


HEALTHY LIFESTYLE HABITS: CHALLENGES FOR CAREGIVERS OF PEOPLE WITH NEURODEGENERATIVE DISEASES

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ABSTRACT

Objective: This study aimed to investigate the challenges that caregivers of people with Parkinson's and/or Alzheimer's diseases participating in the Reviver Project of the Federal University of Amapá face in adopting healthy habits. **Methods:** This is a qualitative and descriptive study, the research was carried out with caregivers of people with Parkinson's and/or Alzheimer's (n=13) participating in the Reviver Project, which has been approved by the ethics committee (66758017.0.0000.0003). **Results:** It was possible to observe that the main challenges to obtain healthier lifestyle habits in this public were lack of motivation (20.51%), lack of time (17.95%), procrastination (15.38%) and financial resources (15.38%). **Final considerations:** The practice of hobbies, the presence of a support network, and adequate rest are fundamental measures to promote the health of caregivers and, consequently, improve the quality of care provided. In this way, the adoption of healthy habits will strengthen and improve the health of these caregivers, providing resources to deal with daily challenges effectively.

Keywords: Healthy Lifestyle; Caregivers; Neurodegenerative Diseases; Alzheimer's disease; Parkinson's disease.

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INTRODUCTION

Based on the historical assumption of humanity, healthy lifestyles were considered as necessary components to promote health for individuals. That is, behaviors molded and adapted according to the environment to develop healthy habits such as: diet, avoiding drug and/or alcohol consumption, practicing physical activity, sleep hygiene and activities that stimulate cognitive function that in addition to benefiting physical health, also contribute to the mental health of human beings.¹

In this context, it is important to highlight that the absence of healthy lifestyle habits can influence the development of chronic non-communicable diseases (NCDs), which are characterized by their non-infectious and non-communicable character, of long duration and slow evolution, with cardiovascular diseases and type 2 diabetes mellitus being highlighted as the main comorbidities associated with the absence of a healthy lifestyle². NCDs were responsible for about 56.9% of deaths in Brazil in 2017, in the age group of 30 to 69 years, and are considered one of the greatest global public health problems today.³ Therefore, the practice of healthy habits is intrinsically related to the prevention of NCDs.⁴

In view of this, it is essential to highlight the caregiver who is the individual who is a family member or not, responsible for providing physical support to people who as a result of certain diseases lose their autonomy and independence, lacking support and assistance to carry out their daily tasks such as going to the market to shop, personal hygiene, identifying signs and symptoms of diseases, administer medications, physical activity and other tasks.⁵

Thus, people affected by neurodegenerative diseases (ND) such as Parkinson's Disease (PD) and/or Alzheimer's (AD), which are specifically characterized by the continuous and progressive loss of neurons resulting in neuropsychomotor disorders that affect language, memory, also causing tremors, bradykinesia and rigidity, thus need a caregiver, since they lose part of their independence and autonomy to continue with their daily routines without difficulties.⁶

Thus, the arduous and exhausting routine of caregivers of individuals with PD and/or AD is transferred to this context, as they have a continuous and exhausting demand to provide proper care, resulting in a physical and mental overload that consequently reduces the caregiver's quality of life, causing significant changes in mood, Sleep disorders altering the circadian rhythm increase the risks of presenting depressive symptoms and cardiovascular morbidity.⁷

In this circumstance, there is a need to implement support networks in psychological and social aspects in order to minimize the physical and mental impact that the overload of care directly causes both on the caregiver and on those affected by PD and/or AD.⁸ From this perspective, the Reviver Research and Extension Project, being interdisciplinary, was articulated to provide multidisciplinary care to people with PD and/or AD and their respective caregivers as a factor in promoting health and quality of life.

Thus, weekly meetings are held with the purpose of providing a welcoming environment to welcome them and offer health care in order to alleviate not only the symptoms of the disease that affects patients, but also to reduce the harmful symptoms to the caregiver through health education interventions, in order to mitigate the effects generated by the overload due to the act of caring.

This research was conducted by the nursing team that works mostly caring for those who care, in view of the essentiality of the nursing professional when it comes to health education, since through educational approaches, the nursing professional is able to positively influence the choices and behaviors that patients should assume, as well as to enable them with the necessary knowledge to make decisions when these can influence their state of health. health.⁹

Therefore, aiming to implement life changes that mitigate the deleterious symptoms of harmful practices to the health of these caregivers, this study aimed to understand the challenges related to healthy lifestyle habits faced by caregivers of people with PD and/or AD participating in the Reviver Project of the Federal University of Amapá (UNIFAP), as well as to analyze their knowledge about measures that help them in this practice.

METHODS

TYPE OF STUDY

This is a qualitative and descriptive study, which is characterized as a result that cannot be translated by numbers, since the researcher is the key instrument for the analysis of the data obtained.¹⁰

POPULATION AND SAMPLE

The research was carried out with PD and/or AD caregivers (n=13) participating in the Reviver Research and Extension Project.

PLACE OF STUDY

The Reviver Project is linked to UNIFAP, located in the municipality of Macapá-AP, the study took place in the Nursing Block of the institution.

DATA COLLECTION

Data were collected at a meeting between the nursing team and caregivers in February 2024. The meeting began with an educational lecture on obesity and discussed the harmful effects of an unbalanced diet and lack of physical activity and the impacts that this could bring to the lives of caregivers.

After the lecture, a structured questionnaire was applied, prepared by the authors, which sought to verify the challenges faced by caregivers to obtain healthy habits, as well as intervention measures so that these caregivers could include them in their routine, thus helping in the development of new healthy habits. The questionnaire listed 14 (fourteen) obstacles to the adoption of healthier lifestyle habits, caregivers should choose 5 (five) that most identified themselves, the order of selection should reflect the intensity of identification, attributing the number 1 (one) to the most relevant problem and so on until the 5th (fifth). Then, they described possible solutions for each of the 5 (five) problems previously ranked.

DATA ANALYSIS

The exclusion criterion was not adequately filled out of the instrument. Excel 2016 was® used for data tabulation. From the tabulated data, it was possible to obtain descriptive statistics of frequencies and percentages.

ETHICAL PROCEDURES

The Ethics Committee of UNIFAP (CAEE 66758017.0.0000.0003) follows all the rules of Resolution 466/2012 of the National Health Council, which establishes the conducts for studies involving human beings.¹¹

RESULTS

The Reviver Project during the meetings at UNIFAP serves PD and/or AD patients and their caregivers with a multidisciplinary team that aims to improve their quality of life. The nursing team holds weekly meetings specifically with caregivers in order to work on

various themes focused on health education in order to improve the habits of these caregivers, as well as the caregiver-patient relationship.

The topics addressed during the meetings are always chosen in advance so that it is possible to carry out dynamics and, when necessary, to apply questionnaires in order to evaluate the profile of these caregivers, considering that the work focused on them is still scarce.

With the analysis of the questionnaires, it was possible to identify the main challenges (Figure 1) to obtain healthier lifestyle habits in caregivers of people with PD and/or AD (n = 13), among the most frequent are: lack of motivation (20.51%) and lack of time (17.95%). Other factors such as: work, mental exhaustion, lack of support, location of residence, devaluation of healthy habits, health problems and overload together add up to 30.73% of the problems faced in acquiring a healthy lifestyle.

Figure 1. Challenges for healthy lifestyle habits in caregivers of people with Parkinson's and/or Alzheimer's Diseases from the Reviver Project (n=13). Macapá, AP, Brazil, 2024.



In addition, the caregivers presented intervention measures in the face of the challenges exposed by them about the adoption of healthy habits, these intervention measures aimed to encourage them to set goals to obtain healthy habits in their daily lives. Among them, we can emphasize the following positions of caregivers:

C1: *"Take advantage of free time and rest when necessary, because it is important"*

C2: *"Be with people who motivate you to develop healthy habits"*

C3: *"Do more activities that make me happy"*

C4: *"Plan your day to day to be able to organize your routine and have time for a healthier life"*

C5: *"Having someone to help motivate me"*

DISCUSSION

Many families, throughout their lives, face situations of illness and need to assume a new role: that of caregiver. Family care becomes an important resource to contribute to the patient's improvement, even if the people who assume this role are not previously prepared to perform tasks that would normally be done by trained professionals. Family caregivers are typically a part of the informal support network, which includes relatives, friends, acquaintances, and neighbors, and work without pay.¹² Thus, in the context of this study, this new role is experienced through a series of diverse needs and feelings, because when a disease such as AD and/or PD affects a family, it makes one of its members dependent, thus there is a need to adapt the individual's daily activities, the family budget, and this new role usually falls on this family caregiver.

The family caregiver of elderly people with neurodegenerative diseases plays an essential role in the patient's life, assuming various responsibilities and being the main responsible for providing or coordinating the necessary resources for care. In this context, it is crucial to highlight the quality of life of the caregiver, who often faces a physical and emotional overload resulting from constant care. This exhaustion manifests itself in stress, tiredness, sadness, irritability, frustration and loneliness, emotions that arise from daily contact with the patient. In addition, these caregivers are unprepared to face the situations resulting from care, evidencing conflicting feelings of denial, guilt, commotion, obligation and seclusion.¹³ Thus, it is inferred that these factors exert a considerable influence on the care offered to the patient. Therefore, paying attention to the caregiver's needs becomes indispensable in this process.

Between 2020 and 2021, the study carried out in Palmas, located in the state of Tocantins, found that 91.84% of caregivers were sedentary, in addition, 81.63% consumed alcohol at a low level, and 68.29% were overweight.¹⁴ Therefore, it becomes evident that a sedentary lifestyle, obesity, and nutritional disorders are risk factors for the prevalence of chronic diseases and the absence of physical activity does not mitigate these factors, and certainly generate cardiovascular and metabolic consequences, and especially with

inadequate diet there will be a deficiency of micronutrients such as essential vitamins that directly impact blood health, such as vitamin B12 and vitamin D, which impacts health of the bones. Based on this assumption, it is notable that healthy eating improves the quality of life of the caregiver in the physiological and mental spheres.¹⁵

Thus, carrying out interventions that are aimed at supporting informal caregivers becomes extremely important, since there are gaps in these interventions to improve the health and well-being of these caregivers, especially those who are low-income and underserved, in which they may face significant challenges to support and care services for their patients.¹⁶ With the implementation of projects that are also aimed at this caregiver, it is possible to teach them possible alternatives to be adopted in their daily lives, helping to improve the caregiver's and patient's diet.

In addition, as discussed in a recent study, healthy habits play a fundamental role in the integral development of individuals. The research highlights that practices such as a balanced diet, adequate sleep, and regular physical activity not only improve physical health, but also directly impact mental health. Healthy eating, rich in essential nutrients, is crucial for optimizing cognitive functions and promoting neuroplasticity, allowing the brain to adapt and learn more effectively. In addition, adopting healthy habits can reduce the effects of stress and anxiety, creating an environment conducive to learning and emotional well-being.¹⁷ Thus, integrating healthy habits into the caregivers' routine is essential not only to promote a balanced lifestyle, but also to ensure a more satisfactory performance and a better quality of life.

Subsequently, it is common for people to postpone important tasks at some point in their lives, which is known as procrastinatory behavior. This tendency is not something simple to measure or understand in a linear way, as it can be influenced by several factors, for example, someone can procrastinate not only by deliberate choice, but also by lack of knowledge about how to perform the task or by feeling aversion to it.¹⁸ Thus, it was noticed that caregivers report that the daily demands they face often prevent them from exercising or eating at the appropriate times, thus prolonging these habits, thus, it is essential to investigate the reasons that lead to procrastination so that effective intervention measures can be established.

Through the meetings and conversation circles with the caregivers, it was possible to observe that this contact between caregiver and elderly, and in the case of this study, elderly people with AD and/or PD, began over time to generate individual and social

obstacles in the care area itself, and these aspects are relevant, especially when caregivers also report that the lack of time management makes them dedicate their lives to the patient with PD and/or OF.

Prior planning allows you to make informed decisions and determine the necessary steps to achieve goals, the planning process helps to identify personal values and goals, understand the state of health, in addition to allowing individuals to reflect on the consequences necessary for the moment they are living, which is a neurodegenerative disease.¹⁹ Therefore, having a plan to carry out activities aimed at a healthier life is essential, and this practice includes leisure activities that also play a significant role in this process.

Planning allows caregivers to anticipate patients' needs and prepare appropriately for challenging situations, given that caring for individuals with ND requires constant knowledge and preparation, as symptoms and needs can change rapidly, and these caregivers often face high levels of stress and exhaustion, which can lead to physical and mental health problems, and planning would be an alternative to include healthy practices in daily life.

Based on this study, it was observed that 17.95% of the caregivers do not adopt healthy habits due to lack of time, which, in most cases, is dedicated to the care of PD and/or AD patients, because they have difficulties in finding time for self-care activities, such as physical exercise, preparation of healthy meals, leisure, among others. In view of this, caregivers usually neglect their own care, increasing the chance of developing health problems both physically and mentally due to unhealthy habits.²⁰ These issues can impair their well-being and negatively impact the quality of care provided.

It is understood that physical activity is one of the ways to obtain healthy habits, from the perspective of the study carried out with the adolescent public, accusing that 63.6% of the respondents mention not performing physical and/or sports activity due to lack of motivation.²¹ According to them, it is necessary to deepen these motivations in order to obtain data to support this argument. Likewise, it was observed that the lack of motivation to adopt healthier lifestyle habits became a central point among caregivers, resulting in the absence of initiatives to achieve a better quality of life.

Physical exercise is an important practice that generates well-being for human beings, in consonance, the regular practice of physical exercise promotes numerous benefits to the health of the body and to the cognitive functions of the brain, including:

improves memory, learning, causes a feeling of well-being and pleasure, reduces anxiety and depression, increases disposition, among others.²² This practice stimulates the production and release of neurotransmitters that help regulate various functions of the human body, by balancing the levels of these substances in the brain, physical exercise can compensate for deficits or excesses, improving overall performance.²³ Thus, based on the reports, it is evident that there is a desire to use physical activity as a means to increase well-being. This underscores the importance of this practice, as it demonstrates the search for a deeper connection between body and mind, seeking to achieve a state of harmony and wholeness.

In this context, adequate sleep and rest are also essential for physical and mental health, in addition to contributing to various functions in the body, such as proper brain development, cell repair and memory consolidation. Thus, the need for adequate rest is notorious, especially for caregivers, since they must be in adequate health to develop the necessary care for patients. In addition, studies show that sleep disorders are related to the development of dementias such as AD.²⁴ Therefore, the need for caregivers to have appropriate rest and sleep for the care provided to be effective is undeniable.

Engaging in activities that provide personal pleasure can have positive impacts on a person's overall well-being, offering experiences ranging from feelings of freedom and creativity to simple satisfaction.²⁵ In this perspective, it is known that there is a relationship that is closely associated with the habits of practicing leisure activities and the physical, mental and social health of the caregiver, as a simple rest provides freedom from their obligations to provide care, feeling free to choose the activity they will perform. These moments of pause bring strength, stress relief, peace, tranquility, factors that contribute significantly to health.²⁶

As mentioned in the account, having someone to help motivate is crucial to addressing the challenges that come with caring for another person. In addition, it is essential to emphasize the importance of interpersonal relationships that play an important role in reducing stress and promoting emotional balance, essential factors for effective performance as a caregiver. Interaction with others also provides opportunities to share experiences, exchange knowledge, and receive guidance that contributes to a better quality of life for both the caregiver and the individual in their care.²⁷

Creating a social support network can have a substantial impact on promoting the health of caregivers. The presence of a support network is essential for a caregiver,

especially when it comes to maintaining healthy habits and motivating oneself on a daily basis. This support network can consist of family members, friends, healthcare professionals, and specific support groups for caregivers.²⁸ Thus, it was possible to observe that when the caregiver is surrounded by people who value health and well-being, he finds an environment conducive to developing and maintaining healthy habits.

In this context, it is crucial to emphasize the value of active listening as an effective means of promoting health. This pioneering study in the state emphasizes the vitality of health education, enabling future nurses to improve their skills when listening to these caregivers. This improvement not only increases sensitivity and attention in the provision of care, but also contributes significantly to improving the quality of care.

STUDY LIMITATIONS

The limitations of the study involve the lack of control over all the factors that can influence the healthy lifestyle habits of the public studied. Although we conducted a comprehensive analysis of the main barriers and facilitators to the adoption of healthy habits, we cannot exclude the possibility of other personal and social aspects that were not considered in this study due to the small sample size.

CONTRIBUTIONS TO PRACTICE

Nurses play a crucial role in the health education of patients and caregivers, by highlighting the relevance of healthy habits, such as physical activity and a balanced diet, to improve quality of life. It is essential that knowledge about this topic is always stimulated, thus allowing individualized care to be offered according to the specific needs of each patient.

FINAL CONSIDERATIONS

It is possible to infer that the challenges faced by caregivers are diverse, involving emotional, physical and social aspects. It is observed that the overload of tasks, lack of time for self-care and procrastination are just some of the issues faced by them on a daily basis, and such issues interfere with the care provided to their patients with PD and/or AD.

Thus, the practice of hobbies, the presence of a support network and adequate rest are fundamental measures to promote the health of caregivers and, consequently, improve the quality of care provided. Such surveys highlight the importance of specific support

policies and programs that address these challenges and promote the integral health of caregivers, thus ensuring more effective and humanized care for patients with PD and/or AD.

In this way, encouraging the adoption of healthy habits can strengthen and improve the health of these caregivers, providing resources to deal with daily challenges effectively. Finally, it is noteworthy that caregivers felt motivated and aware of the benefits of practicing healthy habits, as it is emphasized that investing in their own health is essential to ensure an efficient long-term provision of care, benefiting not only the caregiver, but also the caregiver.

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