, eased the (re) organization process of the daily life. Moreover, they helped to construct a knowledge that enables the coexistence with the different, the unexpected and the uncertainty of tomorrow.

The professors and students reported that the extension activities conducted in the group encourage the adoption of a differentiated gaze, since they have extended the focus, previously given only to the disease, to a contextualized healthcare procedure.

In this study, scientific skills and common sense were joined in search for coping with certainties and uncertainties, which has benefited both the family members/caregivers and the professors and students. It should be evidenced that the healthcare assistance needs to welcome the life and the constant surprises that it presents us and realize the “different” and the “random” as constant sources of growth, renewal and (re) organization.

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English/Portuguese

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