

## QUALITY OF LIFE OF FAMILY MEMBERS/CAREGIVERS OF ELDERLY PEOPLE BEARING ALZHEIMER'S DISEASE: SUPPORT GROUP CONTRIBUTIONS

Qualidade de vida de familiares/cuidadores de pessoas idosas com Alzheimer: contribuição do grupo de apoio

Calidad de vida de familiares/cuidadores de personas idosas con Alzheimer: contribución del grupo de apoyo

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### ABSTRACT

**Objective:** The study's main purpose has been to analyze the QOL of family members/caregivers of elderly people bearing Alzheimer's disease, as well as to assess during this process the influence of the group named Integrated Multidisciplinary Assistance to Caregivers of people bearing Alzheimer's disease (IMACA).

**Methods:** It is a descriptive-exploratory study with a qualitative approach that was performed with six family members/caregivers, who were participants in the aforementioned group. Data collection took place from April to May 2016, through data sharing between the focus group, semi-structured questionnaire and the assessment of the 36-Item Short Form Health Survey questionnaire (SF-36) for quality of life.

**Results:** The independent data were subjected to content analysis resulting in two categories, as follows: IMACA group: sharing knowledge and experiences in favor of the quality of life; IMACA group: (re)thinking about everyday life, helping with the quality of life. By analyzing the SF-36 evaluation scale, the found objective data pointed out the following factors as the most impaired ones: Limitations due to physical, emotional and vital aspects.

**Conclusions:** It was possible to observe that the Integrated Multidisciplinary Assistance to Caregivers of people bearing Alzheimer's disease has shown significant relevance and influence on the participating family members'/caregivers' quality of life.

**Descriptors:** Alzheimer's disease, elderly person, caregivers, quality of life.

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## RESUMO

**Objetivo:** Analisar a qualidade de vida de familiares/cuidadores de pessoas idosas com doença de Alzheimer e a influência do grupo Assistência Multidisciplinar aos cuidadores de pessoas com a doença de Alzheimer neste processo. **Método:** Estudo qualitativo, exploratório-descritivo, realizado com seis familiares/cuidadores, participantes do grupo. Os dados foram coletados, entre os meses de abril e maio de 2016, através da triangulação das técnicas de grupo focal, questionário semiestruturado e pela avaliação do questionário de qualidade de vida (SF-36). **Resultados:** Os dados subjetivos foram submetidos a análise de conteúdo resultando em duas categorias: Grupo AMICA: compartilhamento de saberes e vivências em prol da qualidade de vida; Grupo AMICA: (re)pensar no cotidiano, auxiliar na qualidade de vida. Os dados objetivos, encontrados por meio da análise da escala de avaliação SF-36, foram apresentados em duas tabelas e apontaram como fatores mais prejudicados: Limitações por aspectos físicos, emocionais e vitalidade. **Conclusões:** Foi possível observar que o grupo Assistência Multidisciplinar aos cuidadores de pessoas com a doença de Alzheimer tem significativa relevância e influência sobre a qualidade de vida dos familiares/cuidadores participantes.

**Descritores:** Idoso, Cuidadores, Doença de Alzheimer, Qualidade de vida.

## RESUMÉN

**Objetivo:** Analizar la calidad de vida de familiares / cuidadores de personas mayores con enfermedad de Alzheimer y la influencia del grupo Asistencia Multidisciplinar a los cuidadores de personas con la enfermedad de Alzheimer en este proceso. **Método:** Estudio cualitativo, exploratorio-descriptivo, realizado con seis familiares/cuidadores, participantes del grupo. Los datos fueron recolectados, entre los meses de abril y mayo de 2016, a través de la triangulación de las técnicas de grupo focal, cuestionario semiestruturado y por la evaluación del cuestionario de calidad de vida (SF-36). **Resultados:** Los datos subjetivos fueron sometidos a análisis de contenido resultando en dos categorías: Grupo AMICA: intercambio de saberes y vivencias en pro de la calidad de vida; Grupo AMICA: (re) pensar en lo cotidiano, auxiliar en la calidad de vida. Los datos objetivos, encontrados a través del análisis de la escala de evaluación SF-36, fueron presentados en dos tablas, y señalaron como factores más perjudicados: Limitaciones por aspectos físicos, emocionales y vitalidad. **Conclusiones:** Fue posible observar que el grupo Asistencia Multidisciplinar a los cuidadores de personas con la enfermedad de Alzheimer tiene significativa relevancia e influencia sobre la calidad de vida de los familiares/ cuidadores participantes.

**Descriptorios:** Anciano, Cuidadores, Enfermedad de Alzheimer, Calidad de vida.

## INTRODUCTION

Nowadays, Alzheimer's Disease (AD) represents the most common form of dementia in the elderly. In 2011, estimates indicated 24 million people bearing AD worldwide and by 2030 it is estimated that this number will reach 72 million cases.<sup>1</sup> The first study that described AD was performed by the German psychiatrist and neuropathologist Alois Alzheimer's for over a century. This denomination has been modified over the years, as new research is carried out to assist science in understanding the relationship of the disease and its effects.<sup>1</sup>

Currently, AD is classified as a type of neurodegenerative dementia, which shows significant impairments in cognitive skills, especially in memory, behavior and language. Thus,

it causes losses in the autonomy and independence of those who develop it, being essential the help of caregivers in this process.<sup>2</sup> Caregivers are those who perform services in the home environment, alerting to formal care and informal care. Stresses that the formal caregiver is one who performs a paid function, while the informal caregiver has no remuneration, and may or may not be a member of the family.<sup>3</sup>

It is understood that the process of taking care of a person bearing AD can be an experience capable of generating complications and suffering for people and families, as it is not an easy task to perform since the manifestations of the disease are often devastating. Therefore, the importance of the participation of family members/caregivers in support groups is underlined, since they aim to soften the feelings arising from this process, favor the adaptation of daily life, as well as enabling greater knowledge and understanding of possible changes and complications daily.<sup>4</sup>

Considering this framework, the following support group is presented: Integrated Multidisciplinary Assistance to Caregivers of people bearing Alzheimer's disease (IMACA). This group was delineated in 2006 and began its activities with family members/caregivers in 2007, with the purpose of providing free assistance to caregivers/family members of people bearing AD, aiming to conduct information about the manifestations of illness and collectively collect the demands in a multidisciplinary group composed of professors and students from the Health and Humanities courses at a university, namely: Nursing, Pharmacy, Physiotherapy, Nutrition, Dentistry, Psychology and Occupational Therapy.<sup>5</sup>

Group meetings take place weekly for teachers and students, and fortnightly for family members/caregivers.<sup>5</sup> In 2016 this group completed 10 years of existence, the result of the collective work developed by this group of teachers and students, together with family members/caregivers. For this reason, it is maintained that the IMACA group has strengthened itself on the teaching, research and extension approaches and has managed to contribute to the process of teaching, care and better Quality of Life (QOL) to family members/caregivers.

The definition of QOL that is best known and disseminated worldwide is that of the World Health Organization (WHO), which describes it as the perception of the individual in his position in life, in the context of the culture and value systems in which he lives and concerning to your goals, expectations, standards and concerns, such as physical, psychological status, levels of independence, social relationship, environmental characteristics and spiritual pattern.<sup>6</sup>

Bearing in mind the aforesaid, it is necessary to assess the contributions of this group, based on the experiences of family members/caregivers, to rethink their activities and strengthen them with their participants. Considering this background, it is relevant to investigate the IMACA group and its potential in helping the QOL of family members/caregivers of elderly people bearing AD, justifying the need and relevance of this research.

Given the abovementioned, it is questioned: How is the quality of life of family members/caregivers of elderly people bearing AD, concerning the terms of pain, physical aspects, functional capacity, general health, vitality, social, emotional aspects and mental health? What is the contribution of the IMACA support group to this process?

This research meant to: analyze the QOL of family members/caregivers of elderly people bearing AD, as well as to assess during this process the influence of the group named Integrated Multidisciplinary Assistance to Caregivers of people bearing Alzheimer's disease.

## METHODOLOGY

It is a descriptive-exploratory study with a qualitative approach that was performed with six family members/caregivers, who were participants in the IMACA group. This project has been developed since 2007 in a higher education institution from the *Rio Grande do Sul* State, Brazil.

It was considered as inclusion criteria for the participants: Being a family member/caregiver of an elderly person bearing AD, having already participated or being participating in the project and living in the city where the research was done. Therefore, family members/caregivers who had already participated in the project, but no longer live in the city, were excluded from this research. The exclusion criterion was due to the difficulty of gathering the participants to collect the data. Six family members/caregivers met the inclusion criteria, then forming the corpus of this study.

The data were collected using the Focus Group (FG) technique, which is characterized as a group that meets to discuss a specific theme, common to the participants. The choice of this data collection technique was due to its possibility of promoting horizontal group interaction between the participants, which allows to explore and expand the understanding around the phenomenon investigated.<sup>7</sup> In total, four meetings were held with the participants, out of these, three were FG, which were carried out between April and May 2016, with a maximum duration of 120 minutes each.

The first meeting was intended for the presentation of researchers, research participants, study objectives, signing the Informed Consent Form (ICF), filling in a semi-structured questionnaire to characterize the profile of the participants and application of the Brazilian Version of the 36-Item Short Form Health Survey questionnaire (SF-36) for quality of life, which assesses QOL in eight main components, namely: pain, physical aspects, functional capacity, general health status, vitality, social, emotional and mental health, and is composed by 36 items represented in a score from 0 to 100, evaluating the positive and negative aspects, being a self-administered questionnaire.<sup>3-8</sup>

In the second meeting, the first FG was established, where we sought to understand what it means to care for an elderly person bearing AD. To this end, the participants were invited to express/record on an A4 paper sheet, through writing, drawing, or any other form that they wished the first memory that came to mind when reflecting on AD,

and later, on the meaning of caring for an elderly person bearing AD. Consequently, each participant was invited to reflect with the others on the issues raised, which enabled collective discussions.

In the third meeting and the second FG, some reflections on the previous group were resumed and the participants were invited, as in the previous one, to register possible changes in their daily lives and on the consequences that these changes had on their lives. Subsequently, a collective discussion was held based on each reflection. In the fourth meeting, and the last FG, important points from the previous group were resumed, following the discussion about the strategies used to live and/or overcome the difficulties experienced and the importance of IMACA in this process, as well as its contribution to improvement of QOL. So, the participants presented to the large group their perception regarding what had been proposed.

The meetings were recorded on an MP3 device, after being fully transcribed and analyzed through content analysis, which consists of discovering the nuclei of meaning that make up a communication whose presence or frequency add meaning to the object of study. In this way, the operationalization of the analysis process followed the three steps of the method, in the first, an exhaustive reading of the data was sought, followed by the organization of the material and the formulation of hypotheses. Afterwards, the material was explored, coding the raw data. In the last phase, the data were interpreted and delimited into categories, according to the assigned meanings.<sup>9</sup>

The ethical and legal precepts that involve research with human beings were considered, according to the Resolution No. 466/12.<sup>10</sup> The participants signed the ICF, in two copies, one with the participant and the other with the researchers. This study was approved by the local Research Ethics Committee, according to the Legal Opinion No. 1.432.461. The anonymity of the participants was maintained, identifying them by FC (family member/caregiver), followed by a numeric number (FC-1, FC-2... FC-6).

## RESULTS AND DISCUSSION

Considering the six family members/caregivers participating, four were female and two were male, all within the age group from 27 to 66 years old. Regarding the degree of kinship, four were children, one was a grandchild, and one was a formal caregiver. Four of the six participants were full-time caregivers and two took turns caring for other people.

**Table 1** addresses the results from the 36-Item Short Form Health Survey questionnaire (SF-36) for quality of life applied to each participant, and **Table 2** refers to the average found among the participants for each of the eight evaluation domains. Therefore, the analysis and interpretation of data divided into two categories is described: IMACA Group: sharing knowledge and experiences in favor of the quality of life; IMACA Group: (re)thinking about everyday life, helping with the quality of life.

**Table 1** - Results of the generic quality of life assessment questionnaire (SF-36) by each participant.

Family member/caregiver	Domains							
	Functional capacity	Limitations due to physical aspects	Pain	General health status	Vitality	Social aspects	Limitations due to emotional aspects	Mental health
1	85	25	62	77	65	62.5	0	68
2	95	0	74	72	70	62.5	33.33	88
3	50	25	41	52	35	50	100	64
4	95	0	62	62	40	50	0	56
5	85	100	100	52	85	100	100	84
6	95	100	84	72	80	87.5	100	92

Range: 0 (zero) = worst/100 (one hundred) = best.  
Source: investigation data, 2016.

**Table 2** - Result of the average found among the participants for each of the eight evaluation domains.

Evaluated aspects	Average
Functional capacity	84.1666667
Limitations due to physical aspects	41.6666667
Pain	70.5
General health status	64.5
Vitality	62.5
Social aspects	68.75
Limitations due to emotional aspects	55.555
Mental health	75.3333333

Source: investigation data, 2016.

The results, referring to the SF-36 scale (**Table 1**), demonstrate the relative average among the participants related to each domain explicit in the evaluation. Therefore, it is clear that the domain that appears most prominently is the limitations due to physical aspects, and then limitations due to emotional aspects, and the vitality domain follows.

A research on the QOL of caregivers of elderly people bearing AD, presents similar results concerning those obtained in this study in relation to SF-36. The aforementioned study also showed the most affected domains, the physical, emotional, mental health, physical pain and social aspects, alerting the change in the quality of life of these caregivers, which might also influence the provided care.<sup>11</sup>

Among the aspects most affected in the evaluation of this study, it is noteworthy the presence of value 0 (zero) referred to as the worst, which demonstrates pronounced damage to the QOL of three of the six research participants, being present in the domains of limitations due to physical and emotional aspects. Thus, it is clear that the QOL of the caregivers in this research presents significant losses in the evaluated areas. Although some of the participants have demonstrated good QOL conditions related to some aspects of the assessment, as shown in **Table 1**, where the value 100 (one hundred) appears, referred to as the best; it is believed that the majority of participants undergo changes and perceive changes in QOL, whether due to the fact of

caring for an elderly person bearing AD or even the personal condition of each individual.

A study proposes that the caregiver's QOL is closely related to that of the person who is providing care, since the caregiver experiences the factors and conditions that lead to changes in QOL together and explains that these can be experienced differently for each one.<sup>12</sup>

### IMACA group: sharing knowledge and experiences in favor of the quality of life

Herein, it can be observed that the IMACA group does show influence, then contributing to the improvement of the QOL of family members/caregivers of elderly people bearing AD, over several spheres that permeate:

*[...] I am not a person of speaking much in public, and I have been speaking [...] it is therapy. (FC - 3)*

*Even my husband is sometimes worried, because we went home late, but it was so good that we didn't even want to leave, we were so at ease that we didn't even see time go by. (FC-1)*

*[...] The IMACA is favoring us with broad and satisfactory knowledge, you end up seeing a lot. (FC - 2)*

*[...] I have grown a lot, I arrived very anxious in the IMACA group, then you start to see what it is like, you start to see the stories. Then you breathe easier, my God. (FC - 4).*

*The IMACA brings knowledge, clarification, it supports us. (FC - 3)*

According to the reports presented, it can be seen that the IMACA group has contributed positively in the lives of the participants, providing expressive moments, which according to their speeches also become a "Therapy".

The caregiver must have a solid support network, to assist him/her in facing the challenges of the disease. In addition to social and family support, support groups function as a facilitating strategy in the process of coping with the disease, where groups act as a group of people who have a common goal and, thus, work from the perspective of teaching and learning.<sup>13</sup>

It is observed in the findings of a study also carried out in the IMACA group in 2011, that it had already contributed significantly to the QOL of family members/caregivers, who recognize the group as an enhancer of QOL, claiming to receive the necessary information to respect of the disease in a clear and objective way, emphasizing that it has been reaching its goal as a welcoming group.<sup>14</sup>

A study carried out in the *Santa Catarina* State, with 19 family members/caregivers participating in the “Mutual Support Group for families caring for elderly people bearing Alzheimer’s Disease and/or similar diseases”, highlighted that the group, in addition to providing significant learning about the disease, was considered a therapeutic space, for the possibility of free expression of emotions and feelings and for the certainty of being understood and not judged, based on the relationship of trust and the construction of bonds between group members.<sup>15</sup>

Furthermore, in groups, the union of knowledge between students, professors, community and family members/caregivers about the care process is consolidated as a three-way communication, which favors the growth of all, by sharing experiences. These characteristics and contributions demonstrate the transformative potential of support groups.<sup>14</sup>

Hence, living close and sharing experiences with people who face the same dilemmas, add therapeutic value to the group, which in addition to taking care, assisting and instructing, contributes positively to the improvement of the participants’ expectations and QOL.

### **IMACA group: (re)thinking about everyday life, helping with the quality of life**

This category demonstrates that the IMACA group has helped family members/caregivers of elderly people bearing AD to (re)signify daily life, considering the way they perceive the disease and its influence on the different realities.

*[...] the moment I started to clear up my doubts, I started to know the disease, I started to see reports, you get a little calmer, sometimes you see much worse things. (FC - 1)*

*[...] to think that we are not alone. It’s not just me, it’s not just you, there are many more people than we think. (FC - 6)*

*It is really when we talk that we see that we are not alone! I think her situation is more serious than mine, so it comforts me; I see that I cannot complain so much. (FC - 3)*

The participants stated that in the IMACA group they can strengthen themselves through observation and exchange of experiences experienced in each other’s daily lives, as well as knowing the different realities of the care routine, which also points to the importance of mutual support in this process.

A study carried out in the *Rio de Janeiro* State, with nine informal caregivers, participants of the Brazilian Association of Alzheimer’s Disease and other similar diseases (*ABRAZ-RJ*), showed that the support group is a social support, as it is based on caregiver-care relationships whose result it consists in promoting to the recipient the ability to face environmental stress in times of vulnerability. Moreover, the study pointed out that the groups are important, complex and essential spaces for intervention, awareness and awareness for caregivers, being a space for the promotion of educational and informational actions.<sup>16</sup>

The caregiver often experiences several emotions that result in/from the overload, which can be defined by a set of different problems, physical, psychological and emotional. This overload may be associated with a decrease in QOL, which, in turn, might impact both the daily life of the family member/caregiver and the person bearing AD.<sup>17</sup>

Research shows that the caregiver’s daily life is crossed by different manifestations of the disease and warns that the research participants presented several situations that influenced their QOL as an overload in the physical and emotional aspects. It also highlights that according to the demand and need for assistance during the progress of the disease, these implications may increase, thus considering the support and division of tasks during the care provision.<sup>18</sup>

In a case study carried out in the municipality of *Alfenas, Minas Gerais* State, in 2006, the authors observed daily changes experienced by the caregiver, referred to as stress, frustrations, irritability, among others related to physical and emotional aspects. Added to this, they also evidenced a lack of public resources in coping and helping the elderly with the disease, family and caregiver.<sup>19</sup>

It is known that taking care of an elderly person bearing AD can bring numerous changes to the family member’s/caregiver’s daily life, they often feel deprived of social opportunities due to the care with others. A study carried out with caregivers registered with the Brazilian Association of Alzheimer’s Disease from the *Amazonas* State (*ABRAZ-AM*), presented ambiguity of feelings experienced by caregivers in certain situations experienced during the daily care. Such feelings are sometimes negative, such as: anger, fear and impatience, but they can soon be transformed into satisfaction, happiness and retribution.<sup>20</sup>

In this sense, the importance of support groups and the preparation of health teams and the public sector concerning coping with AD are justified, as well as the consequences that this can generate in the family environment.

## FINAL CONSIDERATIONS

This study is considered relevant since it was possible to scrutinize the QOL of family members/caregivers of elderly people bearing AD, as well as the influence of the IMACA support group as an enhancer of the QOL of family members/caregivers of elderly people bearing AD.

It was evidenced that the QOL of the participating family members/caregivers was altered in some aspects, mainly the physical and emotional ones, as can be seen in the evaluation. So, it is clear the need for more projects that promote a careful look not only at elderly people bearing AD, but also at family members/caregivers to insert them into health care programs. It was also possible to observe that the support group IMACA has significant relevance and influence on the QOL of the participants and also on the daily care, since the family members/caregivers reported feeling united, supported and informed at each meeting. They reported some feelings such as security, comfort and courage, arising from participation in the group.

Furthermore, this study contributes to increase the visibility of the IMACA support group to society, since it seeks to support and welcome family members/caregivers and the community in general who need a space for discussions about the theme AD. Hence, IMACA is perceived as a knowledge generating and welcoming group among professors, students, family members/caregivers and people bearing AD.

Nevertheless, understanding the complexity that involves the issue of being a family member/caregiver of people bearing AD, the need and appeal for further studies to be carried out in different situations and for new discussions on the theme to be proposed are here underlined, with the objective of collaborating with science, seeking to assist in regards to the knowledge of academic society and society as a whole.

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