

Experience of People in Mild and Moderate Stages of Alzheimer's Disease in Spain

Theme: Chronic care

Contribution to the discipline: Despite being aware of their memory loss, people with dementia tend to minimize their memory problems and consider them part of the natural aging process. They choose not to express their feelings to avoid worrying their relatives, who often are their main physical, moral, and emotional support. Some of the people with early-stage dementia claim that they have developed strategies to hide their memory loss from close relatives.

ABSTRACT

Objective: To analyze the meaning of dementia by those affected by it, and to give them a voice. **Material and methods:** Descriptive phenomenology through interviews with people of both genders who are over 50 years old and living in Tarragona (Spain), with a diagnosis of mild or moderate dementia, mainly related to Alzheimer's disease. **Results:** Three main themes emerged: 1) normalization of memory loss in early stages as part of the natural aging process; 2) self-awareness of progressive memory decline, which is concealed from others, and 3) adaptation processes and strategies to coexist with their condition after diagnosis. **Conclusions:** The most evident features were the lack of specialized infrastructures within the health system in terms of care, prevention programs, and early detection.

KEYWORDS (SOURCE: DECS)

Dementia; alzheimer disease; qualitative research; life experience; interviews.

DOI: 10.5294/aqui.2020.20.4.4

Para citar este artículo / To reference this article / Para citar este artigo

Riquelme-Galindo JR, García-Sanjuán S, Lillo-Crespo M, Martorell-Poveda MA. Experience of People in Mild and Moderate Stages of Alzheimer's Disease in Spain. *Aquichan*. 2020;20(4):e2044. DOI: <https://doi.org/10.5294/aqui.2020.20.4.4>

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Received: 05/04/2020
Sent to peers: 16/04/2020
Approved by peers: 20/08/2020
Accepted: 24/08/2020

Experiencia de personas con Alzheimer en fases leves y moderadas en España

RESUMEN

Objetivo: analizar el significado que adquiere la enfermedad para las personas afectadas por Demencia, proporcionándoles voz. **Material y métodos:** aproximación a la fenomenología descriptiva a través de entrevistas a personas de ambos sexos y mayores de 50 años residentes en Tarragona (España) con un diagnóstico de Demencia leve o moderada, principalmente enfermedad tipo Alzheimer. **Resultados:** surgieron tres grandes temáticas: 1) normalización de la pérdida de memoria en fases incipientes en relación al proceso natural de envejecimiento; 2) autopercepción de que existe un problema de memoria instaurándose que se disimula frente a su entorno y 3) procesos de adaptación y aprendizaje de estrategias para convivir con su condición tras el diagnóstico. **Conclusiones:** la falta de infraestructuras especializadas dentro del sistema sanitario en materia de cuidados, programas de prevención y detección precoz son los aspectos más evidentes remarcados.

PALABRAS CLAVE (FUENTE: DECS)

Demencia; enfermedad de alzheimer; investigación cualitativa; acontecimientos que cambian la vida; entrevistas.

A experiência de pessoas com Alzheimer na Espanha nas fases leve e moderada

RESUMO

Objetivo: Analisar o significado que a doença adquire para as pessoas afetadas pela demência, dando voz a elas. **Material e Métodos:** Abordagem da fenomenologia descritiva por meio de entrevistas com pessoas residentes em Tarragona (Espanha) com diagnóstico de demência leve ou moderada, principalmente doença do tipo Alzheimer de ambos os sexos e com mais de 50 anos. **Resultados:** Surgiram três grandes temas: 1) Normalização da perda de memória em fases incipientes relacionadas ao processo natural de envelhecimento; 2) Autopercepção de que existe um problema de memória que se esconde do ambiente; 3) Processo de adaptação e estratégias de aprendizado para conviver com sua condição após o diagnóstico. **Conclusões:** A falta de infra-estruturas especializadas no sistema de saúde, programas de prevenção e detecção precoce são os aspectos mais evidentes.

PALAVRAS-CHAVE (FONTE: DECS)

Demência; doença de alzheimer; pesquisa qualitativa; eventos que mudam a vida; entrevistas.

Introduction

Around 50 million people suffer from dementia worldwide, with 10 million new cases diagnosed each year (1). People with Alzheimer's disease comprise 2/3 of the total number of people who suffer from some type of dementia (2). This is one of the greatest challenges that our society faces nowadays. In 2020, the estimated worldwide cost of dementia-related health care is over US\$ 818 billion, considering the annual increase in the prevalence of people suffering from dementia, which is equivalent to 1.1 % of the domestic product worldwide. This proportion varies between 0.2 % in countries with a medium-low socioeconomic level and 1.4 % in countries with a high socioeconomic level. Moreover, it is estimated that by 2030, the cost of health care of people with dementia worldwide will have risen to US\$ 2 trillion. This amount could undermine social and economic development globally, and overwhelm health and social care services, specifically, those systems bearing the burden of caring for people in a situation of chronicity (3). This situation will affect Spain especially, whose percentage of older population will double by 2050, becoming one of the oldest countries in the world.

Giving a voice to people who suffer from dementia and changing the approach to their care needs are paramount if we are to improve the quality of care provided and reduce the complications caused by poor management in health services and the global economy (4). Awareness campaigns about dementia and the World Health Organization (WHO) document on aging and health emphasize the need to empower people with dementia to become active members in their community, instead of more dependent (5). However, the implementation of these campaigns within the reality of each country has been extremely different.

In the 1990s, several authors highlighted the relevance of listening to the affected person (6-7) to understand more about the subjective experience of dementia and to develop a holistic approach to person-centered care. Although, for some time, it was assumed that collecting information from people with dementia was methodologically difficult and unreliable, due to their cognitive impairment that limited effective reasoning and communication. (8) Therefore, studies carried out in that period that focused on how people with dementia felt and coped with their situation adopted an external perspective based on the answers given by caregivers and professionals (9-10). Opposite to this perspective,

through interviews and data from different sources, other studies offered people with dementia the opportunity to speak about themselves, consequently acknowledging a new perspective and validating the reliability of the subjective responses of people with cognitive impairment, and the significance of the subjective data (11-13). Thus, progressively, studies from the perspective of individuals with dementia have been developed, contemplating their individual experience of the disease (14-17). The lack of scientific evidence from biomedical and pharmacological research has also motivated this change of perspective in recent years, focusing on the needs of people with dementia and their experiences.

A clear example is an article published in 2018, following the European Palliare Project, (18) in which seven participating countries, including Spain, gave a voice to people with dementia, their relatives, and close professionals. The objective was to determine the conditions in Europe and expose the aspects involved in the care of people in an advanced stage of dementia, within the typical context of each nation. This research showed, for the first time in the continent, the experience of care in individuals with dementia through 56 in-depth interviews that assessed six key aspects, namely: 1) dementia/adaptation process; 2) care in dementia; 3) the role of the caregiver; 4) care planning in different stages of dementia; 5) home adaptation for people with dementia; and, 6) essential tools for proper care. Despite the differences between nations, there were common needs throughout Europe, especially the lack of specific training for professionals and caregivers, as well as the absence of a consensus and a common approach.

A European healthcare model based on an individual-centered approach, instead of the traditional biomedical approach, requires a thorough study of the most prevalent diseases and the affected individuals and their environment. This model provides a comprehensive set of data based on evidence and experiences, allowing to develop consensual and holistic strategies and to present them to the scientific community (19). As our population grows older, healthcare needs change accordingly, becoming more complex. In Europe, relevant data show a slight increase in the age-standardized prevalence of people over 65 with dementia in recent years, around 4.4 % (20). The objective of this article is to analyze what this disease means to the people with mild to moderate stages of dementia, immediately after diagnosis, and to invite them to actively participate in their own care.

Material and methods

We performed this study through a descriptive phenomenology approach (21-22) that reflects the interest on this matter, and captures, describes, and helps understand the investigated subject and their personal experiences regarding their condition (23).

The study sample consisted of people of both genders, aged 50 years or more, residents of Tarragona (Spain), and that had been recently diagnosed (12 months or less) with mild or moderate dementia, mainly Alzheimer's disease. The participants have attended Alzheimer's Family Associations and Day Centers, located in the study area. The first contact was facilitated by professionals (a social worker and nurses) of these institutions.

The data was collected through in-depth interviews conducted between March and June 2016. After selecting the participants, a member of the research team called them to explain the characteristics of the study and invited them to participate. An appointment was made with those who agreed to participate. The interviews were conducted either in the participant's home or in the Day Center, according to their preference. In both locations, researchers created a safe and intimate area for the interviews, which were arranged as per the participant's convenience. Interviews lasted between 20 and 50 minutes.

A second meeting was held under the same conditions, between 2 to 3 weeks after the first interview. In some cases, a third interview was conducted, also under the same circumstances. The interviews focused on the following areas: routines and activities of daily living, recent changes perceived during those activities, feelings and thoughts regarding the current situation, social life with their partner, family and friends, concerns, and the meaning of the disease.

The researchers designed an *ad hoc* questionnaire to describe the sociodemographic profile of the participants. Clinical variables were defined based on the functional status and the activities of daily living using the Barthel Index and the Lawton and Brody scale. The Spanish version of The Quality of Life in Alzheimer's Disease scale was used in the interview with the affected person and their caregiver to understand their quality of life concerning the disease (24-25).

Finally, six people were recruited, all of them women with a mean age of 74 years. The participants presented indicators of

mild to moderate dementia according to the Mini-Mental State Examination (MMSE) (26). The Global Deterioration Scale (GDS) (27) showed a moderate dependence on activities of daily living and severe dependence on the instrumental activities of daily living. The perception of the quality of life by the participant and their family member was good (see table 1).

Table 1. Participant data

| Interviewee | Age | MMSE | GDS | Barthel scale | Lawton and Brody scale | QOL-AD Affected person/relative |
|-------------|-----|------|-----|---------------|------------------------|---------------------------------|
| 1 | 84 | 23 | 4 | 75 | 3 | 36/27 |
| 2 | 85 | 23 | 4 | 100 | 3 | 29/27 |
| 3 | 88 | 24 | 4 | 80 | 1 | 36/35 |
| 4 | 88 | 24 | 3 | 70 | 1 | 38/37 |
| 5 | 70 | 24 | 3 | 85 | 2 | 32/38 |
| 6 | 60 | 23 | 3 | 65 | 1 | 35/27 |

Source: Own elaboration

Qualitative research validity is present both in the systematic process of data gathering and analysis (28). Interviews were recorded with an audio device and transcribed verbatim. Researchers used the Colaizzi method (29) for data analysis, in which units of personal experiences are organized and grouped together, disclosing the phenomenon after several readings and analyzes. The data analysis was carried out at the end of 2019.

The interviews were analyzed by the study authors who were in contact by telephone and email. The study authors met on three occasions to discuss and assess the gathered information, thus triangulating the different data. After contrasting the information against the available literature and the conceptual framework, the team refined and agreed on the most relevant data that explain the different themes and subthemes (Table 2). We included quotations in the study to illustrate the different themes.

Table 2. Themes and subthemes arising from the interviews

| Themes | Subthemes |
|--|--|
| 1. Normalization of memory loss in early stages related to the natural aging process | 1.1 Minimizing memory loss 1.2 Delay in seeking medical consultation |
| 2. Self-awareness of memory decline concealed from their environment | 2.1 Hiding changes from their environment 2.2 Limitations in daily life 2.3 Memories from the past |
| 3. Adaptation and strategies used to live with their condition after diagnosis | 3.1 Resignation or adaptation to their current situation 3.2 Importance of family support |

Source: Own elaboration

This study has been approved by the Clinical Research Ethics Committee of the *Hospital Universitario Sant Joan de Reus* (Tarragona, Spain). All interested participants and their appointed family member received a written informed consent document describing the characteristics of their participation and the objectives of the study. Likewise, they were informed about the confidential nature of the study and their voluntary participation, explaining their right to withdraw from the study at any given time.

Results

Theme 1. Normalization of memory loss in early stages related to the natural aging process

1.1 Minimizing memory loss

Although the interviewees are aware of their memory loss, they minimize the issue attributing it to the natural aging process. They do not think it is a problem “every year I lose my memory a little, but that is expected at our age” (P01). They also justify forgetfulness as something they have experienced throughout their lives or due to distraction: “Sometimes my husband tells me they ran into someone [...] and then explains who that person is and suddenly, I cannot remember, but I always had a hard time remembering people” (P04). “I forget things, but it is because I am

not focused, I am not paying attention” (P02). This perception, which is inherent to advanced age, occurs as follows: despite realizing other older persons experience memory loss or forgetfulness, patients consider that their mental health is not affected. “In here, all the older people have some memory loss, but it is normal. I make mistakes sometimes because I am old” (P05).

1.2 Delay in seeking medical consultation

For our interviewees, it was clear that memory loss was to be expected over time. In fact, they did not consider that “mild forgetfulness” should be communicated to the doctor or even relevant enough to seek medical consultation: “I do go to the doctor, but not because of my brain, which is fine, but because I live alone” (P02), “I did not want to go to the doctor, because I am well; my daughter took me” (P06). They also downplay the issue, stating that they do not have any problem, and accusing others: “I’m great [...] it’s the others who say I have a memory problem” (P03).

Theme 2. Self-awareness of memory decline concealed from their environment

2.1 Hiding the changes from their environment

On some occasions, all the women who participated in the study assured that they were aware of their memory loss, but that they had enough strategies to hide this forgetfulness from their closest relatives: “Others don’t notice it, but I do” (P02). They fear the possibility of losing their autonomy: “If it takes me a while to get downstairs when they come for me because I forgot to take something, they immediately tell me that I cannot live alone anymore and that I would have to go to a care home” (P04).

2.2 Limitations in daily life

They are aware that they may have a real problem when they forget important things: “My daughter leaves my clothes ready for me because that way I don’t have to worry” (P03), “I don’t go shopping anymore, because I would always forget something or couldn’t manage money properly. So now, they bring me the groceries” (P02). They also acknowledge that they get disoriented when running errands, but they do not express it explicitly: “They pick me up at home, because I don’t like to go by bus” (P06), “I am well here at the center [...] they bring me everything I need, so I can spend more time reading” (P03).

2.3 Memories from the past

Their discourse about their personal and professional life is very clear, however, when it comes to recent events, it is not: "...and I stayed inside the library, which had glass doors and I was always there, reading books [...] I can't tell you about the news that I read this morning in the newspaper" (P01), "I owned a butcher shop and my aunt would bring us all the clothes [...] tomorrow, Saturday, they will bathe me and then I'll go home... wait, today, Tuesday, Wednesday ... well, on Saturdays." (P04).

Theme 3. Adaptation and strategies used to live with their condition after diagnosis

3.1 Resignation and adaptation to their current situation

Once they become aware of their new reality, they try to adapt and normalize their memory loss to avoid further changes to their life "although it is very variable... I am adapting" (P01). Moreover, all the interviewees, to a greater or lesser extent, consciously carry out activities that improve cognitive abilities (reading, studying, discussing current affairs, writing, crocheting, etc.) as part of the adaptation process: "I think reading is key to keeping my head sane" (P01), "and I crochet, even if I don't need it, and then I give them away" (P03). They have also developed routines and strategies: "Since I can't remember it, I write down the phone number on the back of the phone and look at it when I need it" (P06), "I always do the same: I get up, go to the bathroom, have breakfast and sit on the sofa to wait for the bell to ring" (P05).

3.2 Importance of family support

Despite trying to prove that they do not have any difficulties, the interviewees emphasize that without family support they would not be autonomous: "My husband takes care of me and my children too; they love me very much" (P04), "My daughter buys my clothes because I can't anymore" (P03), "She [daughter] takes care of the household supplies and I am very happy because there is nobody better than her to take care of me" (P02). Also, in all the interviews, they exclaim how lucky they are for their families and that they do not feel alone: "I have lived many years with my husband and with my children and my grandchildren, and always having someone to talk to makes me feel alive" (P01), "My whole family loves me and thinks about me a lot; of course, I have always been there for them" (P06).

Discussion

This study explored the experiences of people suffering from mild to moderate dementia immediately after the diagnosis, which is when it tends to go unnoticed, mainly due to contextual and cultural beliefs, as we have shown. The selected cases were in the range of mild to moderate stages of development. Since there is no infrastructure for early detection in the Spanish system, many cases are diagnosed during the moderate or intermediate stage of the disease. However, all the participants were taking the first steps, from a chronological point of view, after their diagnosis.

The most characteristic and predominant symptom in the different types of dementia is memory loss (30). Despite this, our participants attributed their memory loss to the aging process itself. The attribution of symptoms as part of the normal aging process rather than a disease is a coping strategy since normalizing the situation helps to understand and eases suffering (31). Furthermore, this social construct is inaccurate, since studies show that there are hardly any memory deficits associated with aging. The degree of impairment is more related to attention and learning disorders rather than with specific alterations (32). Also, we need to add that the lack of access and of clinical guidelines in Spain causes that many people spend years experiencing a decrease in their cognitive abilities without any type of professional intervention, unlike other European regions such as Scotland, where the strategy to approach dementia has been further developed not only at the professional level but also in civil society.

Failure to recognize memory loss as a symptom of the disease and to normalize the situation result in our interviewees not going to a health center since it is not perceived as a health problem, therefore, delaying the diagnosis (33). These findings coincide with the known framework of other chronic diseases in which people struggle not to lose their health identity. Like with any other chronic disease, they assume that dementia threatens their identity, encouraging them to seek balance through coping strategies (34-35).

Achieving emotional balance and a sense of self is one of the main obstacles they need to endure in the adaptation process of the disease (36). These statements may be intended to assert their well-being and not to seek health care for that deficit. In other similar studies, the interviewed subjects admitted to suffering from memory loss as a symptom of their dementia (37). Furthermore, some cases showed that memory loss prevented individuals from

remembering their disease during the interview (38). In this study, the authors reflected upon the importance of having watched documentaries and audiovisual resources introducing people with the same diagnosis and how they recognized their memory loss. Concerning this, qualitative interviews and participant observation (39), have shown that patients with mild Alzheimer's disease deliberately and effectively implement certain strategies to socialize with the environment and to understand the change in their identities and their lives, as a result of the memory decline. According to this author, people with Alzheimer are engaged in preserving their personal and social identity, thus explaining their refusal to accept the disease by hiding their memory loss, which coincides with the accounts of our interviewees.

People with dementia often speak about past experiences and seem more comfortable holding a conversation about past times instead of recalling more recent events. This process of recalling past personal experiences is called "reminiscence" (40). Other authors add that reminiscence is an interaction between the person who remembers the memory and one or more individuals. In parallel, the term "nostalgia" arises, which is described as the longing for things, people, or situations that are not present, or a perceived ideal past (41). Throughout our interviews, episodes of reminiscence and nostalgia were frequent, which is characteristic of people with mild dementia. These studies suggest that using reminiscence therapy in patients with dementia helps maintain higher levels of well-being and improves the interaction with healthcare personnel when introducing it as an inclusive, stimulating, and social activity. (42) Thus, authors, such as Woods, demonstrated in a review carried out in 2005 that reminiscence therapy leads to improvements at the cognitive level, mood, and behavior, as well as a reduction in the burden on the caregiver (43).

Regarding the signs of memory loss, the interviewees were also aware that they encountered limitations when carrying out activities such as shopping or remembering a scheduled task. Recognizing these limitations leads people with mild dementia to feel frustrated because they do not understand what is happening to them. As they do not realize it is a disease, they are unable to determine what cognitive tools are needed to delay the consequences of their dementia (44).

Another important theme found in the interviews was the relevance of family support during the development of the disease. In Spanish culture, family plays a fundamental role in ensuring the well-being of a person suffering from dementia (45). The loss

of autonomy to perform basic activities of daily living causes the person to leave their home, sometimes prematurely, due to the risk of injury or inability to satisfy their needs (46). That is why cohesive families with defined roles and with tasks divided between family members ease the caregiver's burden, hence, avoiding overload and exhaustion that negatively impacts the care of the person with Alzheimer's (47).

These experiences, recounted in the first person, allowed us to understand the crucial aspects when approaching people with some type of dementia from a holistic perspective. Similar to the cases in the European Palliare study aforementioned, our results suggest that they will only achieve better control over their own lives by increasing the communication channels and allowing them to express themselves whilst they still preserve their communication skills (18). It is of the utmost importance that their demands and wishes are heard while they can still express their rights, such as autonomy and independence, as established by the Spanish law. Helping them express their own voice in the scientific literature allows this resource to be used as a teaching tool for professional development and for the preparation of guides, protocols, projects, and other scientific articles.

Conclusion

Through the analysis of representative cases, this study provides the key to understanding how people with dementia experience Alzheimer's disease during mild and moderate stages, immediately after diagnosis, in Spain. The step from being unconscious to being aware of the clinical situation and of the social consequences of this disease are highlighted as the most relevant elements. Indirectly, the lack of specialized infrastructure within the healthcare system in terms of care, prevention, and early detection programs becomes evident, as well as the insufficient training of professionals and caregivers to deal with an increasing phenomenon. This information can contribute to the design of new resources within the health system directed at the affected individuals, and for developing further awareness about dementia and other neurodegenerative diseases to improve their inclusion in society.

Limitations

Although the cases we studied were representative in terms of the period after the diagnosis and the stage of dementia of the participants, we found a limitation of gender and context.

However, the outreach of the saturation of data should be noted, considering that there are no substantial differences between the infrastructure available in the different autonomous regions that comprise the Spanish health system. Therefore, we can extrapolate

late that the *a priori* situation should not affect the results obtained in another region of our territory.

Conflicts of Interest: None declared.

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