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ALZHEIMER'S DISEASE IN THE FAMILY

Abstract:

Alzheimer's, accounting for 60-80% of dementia cases, presents a specific pathology and a range of symptoms, including memory loss, impaired reasoning, and other cognitive declines. The disease's progression and management require a comprehensive approach involving professional care, family involvement, and individualized care plans.

The research focuses on methods for working with individuals with Alzheimer's disease and their families, highlighting the importance of communication in implementing individualized care plans. It aims to show that a well-prepared care plan, coupled with effective communication with family members, can improve quality of life and potentially slow disease progression. It was conducted in two parts: a questionnaire for caregivers working with Alzheimer's patients and a semi-structured interview with 33 family members of individuals diagnosed with the disease. This approach provided both quantitative and qualitative data, offering a comprehensive understanding of the issues.

To improve Alzheimer's care, we recommend enhancing family involvement through structured models and training, increasing the accessibility of specialized services, promoting professional development, strengthening ethical communication standards, implementing comprehensive support systems, and regularly evaluating care plans. These measures aim to provide holistic and effective care strategies, improving the quality of life for individuals with Alzheimer's and their families.

Keywords: *Alzheimer's disease, Dementia care, Individualized care plans, Family involvement, Professional training.*

1. Introduction

Old age represents the final stage in the human life cycle, marked by substantial physiological transformations, including the decline in sensory functions. Additionally, this period is often associated with cognitive changes precipitated by medical conditions such as Alzheimer's disease. While age (the passing of chronological time) and aging (the increased risk of adverse outcomes over time) are intimately connected and exhibit a causal relationship, they are not synonyms (Gordon & Hubbard, 2022). According to the World Health Organization (WHO), healthy ageing is defined as developing and maintaining the functional ability that enables well-being in older age. Functional ability is determined by the intrinsic capacity of an individual (i.e., an individual's physical and mental capacities), the environment in which he or she lives (understood in the broadest sense and including physical, social and policy environments) and the interactions among them.

A comprehensive understanding of aging requires a broader perspective. Aging can be classified into five categories: biological, psychological, social, chronological, and functional aging (Chalise, 2019):

Chronological Aging: This refers to the number of years a person has lived. For instance, an 85-year-old woman is chronologically older than a 75-year-old man. However, chronological age may not align with biological, psychological, or social age. An 85-year-old might be an active volunteer, while a 75-year-old could be homebound. Phrases like "he looks younger than his age" highlight the disparity between chronological and other forms of aging.

Biological Aging: This involves cellular decline over time, leading to reduced tissue and organ efficiency, slower self-repair, and diminished immune functions. Physical activity and regular check-ups can result in someone appearing biologically younger than their chronological age.

Psychological Aging: This encompasses changes in memory, learning, intelligence, personality, and coping abilities. A mentally active older person who adapts well to new situations is considered psychologically young.

Social Aging: This relates to changes in roles and relationships with age. Older individuals often take on new roles, such as becoming grandparents or transitioning from employees to retirees. Society's expectations can influence how people perceive and experience aging, shaping whether it is a positive or negative experience.

*Functional Aging:*It highlights how well individuals maintain their ability to perform daily activities and adapt to changes over time, regardless of their actual age in years.

1.1. What is Alzheimer's disease?

Dementia is a broad term that denotes a significant decline in cognitive abilities severe enough to impede daily functioning. Alzheimer's disease, a specific pathology, is the predominant cause of dementia. Dementia encompasses a range of symptoms associated with deteriorations in memory, reasoning, and other cognitive functions, arising from various etiologies. Mixed dementia occurs when brain alterations characteristic of multiple dementia types coexist. Alzheimer's disease accounts for 60-80% of all dementia cases, making it the most prevalent form (Kapasi et al., 2017).

The neuronal damage caused by Alzheimer's disease extends to areas of the brain responsible for basic bodily functions such as walking and swallowing. As a result, individuals may experience significant mobility limitations, often confining them to a wheelchair or bed. This loss of mobility, coupled with cognitive impairments, necessitates round-the-clock care. Ultimately, Alzheimer's disease is fatal; however, many individuals succumb to other conditions before Alzheimer's itself proves fatal. Research indicates that individuals aged 65 and older typically survive an average of four to eight years following a diagnosis of Alzheimer's dementia, although some may live as long as 20 years. The progression and duration of the disease vary greatly among individuals, influenced by factors such as overall health, the presence of comorbid conditions, and the level of care received (Tom et al., 2015).

In 2024, the Alzheimer's Association in the United States highlighted the most common signs of disease:

Memory loss that disrupts daily life: A hallmark of early-stage Alzheimer's dementia is the frequent forgetting of recently learned information. Other signs include repeatedly asking the same questions, increasingly relying on memory aids (such as reminder notes or electronic devices), or depending on family members for tasks previously managed independently. Individuals may also occasionally forget names or appointments but recall them later.

Challenges in planning or problem-solving: Some individuals encounter difficulties in creating and adhering to plans or working with numbers. They might struggle to follow a familiar recipe or manage monthly bills. Concentration may become challenging, leading to tasks taking significantly longer to complete than before. Occasional errors in managing finances or household bills are also common.

Difficulty completing familiar tasks: Individuals with Alzheimer's often struggle to complete daily tasks. They may have trouble driving to a familiar location, organizing a grocery list, or remembering the rules of a favorite game. Occasionally, they might need help with tasks like using microwave settings or television.

Disorientation in time and space: Individuals with Alzheimer's may lose track of dates, seasons, and the passage of time. They can struggle to comprehend events that are not occurring immediately. Occasionally, they may forget where they are or how they arrived there.

Trouble understanding visual images and spatial relationships: Vision problems can be a sign of Alzheimer's for some individuals. They may experience difficulties in judging distance, determining color and contrast, which can lead to challenges with driving. These vision changes are distinct from those caused by cataracts.

Problems with pronouncing, finding, or writing words: Individuals with Alzheimer's may find it difficult to follow or participate in conversations. They might stop in the middle of a conversation without knowing how to continue or repeat themselves. Vocabulary issues are common, such as struggling to name a familiar object or using incorrect terms. Occasionally, they may have trouble finding the right word.

Misplacing things and losing the ability to retrace steps: Individuals with Alzheimer's may place items in unusual locations and frequently lose them, often unable to recall their steps to locate the missing items. As the disease progresses, they may accuse others of stealing. This is distinct from occasionally misplacing things and successfully retracing steps to find them.

Decreased or poor judgment: Individuals may exhibit changes in judgment or decision-making abilities. They might demonstrate poor financial judgment or neglect personal grooming and hygiene.

Withdrawal from work or social activities: Individuals with Alzheimer's disease may struggle to hold or follow conversations, leading to withdrawal from hobbies, social activities, and other engagements. Sometimes may show a lack of interest in family and social obligations.

Changes in mood, personality, and behavior: Individuals with Alzheimer's can experience shifts in mood and personality. They may become confused, suspicious, depressed, fearful, or anxious, and are often easily upset at home, at work, with friends, or when out of their comfort zones. They may develop specific routines and become irritable when these routines are disrupted.

Recognizing the signs of Alzheimer's disease is crucial for early intervention and management. Early detection allows for timely medical and therapeutic interventions that can help slow the progression of the disease and improve quality of life. Caregivers, family members, and healthcare providers need to be vigilant and proactive in identifying these signs to provide the necessary support and care for those affected by Alzheimer's disease.

1.2. Stadiums of development of Alzheimer's disease

Alzheimer's dementia typically begins subtly and progresses slowly, with a duration that can extend up to 12 years. The rate of disease progression is highly variable and difficult to predict; however, evidence indicates that an earlier onset is associated with a more rapid progression, whereas later onset corresponds to a slower progression.

The most widely accepted classification of Alzheimer's disease stages is provided by Reisberg & Franssen (1999). They delineates seven stages of disease progression, a framework extensively utilized by caregivers and Alzheimer's associations. The stages are as follows:

First stage (Normal) -No problems could be detected at this stage, meaning the disease cannot be identified. The individual exhibits no symptoms of memory difficulties or any other typical indicators of Alzheimer's dementia.

Second stage(Normal-aged subjective forgetfulness) - Second stage:Small changes can be observed at this stage, but memory difficulties and issues such as losing objects are minimal. The individual typically performs well on memory tests, making it difficult for doctors and immediate family to diagnose or detect the disease.

Third stage(Mild cognitive impairment) - At this stage, mild impairments become noticeable to friends and close relatives, including cognitive and memory changes. Individuals with Alzheimer's dementia may exhibit difficulties in finding the right words during conversations, remembering new names, planning and organizing, and may frequently lose personal items.

Fourth stage (Mild Alzheimer's disease) - There is intermediate damage with visible symptoms. Individuals with Alzheimer's dementia experience difficulties performing simple mathematical functions, forget details of their personal history, have poor short-term memory, and are unable to manage financial resources. This stage typically lasts about 2 years.

Fifth stage (Moderate Alzheimer's disease) – At this stage, moderate impairment is present, indicating that the individual requires assistance with daily activities. A person with Alzheimer's dementia experiences significant confusion, cannot recall basic personal details, dresses inappropriately, and is unable to independently meet physiological needs. Notably, they may still remember certain details from their life, particularly from their childhood or youth. The main duration of this stage is 1.5 years.

Sixth stage(Moderately severe Alzheimer's disease) – At this stage, the individual with Alzheimer's dementia experiences severe impairment and requires professional care. They are completely disoriented, unaware of their environment and surroundings, and need assistance with personal hygiene.

Seven stage (Severe Alzheimer's disease) - This is the final stage, characterized by severe impairment. As Alzheimer's disease reaches its terminal phase, individuals are nearing the end of life. They lose the ability to communicate, have no awareness of their condition, and require assistance with all daily activities. In the final stage, they may even lose the ability to swallow food.

According to those stages, Alzheimer's disease continuum begins with preclinical Alzheimer's disease (characterized by no symptoms) and progresses to severe Alzheimer's dementia (characterized by severe symptoms). The duration that individuals spend in each phase of this continuum varies and is influenced by factors such as age, genetics, and other variables (Vermunt et al., 2019) .

1.3. Individual care plan for a person with Alzheimer's disease

Before initiating any activity, work, treatment, or intervention, caregivers and family members of a person with Alzheimer's dementia develop an Individualized Care Plan (ICP). This plan is essential as it documents all key aspects of the person's condition, including their potentials, opportunities, needs, interests, and the severity of their problems. It also considers their social life, particularly their level of communication with family members. The ICP is designed to implement activities tailored to the specific characteristics of the individual and their family, with the primary goal of meeting the needs of the person receiving care (Stanojkovska at all, no date).

Developing an Alzheimer's care plan centers on the individual user and follows a social approach model, based on two key points:

- The user's current physical condition, encompassing their strengths, subjective perspective, and overall life.
- Activation, which involves setting goals and activities aimed at enhancing the user's potential, as well as fostering proactivity, productivity, and creativity in the implementation of the plan.

The individualized care plan for a person with Alzheimer's disease and their family outlines and defines the necessary actions and activities, specifies the timeline for their implementation, and establishes when progress will be evaluated.

The ICP is also defined in the Law on Social Protection in 2019, where it is stated that it is mandatory and according to Article 278 and 279, it is drawn up by the case manager based on a prior professional assessment, in cooperation with the individual and the family, as well as other experts from social, health, educational institutions and other state bodies and authorities, associations and other legal and natural persons.

The tasks of the people who provide care and support services to people with Alzheimer's dementia, regardless of whether it is at home or in an institution, those tasks are carried out on three levels, namely: (1) Hygienic – health, (2) Educational - educational and (3) Spatial – technical.Each of these tasks includes specific subtasks that must be executed to provide the highest quality service to individuals with Alzheimer's dementia. For hygiene and health-related tasks, it is essential to continuously motivate and remind the person of their responsibilities to successfully complete daily activities such as nutrition, dressing, and maintaining personal hygiene. Educational tasks involve planning and organizing recreational activities. Spatial and technical tasks focus on ensuring safety and preparing the environment for planned activities, both indoors and outdoors. By completing these tasks, we aim to achieve the fundamental goal of improving the user's quality of life, enabling them to exercise control according to their abilities and capacities. The execution of each task varies depending on the stage of Alzheimer's disease the individual is experiencing.(Stanojkovska at all, no date).

According to the Alzheimer's Association (2024), dementia caregiving tasks encompass a wide range of responsibilities. These include assisting with instrumental activities of daily livingsuch as household chores, shopping, meal preparation, transportation, scheduling doctor's appointments, managing finances and legal matters, and answering the phone. Caregivers help ensure correct medication intake through reminders or direct administration and support adherence to treatment recommendations for dementia and other medical conditions. Personal activities of daily living assistance includes bathing, dressing, grooming, feeding, and helping with mobility, toileting, and managing incontinence. Caregivers also manage behavioral symptoms like aggression, wandering, depression, agitation, anxiety, repetitive activities, and nighttime disturbances. Additionally, they find and utilize support services such as support groups and adult day programs, arrange for paid care (in-home, nursing home, or assisted living), and oversee other caregivers. They take on broader responsibilities, including overall daily management, addressing family issues related to caregiving, managing other health conditions (comorbidities), and providing emotional support and a sense of security.

2. Research Methodology

The subject of research is the methods of working with individuals with Alzheimer's disease and their families, emphasizing the importance of communication during the implementation of individualized care plans.

This research aims to demonstrate that a well-prepared individualized care plan, combined with constructive communication with family members, can enable individuals with Alzheimer's disease to lead a quality life and potentially slow the progression of the disease.

Research Instruments: Two questionnaires were utilized: one for families with a member who has Alzheimer's disease and another, in the form of an Attitude Assessment Scale, for licensed caregivers trained to work with individuals with Alzheimer's and their families.The Attitude Assessment Scale is a Likert-type scale, where caregivers rated their responses from 1 to 5 (1 - strongly disagree to 5 - strongly agree).

Sample:For the purposes of the research, two convenient samples were used.

The first group of respondents included 17 people – caregivers specially trained to work with people with Alzheimer's disease and their families. Regarding the gender structure, 13 (76%) of the caregivers are female and 4 (24%) are male. Among them, 14 (82%) work in institutions, such as homes for the elderly, and 3 (18%) provide home care through the Citizens' Association "Humanost".According to age, 5 (29%) caregivers are aged 25-30, the largest number of caregivers are aged 35 to 45 or 9 (53%) of them, and in the age group from 45 to 55 there are 3 (18%) caregivers. Regarding the level of education, 8 (47%) of them have primary education, 6 (35%) have secondary education, and 3 (18%) have higher education.Of them, 12 (71%) caregivers have work experience up to 10 years, and 5 (29%) caregivers have experience from 10 to 20 years. Before the start of their work, all of them have undergone 6 months of training, and during the implementation of their work they are in constant coordination with the professional teams of the institution they represent.

The second group consists of 33 family members who have a family member (parent) suffering from Alzheimer's disease and they filled out a semi-open questionnaire. According to the gender structure, 24 (73%) are female and 9 (27%) are male. Depending on the age group they belong to, 10 (30%) of them are between 35 and 45 years old, 17 (52%) are between 45 and 55 years old, and 6 (18%) respondents are over 55 years old.

3. Results and analyses

3.1. Results and analyses of the professionals' perspectives regarding the treatment of Alzheimer's disease and family involvement

Based on the assessment results from professionals working with Alzheimer's patients, it is evident that all respondents concur that treatment should be administered by specially trained professionals using specialized methods, techniques, and approaches to ensure individualized care. Additionally, a significant majority, 94%, believe that addressing the basic needs of those affected will greatly enhance their quality of life.From these responses, we can conclude that professionals believe in their ability to positively impact the lives of individuals with Alzheimer's and their families. This belief is particularly important for maintaining their motivation and professional growth.

Regarding the organization of work, a smaller percentage (18%) absolutely believe that each stage of the development of the disease requires a special approach to work, while the rest of the caregivers (82%) consider this way of organizing work as partially important. However, the answers of the caregivers are very close and we can interpret this minimal difference as a result of the individual experiences that each of them had, which according to the results are close, but not identical.

The responses reveal a dilemma among professionals regarding the positive role of involving family members in Alzheimer's treatment. Only 23% of professionals believe that regular communication with family members is fundamental, while 60% rate its importance as partially important, and 17% as less important. There is a notable disparity in attitudes towards family involvement, with only 23% believing families should be fully involved, 35% considering it partially important, 18% seeing it as somewhat important, and 6% deeming it absolutely unimportant.These data suggest that professionals may not be sufficiently informed or trained about the importance of family involvement, suggesting a need for additional education and development of strategies to more effectively engage families in patient care.

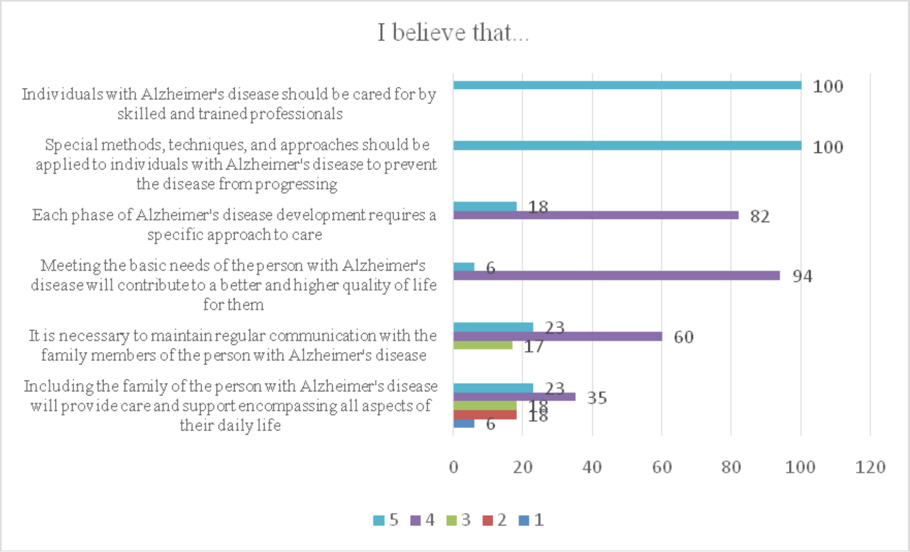

Figure 1: Assessment of professionals' perspectives regarding the treatment to Alzheimer's disease and family involvement

3.2. Results and analysis of perspectives from family members with parents diagnosed with Alzheimer's disease

A semi-structured interview was conducted with 33 individuals who have a close family member suffering from Alzheimer's disease. The duration of the disease varied among respondents: in 21 (64%) families, the diagnosis has been present for the past three years. Furthermore, 11 (33%) respondents reported that their family member has been diagnosed for more than six years, and only one (3%) respondent indicated a duration of eight years. Regarding where they receive the treatment, 19 (58%) respondents pointed out that their family member who has been diagnosed with Alzheimer's disease receives help, care, and nursing at home, considering that he is in the initial phase of the disease, while 14 (42 %) pointed out that their family member is a user of services and is placed in a Home for the elderly.

The respondents listed the first signs they noticed in their family members diagnosed with Alzheimer's. Their answers were almost identical, and included:

- Incoherent talking;
- Forgetting whether she/he ate;
- Forgetting to maintain personal hygiene;
- Forgetting important dates;
- Hiding objects, especially money;
- Denying that there are changes in behavior;
- Refusal to take medication;
- Constantly talking only about a certain period of life;
- Withdrawal and isolation.

All respondents concurred that individuals with Alzheimer's disease should receive care exclusively from skilled, trained, and specialized professionals. They also noted that such services are currently accessible to all families. Regarding their satisfaction with the quality of the services, it was found that all families expressed contentment with the support provided. However, satisfaction was notably higher among those receiving in-home services. These families felt they had greater control over the overall situation and the progression of the disease, which contributed to their higher levels of satisfaction. The personalized nature of in-home care and the ability to be directly involved in the caregiving process were significant factors in this increased satisfaction.

Regarding the involvement of family members in the development of the Individual Care Plan (ICP), all respondents emphasized their full participation and awareness of the plan's details and implementation activities. They reported being actively involved in fulfilling the IWP objectives and engaging in activities as much as their schedules and other commitments allowed.

Moreover, respondents highlighted that the ICP serves as the foundation for effective treatment, contributing to the slower progression of Alzheimer's disease. This sentiment was strongly expressed by 27 (82%) out of the 33 respondents, with the remaining 6 (18%) maintaining a neutral stance. Families acknowledged that the ICP's structured approach is crucial in managing the disease and enhancing the quality of life for their loved ones. Their involvement not only ensures a more personalized care experience but also fosters a collaborative effort in addressing the challenges of Alzheimer's care.

4. Conclusion and recommendations

Social protection for individuals with Alzheimer's disease primarily involves providing social services, including professional assistance, suitable institutional accommodation, home care, and help with daily needs. Ensuring these services are available is essential for granting access to social security and creating equal opportunities for all.

Professionals working with Alzheimer's patients and their families should adhere to the formula:

COMMUNICATION + EMPATHY + TRUST = QUALITY CARE AND SATISFIED CUSTOMERS

This approach balances maintaining a professional relationship and ensuring the user feels genuinely cared for. The guiding motto should be: “I THINK OF THE USER, JUST AS I THINK OF MYSELF.”

Care providers must gather extensive information about the user, including their previous life (hobbies, job, education, interests), habits, routines, likes, and dislikes. The primary focus of their role is the care and engagement of the user through activities they enjoy.

The cooperation between the caregiver, the family, other professionals, institutions, team members, and individuals from the user’s social environment must adhere to fundamental ethical principles, including respect for privacy, security, and confidentiality. In essence, “Alzheimer’s disease can be seen as a reverse process of maturing.”

From the results of our research, we can conclude that there is a consensus among professionals that Alzheimer’s patients benefit most from care provided by specially trained persons who employ individualized methods and techniques. Furthermore, there is a strong belief that meeting the basic needs of these individuals is crucial for significantly improving their quality of life.

We can conclude that there is a lack of consensus among professionals regarding the role of family involvement in the treatment of Alzheimer’s patients. While a small percentage view regular communication and family involvement as fundamental, the majority see it as only partially important, and a notable minority even consider it unimportant. This indicates a need for further discussion and possibly training on the benefits of family engagement in Alzheimer’s care.

These results certainly warrant further analysis. It is crucial to determine whether the professionals’ experiences stem from a disinterested attitude among family members toward involvement in the treatment, or if the professionals lack effective models and techniques for family inclusion. Regardless of the underlying cause, it is imperative to restructure the treatment approach to enhance family involvement. Increasing family participation can provide comprehensive support to Alzheimer’s patients, ensuring a more holistic and effective care strategy. This restructuring may involve training for professionals on family engagement techniques and developing new models that facilitate meaningful family participation in the care process.

The second part of the research allowed us to summarize several things:the necessity of professional care, the benefits of family involvement, and the critical role of individualized care plans in managing Alzheimer’s disease effectively.

Semi-structured interviews with 33 individuals caring for family members confirmed noted early signs of Alzheimer’s included incoherent speech, forgetting meals and hygiene, missing important dates, hiding objects, denial of changes, medication refusal, repetitive discussions about specific life periods, and social withdrawal.

All respondents agreed that Alzheimer's patients should receive care from skilled, trained professionals, noting that such services are accessible to all families. Satisfaction with care quality was high, especially among those receiving in-home services, who appreciated having greater control over the situation and disease progression. Furthermore, family members reported full participation in developing and implementing the ICP, emphasizing its role in effective treatment. They actively engaged in ICP activities, balancing their involvement with other commitments.

To enhance the treatment of Alzheimer's patients and improve collaboration with their families, we propose the following for the future:

- Develop and implement training programs for professionals on techniques to engage families more effectively in the care process.
- Create structured models that facilitate and encourage family participation, ensuring families are well-informed and actively involved in the Individual Care Plan.
- Ensure that professional assistance, suitable institutional accommodations, and comprehensive home care services are widely accessible to all families dealing with Alzheimer's disease.
- Develop policies that support the funding and availability of these essential services.
- Provide ongoing education and specialized training for caregivers and healthcare professionals focused on individualized methods and techniques for Alzheimer's care.
- Emphasize the importance of understanding the patient's history, habits, and preferences to tailor care approaches effectively.
- Encourage open and empathetic communication among caregivers, professionals, and family members to build trust and ensure high-quality care.
- Establish support services such as counseling, support groups, and respite care for families and caregivers to alleviate everyday stress.
- Promote community-based programs that offer social and recreational activities tailored to Alzheimer's patients to enhance their quality of life.
- Conduct regular assessments of the Individual Care Plans to ensure they remain relevant and effective in addressing the evolving needs of Alzheimer's patients.
- Adapt care strategies based on the progression of the disease and feedback from both professionals and family members.

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