UM OLHAR SOBRE O CENTRO APOIO ALZHEIMER VISEU
A LOOK AT THE ALZHEIMER SUPPORT CENTER VISEU
UNA MIRADA AL CENTRO APOYO ALZHEIMER VISEU

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RESUMO

Introdução: Em todo o mundo é diagnosticado um novo caso de demência a cada 3 segundos, perfazendo cerca de 9,9 milhões de novos casos em 2015 (Prince, et al., 2015). A demência é uma síndrome orgânica adquirida, geralmente crónica, caracterizada pela perda progressiva de capacidades cognitivas e funcionais devido à degeneração gradual de diversas zonas cerebrais. Compreende a vida pessoal, familiar, profissional e social do indivíduo, afetando severamente a sua autonomia e independência. (Nunes, 2014).

Objetivos: Divulgar o trabalho desenvolvido pelo Centro de Apoio ao Alzheimer Viseu (CAAV); Caracterizar o perfil e as necessidades dos cuidadores que o procuram os serviços do CAAV.

Métodos: Estudo exploratório desenvolvido tendo por base os dados de uma amostra de 166 cuidadores de pessoas com demência que recorreram ao do CAAV entre 2014 e 2017. São maioritariamente cuidadores informais (137), que em algum momento prestaram apoio a tempo inteiro ao doente, sem qualquer ajuda externa, prevalecendo a procura por parte do sexo feminino, com 128 pedidos de apoio, contra 38 cuidadores do sexo masculino.

Resultados: Os serviços mais procurados no CAAV são: apoio técnico, social/médico/jurídico, bem como o apoio psicológico e o grupo de suporte. A maior parte das pessoas que solicitam estes serviços são mulheres, nomeadamente filhas/os dos pacientes (49%), seguindo-se os conjugues (27%), sendo a demência de Alzheimer a patologia mais frequentemente referenciada.

Conclusões: Os resultados mostram que o CAAV se assume uma entidade com impacto individual e social, pelo que tendo por base o modelo de Atenção Centrado na Pessoa, o CAAV pretende a curto e médio prazo criar novos serviços de suporte às necessidades e exigências das pessoas com demência e seus cuidadores.

Palavras-chaves: Alzheimer; Demência; Cuidadores; Intervenção.

ABSTRACT

Introduction: Every 3 seconds, a new case of dementia is diagnosed around the world, amounting around 9.9 million of new cases in 2015. (Prince, et al., 2015) Dementia is an acquired organic syndrome, usually chronic, characterized by the progressive loss of cognitive and functional capacities due to the gradual degeneration of the several cerebral zones. It compromises the personal, family, professional and social life of the individual, severely affecting their autonomy and independence. (Nunes, 2014)

Objective: To disseminate the work developed by the Centro de Apoio ao Alzheimer Viseu (CAAV); To characterize the profile and needs of caregivers who seek the services of CAAV.

Methods: An exploratory study developed based on data from a sample of 166 caregivers of people with dementia who recruited the CAAV between 2014 and 2017. They are mostly informal caregivers (137), who at some point provided full-time support to the patient without any outside help, with female demand prevailing with 128 requests for support against 38 male caregivers.

Results: The most sought after services in CAAV are: technical, social / medical / legal support, as well as psychological support and support group. Most of the people who request these services are women, especially the patients’ daughters (49%), followed by the spouses (27%), with Alzheimer dementia being the most frequently referred pathology.

Conclusions: The results show that the CAAV assumes an entity with individual and social impact, so based on the Person Centered Care model, CAAV intends in the short and medium term to create new services to support the needs and demands of people with dementia and their caregivers.

Keywords: Alzheimer; Dementia; Caregivers; Intervention.
The dementia are one of the leading causes of disability and dependence among the older people all over the world. According to the Alzheimer's disease International there are currently approximately 46.8 million people with dementia worldwide, it is expected that this number could double in the next 20 years (Prince et al., 2015).

Dementia designates an acquired organic syndrome, usually chronic, characterized by the progressive loss of cognitive abilities and functional, due to the gradual degeneration of various areas of the brain. This results in different symptoms and disabilities of the subject to make the most diverse family activities, social, labor and daily, producing a personal maladaptation to their environment. As the dementia progresses, there is an overall loss of independence and autonomy, requiring an aid and a constant supervision (Peña-Casanova, 1999).

Alzheimer's disease is the most common - 50% to 70% of cases of dementia (Bridges, 2016), and although not a normative pathology to the aging process, is often labelled as a "disease of the elderly".

Although age is the risk factor most referenced to the emergence of dementia, other factors can interconnect to provide your appearance, including genetic factors, oxidative stress, factors of vascular nature, traumatic brain injury, toxic environment, tobacco, sleep apnea, low education, among others (Nunes, 2014).

In the wake of several studies, we believe that there is no one factor that is the cause in particular, deriving from a set of factors that affect each subject, developing over the years upon their individuality (U.S. Department of Health & Human Services, 2006).

In spite of the investment that has been made in the search for the cure of the disease, it is still irreversible and the pharmacological treatments combined with cognitive techniques for rehabilitation, so widely disseminated in these cases only allow an improvement and a reduction in the behavioural changes, a stabilization of cognitive deficits for some time, as well as the improvement of the quality of life of patients and their families (Bottino et al., 2002; Marksteiner & Schmidt, 2004).

In the absence of cure, one of the priorities lies about looking for strategies to help caregivers to deal properly with these patients, as well as the identification of symptoms and risk factors to reduce the prevalence and impact of the pathology (U.S. Department of Human Health & Human Services, 2008).

In the absence of specialized responses at the support level for caregivers, patients and their families in the municipality of Viseu, the Obras Sociais do Pessoal da Câmara Municipal e dos Serviços Municipalizados de Viseu (IPSS) developed the project Alzheimer Support Center Viseu (CAAV).

The initial purpose is to provide psychological and social support to families and caregivers - both formal and informal - of people who suffer with the Alzheimer’s disease (AD) or other dementias. Currently focuses its activities on four fundamental pillars - Prevention, Diagnosis, Monitoring the course of the disease and in the Mourning process-, while offering a range of services directed to the patient as well as for the general population.

### 1. THEORETICAL FRAMEWORK

The Alzheimer disease is characterized by a total change and persistent cognitive functioning, severe enough to have an impact on the patient’s life. Of degenerative character, associated to an organic process, with a slow and insidious start, evolving progressively and gradually (Peña-Casanova, 1999). It begins with an asymptomatic or pre-clinic phase in which the disease is not yet sufficiently developed to cause changes in cognitive functioning. There are changes in the verbal memory, difficulty to distinguish the changes in memory of normal aging. The symptoms of early dementia, will steadily deteriorated, starting to interfere in a person’s life. The deterioration of cognitive disorders and psycho-behavioral disorders lead to loss of autonomy and independence, and subsequently, to death, a process that can last between 8/12 years (Nunes, 2014).

Even though the signs, symptoms and the development of the manifestations of Alzheimer’s disease are different for each person, there are common traits in its temporal evolution which allow you to define some stages of progression. The World Health Organization (2012) has established three stages:
1-Initial - difficulties in language, memory, disorientation in time and space, difficulty in making decisions, lack of initiative and motivation to start tasks (both more familiar or pleasant as new ones) or conversations, manifestation of signs of depression and aggressiveness and loss of interest in the work or hobbies;

2-Intermediate - serious changes in memory (forgetfulness of recent events, the name of familiar people, etc.), inability to live and play alone activities of daily living (ADL), prominent communication difficulties, ambulation, disorientation in familiar environments, systematic repetition and hallucinations;

3-Late - total dependence and inactivity, apathy and silence, serious memory problems, physical deterioration, difficulty in feeding, non-recognition of relatives or friends or known objects, total disorientation, inability to understand and correctly interpret the situations, difficulties in walking, appearance of urinary incontinence and fecal matter, travel is only possible in a wheelchair or even be settled, total loss of communication between the brain and the body.

It is mainly the changes of functionality (performance in activities of daily living - ADL - which are the set of activities that a person performs daily to live independently and integrated in its environment and to fulfill their social role) which determine the time at which the person with dementia begins to need the help of others (Figueiredo, 2007; Pimentel, 2001).

The caregiver is the person providing care to someone who need them, being a complex activity that include psychological dimensions, ethical, social, clinical, technical and Communitarian aspects (Luders & Scott, 2000). The provision of care involves three main dimensions: responsibility for others; responding to the needs and interests of those who take care (Squire, 2005). The caregiver may be formal (provides care in the context of their professional functions), or informal (provides care on a regular basis, without receiving any economic contribution) (Feldberg et al., 2011; Figueiredo, 2007). Informal caregivers performs tasks such as promoting adequate surveillance of the state of health of the person cared; extend their independence and autonomy; promote a safe environment in order to avoid accidents, and comfortable to provide a proper sleep; the supervision and guidance of the activities performed; encourage communication, socialization, physical activity and the interest of leisure and social activities; help to remember their history and life project; provide other types of care recommended by health professionals; among others (Sequeira, 2007).

In most cases, especially in southern European countries, this care come from the family (Figueiredo, 2007). The role of main caregiver is made naturally by a member of the family, and is in most cases the only source of help for the patient (Fernández-Casaccone & Crespo, 2011). Within the family the role of main caregiver is assumed based on some factors, in particular the degree of kinship and gender (female), physical and affective proximity. Therefore they are, as a general rule, the spouses to assume that role, followed by the daughters and daughters-in-law (Figueiredo, 2007).

The family plays this role, by social and moral duty, for altruism, by obtaining social approval or avoidance of censorship, by feelings of gratitude and reciprocity in relation to the person cared, or even for material reward (Figueiredo, 2007). The institutionalization is usually the last resort, only when the main caregiver and others (who provides care occasionally, without the responsibility of caring) are no longer able to provide all necessary care or when its provision entails a suffering and a wear so strong that the caregiver feels unable to continue to perform (Pimentel, 2001; 2007). The functions of the caregiver are intrinsically linked to the degree of dependency of the patient, while the responsibilities of this constantly changes through the progression of the disease (Figueiredo, 2007). In an initial phase, care focuses mainly on supervision with vigilance and constant attention. With the progression of the disease, supervision gives place to the replacement of the person in their own activities. The final phase represents a total dependence on the caregiver (Ferreira, 2008).

The assumption of the role of caring brings negative impacts to the life of the caregiver, being one of the most studied the overburden. Defined by George & Gwyther (1986) (cit in Figueiredo, 2007, p. 53) as "the physical, psychological, emotional, social and financial problems that can be experienced by family members who take care". The burden of caregivers presents itself as taking them to reach their limit, with references to the extent of physical and emotional exhaustion on the part of these, as well as feelings of guilt by the difficulty in responding to all the needs of the patient (Gariga, 2007). It also contributes to a lower sense of well-being and an increased health problems (Figueiredo, 2007). It is often associated with the tasks that the person has never before had to play, the ignorance about the manifestations of the disease and the best strategies to cope with the changes, in particular related to the changes and psychopathological behavioral, as well as the growing difficulties of communication, and the style or coping strategies adopted (Sequeira, 2007).

Like other negative consequences, it is often the caregiver who feels the loss of freedom (inability to enjoy leisure time), social isolation (ceases to carry out social and communitarian activities), financial difficulties (greater need of resources), the implications at the level of their mental health (higher risk of development of psychopathological disorders, particularly depression, anxiety, and stress) and physical morbidity (due to excessive physical effort), changes in family relationships (with the dependence there are changes of power within the household, the history of life and the interaction of its components over time will influence more than ever the quality of their interaction), constraints at the level of the labor activity (work and provide care may be two activities almost incompatible, since both require a lot of time and mental availability, although due to financial constraints and lack of social support on the part of state agencies, the caregiver is obliged to keep working in order to support the expenses) (Figueiredo, 2007; Sequeira, 2007).

The provision of care to the patient, presents itself as a source of chronic stress, representing serious consequences both for the health of the caregiver such as for the whole family (García-Calvente, Mateo-Rodríguez, & Maroto-Navarro, 2004). According to Moreira...
(2001) (cit in Carvalho & Augustus, 2002, p.108), "The family needs emotional support, and essentially to be heard, making easier the expression of their feelings and of their weariness, while being informed about the care and the reactions of the patient."

According to this, the monitoring of families and caregivers should be part of a multidisciplinary intervention of the disease. Having as its main focus the stress reduction of the caregiver, help families to cope with the burden of care and although it does not allow any changes in the course of the disease, can bring significant benefits to care for the patients and therefore, positive impact on their behavior (Marriott, Donaldson, Tarrier, & Burns, 2000; Bottino et al., 2002).

On this intervention, psychoeducation and information about the disease are fundamental, but essentially a reflection about the consequences that this will bring long term (Marriot et al, 2000).

In addition, it is still necessary for the intervention with the caregivers to meet other needs, including: support in domestic tasks (through the use of social responses); assess their need in financial terms and enable state mechanisms which can provide this type of aid; to provide psychosocial support in individual terms and from support groups; allow the caregiver to have moments of rest and perform activities that provide welfare and provide more information and training related to dementia and provision of care (Rodríguez, 2010a; Figueiredo, 2007).

2. METHODS

An exploratory study developed based on data from a sample of 166 caregivers of people with dementia who recruited the CAAV between 2014 and 2017.

They are mostly informal caregivers (137), who at some point provided full-time support to the patient without any outside help, with female demand prevailing with 128 requests for support against 38 male caregivers.

This article has the main objective to make the CAAV known and the work that has been done since 2014, as well as present the profile of caregivers to people in need. In this study will be described all the services that this institution(CAAV) has been developing, to caregivers and people with dementia.

The data needed for this study were collected from the database containing information regarding the Contact Form that is filled individually or for each service requested from some part to the CAAV. On this database, we have the biographical data of each subject, information concerning the clinical case of the patient and also information related to the services the Center is providing or provided to each person. These data were analyzed through the use of the software Microsoft Excel ™.

3. RESULTS

As previously mentioned, the CAAV started his activity with a set of targeted services for caregivers, since these are the base references in the lives of the patients and for who is at their side most of the time and constantly available for the patient and is suffering from physical and psychological burden from this condition that sets in around the family system (Figueiredo, 2007; Sequeira, 2007). Caregiver often forget his own life and the need to take care of himself, which can lead to a downward spiral in terms of life quality, well-being and decline of their own physical and mental health (Figueiredo, 2007). Having this is mind, the CAAV offers a set of services, considering the support of caregivers and improving their care practices:

- Psychological Support: service directed to the caregiver and the patient, which aims to provide emotional support, to facilitate the adjustment and acceptance of the disease and emotional regulation, focusing on prevention of depression and anxiety disorders resulting from this process. Regarding the caregiver, there are three moments: diagnosis, evolution of the disease, grieving process. It intends to work aspects as Resilience and Emotional Intelligence, including personal aspects such as: self-esteem, empathy, autonomy, humor, self-control, self-care, among others. These concepts have been mentioned in several studies, as being relevant for caregivers to acquire personal skills to take care of people with dementia (Fernández-Lansac & Crespo, 2011);
- Social, Medical and Legal Support: Forward to other services, such as looking for external care responses; inform the rights and support provided by social policies to the patient and the caregiver; forward to other health professionals, with the purpose of obtaining a diagnosis to clarify other medical questions; and finally, to provide legal services through established protocols with lawyers;
- Technical Support: focuses on Psychoeducation, looking to provide patients more knowledge/information about the disease and to enable the improvement of strategies/best care practices;
- Support Groups: Meeting point, exchange of experiences, expressing feelings, ideas and opinions offered to formal or informal caregivers. Through this interaction (in a secure and confidential environment) participants have the opportunity to reflect on their care practices, looking for strategies to adapt to changes, as well as to overcome difficulties, empowering self-control and self-esteem. Also providing a social environment for caregivers, offering emotional support and promotes self-care, preventing physical and emotional burden;
- Memory Café: informal meeting space, which occurs once a month. Aiming caregivers, people with dementia or with memory problems. In a cozy, quiet and secure environment, promotes sharing of experiences and mutual support between the participants, sharing useful information, encouraging participation with funny and stimulating activities, and giving emotional
support, contributing to the reduction of social isolation and increasing quality of life; this initiative has the support of health or social professionals who guide the lecture or activity sessions.

The CAAV has also interventions for people with dementia or other neurological/neuropsychological problems:

- **Neuropsychological Assessment**: through the administration of Neuropsychological battery testing, questionnaires and interviews, this allows to define a neuropsychological profile of the person, providing information about the cognitive areas preserved and those that have some kind of commitment, as well as information about the emotional/psychological state. Beside the importance as an instrument of diagnosis to help other health professionals, this is crucial to plan the cognitive stimulation sessions.

- **Cognitive Stimulation**: This service is intended for patients with dementia or other neuropsychological affectations and takes place in combination with rehabilitation techniques, training, learning, educational and fun activities, in order to develop, improve or maintain the cognitive abilities of the individual looking to improve or preserve his functionality, autonomy and independence, reduce symptoms of neuropsychiatric disorders (anxiety, depressive symptoms, sense of inability, disruptive behaviours), increase self-esteem and positivity towards life, and reduce the disconnection with the environment.

Focusing on prevention, the CAAV also developed the Memory Space, this group sessions, have the purpose to optimize cognitive functions of the elderly with memory changes or mild cognitive impairment. It seeks to enhance occupational and functional performance, improve personal performance, self-esteem and self-confidence, stimulate the reminiscences and promote social participation.

At the same time, since the beginning, in order to developed Awareness and sensitize the community about the problem of dementia, we promote Information and Dissemination Actions, in partnership or collaboration with various entities. This service comprises seminars, conferences, presence at fairs and other events which make it possible to reach more people.

Since 2014, the CAAV has been experiencing a growing demand for its services, having received 166 caregivers and people with dementia to this date, 137 are informal caregivers, who at some moment provided full-time support to the patient without any outside assistance, by nursing homes or formal care.

From the 166 caregivers, prevails the female demand, with 128 support requests, against 38 male caregivers (Graphic 1).

Forty nine percent (81) of the caregivers who looked for the CAAV are children, followed by the spouses which represent twenty seven percent (44 caregivers) as shown in Graphic 2.
Considering the types of dementia in presence, AD is the most prevalent, representing 78% of dementia cases (122 patients), but this number may be even higher, 14% of the total of cases are referenced as suspicion of AD, without confirmed diagnosis (Graphic 3).

![Graphic 3: Types of Dementia Registered](image)

The various services that the CAAV offers have been used in different percentages from who is demanding them, as reflected in Graphic 4. It is important to note that the vast majority (79 caregivers), comes above all in search of social, medical and legal support, as well as technical support (42 caregivers), requesting later on other services that the Center offers.

![Graphic 4: Percentage of Clients Attending the CAAV Services](image)

It stands out the adherence to psychological support (48 caregivers) and the support group (43 caregivers), which allows to understand, in addition to the informational issues and referrals to other services, there is a great need of caregivers for emotional support, a space where they can share their challenges and needs, and speak about strategies that improve the cares, as well as having the feeling that they are not alone facing this situations.
4. DISCUSSION

The data collected about types of dementia referenced above, which were cases followed by the CAAV are accordingly also met by Alzheimer Europe (Pontes, 2016) that demonstrate that the AD is the most prevalent dementia, representing approximately 50% to 70% of all types of dementias in Europe, and also in the whole world (WHO, 2012).

When dementia comes up, it does not only change the individual’s life but it has repercussions in the whole family system, either professional or social, forcing an adaptation that in general is difficult for all that are involved (Figueiredo 2007; Sequeira, 2007). Over time in the CAAV this reality has emerged, it’s not just the family members most directly involved in care (main informal caregivers) that are seeking for this services, but there is also a demand on part of the extended family, neighbours or friends. It turns out that especially daughters (usually secondary or even tertiary caregivers) who come to the Centre in search for help having the main caregiver in mind (spouse of the person with dementia) referring to the overload in need of psychological/emotional support. As unanimously described (Figueiredo, 2007; Sequeira, 2007), there is a prevalence of female (77%) in the provision of care, which matches with the data from the WHO (2012) that shows that 76% of informal caregivers in Europe are women. In the case of registered male caregivers, the search for external support did not come from the primary caregiver, but of a third person, there is a certain resistance on their behalf to search and receive any kind of support, which relates to the stigma associated with these disorders, as well as cultural and gender issues.

In general, the search comes from the Social/Medical/Legal and Technical Support, despite the visible fatigue and emotional weakness of caregivers.

The shared information about existing services leads many caregivers to adhere to the available services, namely the Psychological Support and the Support Group, which have proved to be extremely useful for caregivers, finding a space for themselves, where they can share their anguish, doubts and difficulties in search of answers to their needs and desires, helping to decrease social isolation, their sense of overload and symptoms of depressive and anxious problems (Sequeira, 2007). Optimizing its own internal resources, improves not only the well-being and quality of life of the caregiver, but also the person with dementia (Figueiredo, 2007).

Regarding the intervention with people with dementia, we acknowledge today that the most effective for optimization of cognitive functioning and great enhancer of autonomy and independence of individuals is the combination of pharmacological and non-pharmacological interventions (Sequeira, 2007; Taborda & Melo, 2014). We noticed that people with dementia followed by the CAAV, were just on drug therapy (in absence of any other type of intervention), the need arose to implement services of Neuropsychological Assessment and Cognitive Stimulation. Those services have demonstrated a growing interest on the part of caregivers and targeted persons, because there is a growing awareness that may contribute to the maintenance of their cognitive abilities, well-being and quality of life, allowing them to get out of a spiral of withdrawal, hopelessness that does not contribute to the improvement of their condition. In this sense, there are more and more people to join this service.

As in general the population has been aware to the need to prevent situations of dementia and that greater cognitive activity decreases in 47% the risk of suffering from Alzheimer's disease by promoting improvements in the performance of several cognitive functions (Franco-Martín & Orehuela-Villameriel, 2006), emerged the need to create a new service that offers anyone older and with a normal aging a moment of cognitive stimulation. This leads to creation of the latest service, the Memory Space, whose implementation is now being initiated.

CONCLUSION

With the tendency towards ageing of population and the increase of people with dementia, in particular AD, it is becoming urgent to promote situations to ensure physical, psychological and social health of these patients, as well as their caregivers.

The AD affects not only the patient, but causes adverse changes around the nuclear family, which validates the need for special attention to this group. Assuming that these patients should be on behalf of their families as long as possible, to give continuity to their personal and social identity and to promote the security and stability that only a familiar environment can offer, the informal caregiver represents the central pillar in the promotion of life quality for the patient, therefore, a plan of intervention for people with dementia must always take into special consideration the needs of caregivers, investing on their assistance.

It is in this sense that the CAAV has developed its activity and in this article you can realize that the demand by caregivers (which reflect their needs) are the Social/Medical/Legal Support, Psychological Support, the Support Group and the Technical Support. In terms of profile, caregivers that mainly come to CAAV are women, in general, daughters of patients with AD (majority). Despite all the efforts made in order to promote the services provided by the CAAV, there is clearly still a long way to go for the awareness of society in general and of professionals for the problems associated with this issue. Based on the Model of Integral Attention Person-Centered (Rodriguez, 2010) it is intended not only to continue current services, as well as in a short or medium term to create new services and answers that enrich this work, meeting the needs and requirements of this population. Currently we are making efforts for the creation of a Life Quality Center for people with dementia and for starting up specialized training related to dementias for formal, informal caregivers and healthcare professionals.
Furthermore some manual/practical guides on the dementia and associated themes are being designed, and through participation in the project “Nas Freguesias para Lembrar” do CLDS 3G – Viseu Igual, we expect to get closer to the population through the creation of various Support Groups, Cognitive Screening and Awareness Actions focusing on prevention to support the caregiver.

REFERENCES


