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EXPERIENCE IN CARING FOR THE OLDER PEOPLE WITH DEMENTIA IN THE HOME ENVIRONMENT: A QUALITATIVE SYNTHESIS OF EVIDENCE

Experiência em cuidar de idosos com demência no ambiente domiciliar: uma síntese qualitativa de evidências
Experiencia en el cuidado de mayores con demencia en el ambiente doméstico: una síntesis cualitativa de evidencia

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ABSTRACT

Objective: to understand the experience of family caregivers in caring for older people with dementia in the home environment. **Methods:** a systematic search for qualitative studies and a thematic analysis was carried out to synthesize the results. **Results:** nine studies were included. Four analytical themes emerged. Recognizing dementia and unraveling care; “You are alone”; Limitations and lack of knowledge in caring for dementia; “It’s a last resort [full institutionalization nursing home].” The older people’s loss of autonomy generated feelings of grief and loneliness. Limited knowledge about dementia has given rise to awkward care. Temporary care was perceived as a solution to the need for help. However, institutionalization was approached as a last alternative. **Conclusion:** the results obtained are important to provide support for the creation of more humanized public policies that consider comprehensive care, assist health professionals in providing care to older people with dementia and their families.

DESCRIPTORS: Integrality in Health; Family; Caregivers; Cognitive Dysfunction; Institutionalization.

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RESUMO

Objetivo: compreender a experiência de cuidadores familiares no cuidado de idosos com demência em ambiente domiciliar. **Métodos:** foi realizada uma busca sistemática por estudos qualitativos e análise temática para sintetizar os resultados. **Resultados:** foram incluídos nove estudos. Emergiram quatro temas analíticos: Reconhecendo a demência e desvendando o cuidar; “Você está sozinha”; Limitações e desconhecimentos no cuidar com demência; “É um último recurso (colocação em instituição de longa permanência)”. A perda de autonomia dos idosos gerou sentimentos de luto e solidão. O conhecimento limitado sobre demência suscitou em um cuidado inábil. Os cuidados temporários eram percebidos como uma solução frente à necessidade de ajuda, porém, a institucionalização foi abordada como uma última alternativa. **Conclusão:** os resultados obtidos são importantes para fornecer subsídio para a criação de políticas públicas mais humanizadas que considerem a integralidade no cuidado, auxiliar profissionais de saúde na prestação de cuidados aos idosos com demência e sua família.

DESCRITORES: Integralidade em Saúde; Família; Cuidadores; Disfunção Cognitiva; Institucionalização.

RESUMEN

Objetivo: comprender la experiencia de los cuidadores familiares en el cuidado de personas mayores con demencia en la residencia. **Métodos:** se realizó una búsqueda sistemática de estudios cualitativos y un análisis temático. **Resultados:** se incluyeron nueve artículos. Surgieron cuatro temas analíticos: Reconocer la demencia y deshacerla atención; “Estás sola”; Limitaciones y ignorancia en el cuidado de la demencia; “Es un último recurso [institución de larga permanencia]”. La pérdida de autonomía de los ancianos generó sentimientos de dolor y soledad. El conocimiento limitado sobre la demencia ha dado lugar a cuidados incómodos. El cuidado temporal fue una solución a la necesidad de ayuda, sin embargo, la institucionalización se abordó como última alternativa. **Conclusión:** los resultados obtenidos son importantes para apoyar la creación de políticas públicas más humanizadas que consideren la atención integral, ayudar profesionales de la salud en la atención a las personas mayores con demencia y sus familias.

DESCRIPTORES: Integralidad en Salud; Familia; Cuidadores; Disfunción Cognitiva; Institucionalización.

INTRODUCTION

Aging, as well as frequent health conditions among the elderly, such as dementia, lead to dependence, disability and loss of autonomy, increasing the complexity of geriatric care.¹⁻² Currently, 47 million people live with dementia worldwide, and about 70% of them are in the community.³ Moreover, the incidence of dementia is expected to continue to rise, especially among older people.⁴

Dementia is a chronic and progressive disease that can be caused by a variety of brain changes affecting behavior, memory, and the ability to perform basic activities of daily living (ABVD) and instrumental activities of daily living (IADL).⁵ It is a major cause of dependency and can be considered a destructive disease that takes away an individual's autonomy.¹

The family continues to be the foundation of care for the elderly with dementia around the world, which causes changes in family dynamics that can generate stress and multiple and complex personal and interpersonal conflicts.⁶ The gradual and prolonged progression, and the scarcity of treatments that cure or considerably modify the course of the clinical picture, make caring for an individual with dementia a burden that can last for several years.¹

In this context, the burden caused by caregiving is remarkable and negatively influences the caregiver's quality of life. Understanding this experience is relevant to foster empathy and the adoption of actions that help family members in the

provision of care. Thus, the objective of this study is to understand the experience of family caregivers in caring for elderly people with dementia in the home environment.

METHODS

A qualitative synthesis was conducted, following the guidelines of the Preferred Reporting Items for Systematic reviews and Meta-Analysis⁷, from question formulation to data analysis.

Search Strategy

The systematic search for qualitative studies was conducted in November 2018 in the electronic databases MEDLINE (PubMed), Cochrane Library, and LILACS, in addition, manual and gray literature searches were conducted. The search strategy for this research was prepared using an adaptation of the PICO model for PICO (with the lowercase “o”), where: the “P” refers to Participants; “I”, to the phenomenon of Interest; and “C”, to Context.⁸ For each database, a specific strategy was built with the MeSH descriptors – “Caregivers”, “Qualitative Research”, “Narrative Medicine”, “Personal Narratives as Topic”, “Aged” and “Frail Elderly” – and the combination of them with their synonyms.

For manual search, the authors checked whether there were any articles in the topic of this qualitative synthesis in all journals in which the included articles were published (in the years 2017

and 2018) and also searched the reference lists of the included studies. The gray literature search was conducted on articles from non-indexed journals that publish in the field of geriatrics and gerontology.

Eligibility Criteria

Family caregivers were defined as persons of either sex, 18 years of age or older, who had some degree of kinship with the elderly receiving care, such as, spouses, siblings, children, sons-in-law, and grandchildren. The criteria for including or excluding articles for the present synthesis are presented in Chart 1.

Study selection

After removing duplicates, the articles identified in the search were assembled in the Rayyan[®] software. First, two reviewers read the title and abstract of all selected articles simultaneously and blinded.⁹ Disagreements were resolved by a third reviewer. Then, the articles that met the eligibility criteria were read in their entirety, independently, to confirm their inclusion in this qualitative synthesis.

Evaluation of the methodological quality of the included studies

The quality assessment of each study included in this research was independently performed by two authors and guided by the guidelines of the Critical Appraisal Skills Programme.¹⁰ The maximum score of this checklist is 10 points, and the higher the score, the higher the quality of the studies. In this qualitative synthesis, articles with a score less than or equal to five were excluded.

Data extraction and thematic analysis

All data were independently extracted by two reviewers: data on study characteristics – country, objective, study design, sample size, data collection methods; and data for thematic analysis extracted from the results topic of the included studies. The texts of each study were organized and analyzed in QSR's Nvivo[®] software, and the thematic analysis was performed in three steps: Stage 1 – the results of each study were coded line by line and

these codes were examined and compared with the other studies repeatedly; Stage 2 – the existing codes were related and grouped, forming descriptive themes, which are still very close to the themes of the original studies; Stage 3 – the descriptive themes were examined repeatedly, to generate the analytical themes, through the interpretations and new constructs of the authors of this research. In the last step, the researchers went beyond the results of each included study and generated the analytic themes of this qualitative synthesis, which were examined and validated by all the authors of this synthesis.

RESULTS

A total of 4,912 publications were found, of which nine met the inclusion criteria (Figure 1). Information regarding 184 caregivers from 14 countries was included from articles published between 1999 and 2017. Chart 2 presents the main characteristics of the included studies, as well as the evaluation of their methodological quality.¹⁰

In the final analytic step of the thematic analysis, four analytic themes were generated: Recognizing dementia and unraveling caregiving; “You are alone”^{16:11}; Limitations and unknowns in dementia caregiving; and “It is a last resort (placement in a long-term care facility)”^{18:1187}.

Recognizing dementia and unraveling caregiving

The symptoms of dementia can be noticed in the context of loss of objects, money, traffic and domestic accidents.¹²⁻¹³ Moreover, the symptom of forgetfulness is perceived more by family members than by the elderly: “We discovered the disease because she left the gas open, so much so that sometimes the neighbors would pass by on the street and say: ‘Lady, the gas is open [...]’.”^{12:304}

Forgetfulness, present in dementia, generates loss of autonomy in the elderly. Initially, the performance of IADLs, such as taking medications, cleaning the house, and preparing meals, becomes the caregivers' responsibility.¹³⁻¹⁴ As the elderly present a more pronounced cognitive decline, the ABVD, such as bathing, dressing, and eating alone, also become performed with the support of the caregiver.^{5,13}

Chart 1 – Inclusion and exclusion criteria of the articles identified in the literature search. Belo Horizonte, MG, Brazil, 2022

Inclusion Criteria	Critérios de exclusão
<ul style="list-style-type: none"> - Articles published and indexed in English, Spanish or Portuguese, but with no publication date limit; - Publication of qualitative studies that used interviews and focus groups/group discussions; - Studies including caregivers of older adults aged 65 years or older with a diagnosis of dementia or presence of cognitive decline or who use medications to improve cognition, who live in the community (aged 60 years or older if from a developing country). 	<ul style="list-style-type: none"> - Opinion-based studies, literature reviews, study protocols, and mixed-methods studies; - Studies including other participants (e.g., formal caregivers, care recipients, and/or care professionals); - Studies that included family caregivers whose care recipients did not have a diagnosis of dementia or presence of cognitive decline or who use medications to improve cognition; - Studies that included caregivers who no longer performed the role of primary caregiver when the research was conducted; - Studies focusing on caregivers' perspectives related to experiences with health care systems, transitions of care (such as hospital discharge), or clinical interventions to which care recipients have undergone.

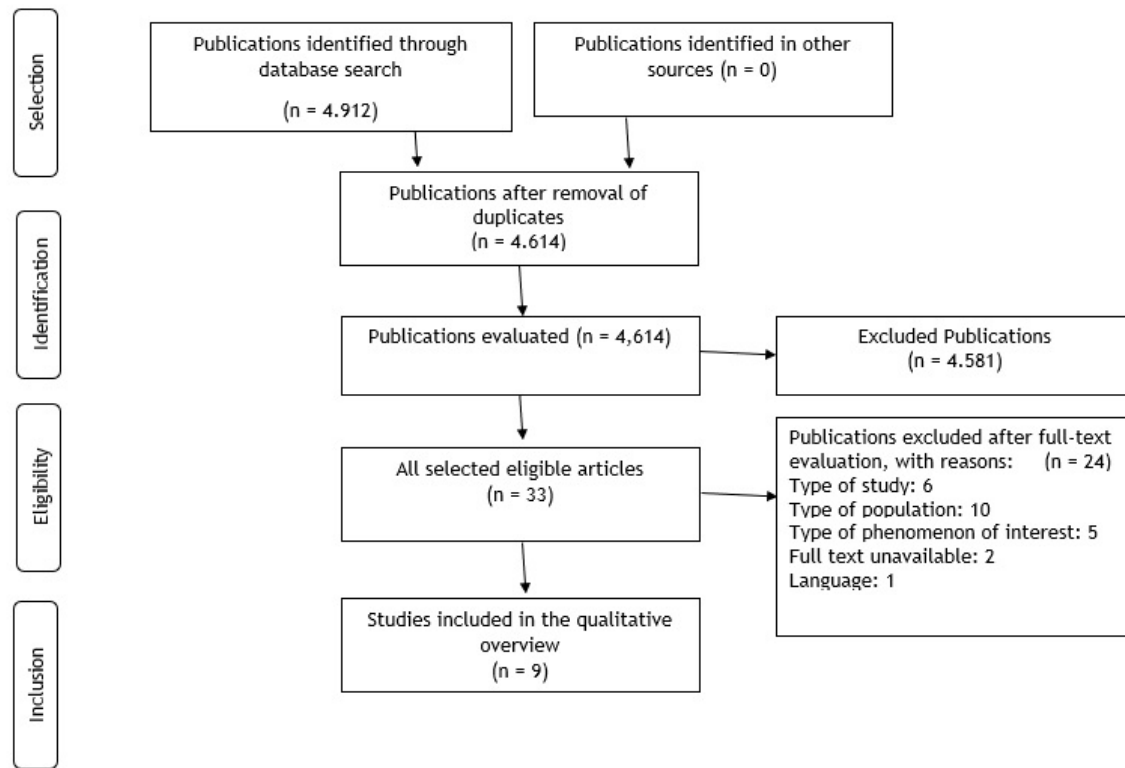


Figure 1 – PRISMA Flowchart: study selection process for qualitative evidence synthesis. Belo Horizonte, MG, Brazil, 2022

The elderly's dependence and the risks of inappropriate actions due to forgetfulness raise feelings of insecurity and fear of leaving the elderly alone, and end up changing the family dynamics and motivating caregivers to provide exclusive care¹¹: "I quit my job, my house, to take care of her [...]"^{12:305}

Integral care involves a responsibility, which brings with it a physical and psychological effort¹²⁻¹⁵. The support in performing the ABVD provoked in the caregivers a feeling of weariness, producing a discontentment, especially when the disinterest of the elderly individual in performing personal hygiene was experienced: "Bath time is difficult for me, because she doesn't like to take a bath, so we have to keep asking for a time until she goes into the bathroom"^{12:304}

Feelings of self-sacrifice, sadness, isolation, and anguish also surfaced when the caregivers adapted their routine to perform their role as caregiver.¹⁶ In parallel, due to the elderly's behavioral and functional changes, the family caregivers felt limited to leave the house, negatively impacting their physical and emotional well-being.¹⁵

Specifically in the case of spousal caregivers, specific demands were observed in the new caregiving responsibility. The expansion in the role of husbands, for example, was reported in the face of the need to perform domestic tasks originally performed by their wives. One of the most critical changes noted by spouses was associated with the need to assume responsibility for their wives' personal care. Some commented that they had not anticipated their indispensability in supporting the performance of ABVD.¹³⁻¹⁴ A caregiving spouse stated:

So in the shower, I used to get in and we'd both take a bath, but she didn't like me washing her hair because I'd get soap in her eyes. So I solved that problem by making her go to the beauty salon once a week to wash her hair, and I just give her the bath.^{14:45}

The progressive dependence for daily survival and the caregivers' concerns for the elderly increase as dementia progresses, further transforming family relationships and the stability needed to care and live. From this perspective, caregiving was expressed as obligation, generating tension and limitation that affected the caregiver's sense of independence.^{12,16} As can be noted in the speech, "I have always been a person used to freedom of movement and now I feel very tied down [...]"^{17:7}

"You are alone" ^{16:11}

Daily living alongside a family member with dementia has been shown to have a psychological burden of worry, frustration, loneliness, and grief.^{12,14,17} The reported experience of loss configured the caregivers' sense that the person with dementia was losing their memories and personality. Statements such as "my spouse is no longer there" elucidate deep and painful changes in family relationships.^{13-14,17} Grief was associated with transformations in marital relationships, as can be exemplified with the following account of a spouse when describing his feeling in the face of the ephemerality of their relationship: "I know I'm losing her, and from time to time you feel sorry for yourself and allow yourself to suffer. Brief moments of weakness."^{14:49}

Chart 2 – Key characteristics of included studies and assessment of methodological quality. Belo Horizonte, MG, Brazil, 2022

Year/Country	Purpose of the study	Design	Sample	Methods	CASP (10)
(1999), European Union (except Germany) ¹³	To understand the experience of caregivers of older people with dementia, considering that their beliefs and attitudes are culturally influenced to the different countries where they reside and important for understanding caregivers' feelings and behavior.	Content Analysis	20 caregivers (spouses)	Semi-structured interviews.	8
(2005), England ¹⁹	To explore the coping experiences of spousal caregivers of older adults with dementia.	Phenomenology	46 caregivers (spouses)	Semi-structured interviews. Analysis guided by an adaptation of Sketch of a Psychological Phenomenological Method by Amadeo Giorgi.	8
(2006), Japan and USA ¹⁸	To explore how cultural values interfere with the experiences of caregivers of older adults with dementia by comparing caregivers residing in the United States of America and Japan.	Comparative Data Analysis	16 caregivers (12 daughters, 3 daughters-in-law and 1 niece)	Unstructured interviews. Analysis guided by the constant comparative technique (Glaser; Strauss and Corbin).	8
(2009), United States ¹⁴	What are the changes in social roles, responsibilities, and relationships that husbands experience while caring for their wives with chronic illnesses?	Phenomenology	17 caregivers (spouses)	Semi-structured interviews. Creswell guided analysis.	10
(2010), Brazil ¹²	To reveal the knowledge and care system of family caregivers of older adults with Alzheimer's disease.	Taxonomic and cultural domain analysis	14 caregivers (6 spouses, 4 sons/daughters, 1 sister, 1 niece, 1 granddaughter and 1 cousin)	Semi-structured interviews. Analysis guided by Spradley.	8
(2013), USA ²⁰	To describe the experience of spousal caregivers of people with dementia who reported finding meaning in their care.	Thematic Analysis	11 caregivers (spouses)	Semi-structured interviews. Boyatzis guided analysis.	10
(2016), India ¹⁵	Finding relevant themes of the lived experience of family caregivers of people with dementia in view of the use of coercive measures in the community setting in South India.	Phenomenology	13 caregivers (12 sons/daughters and 1 daughter-in-law)	Narrative interview. Analysis guided by interpretative phenomenological analysis.	8
(2017), Sweden ¹⁷	To understand the experiences of family caregivers in urban and rural areas and the sociocultural spheres that these two areas represent.	Hermeneutical approach	23 caregivers (18 spouses and 5 children)	Open in-depth interviews. Ödman guided analysis, whose methodological foundation is based on the philosophy of Ricoeur and Gadamer.	10
(2018), Australia ¹⁶	Examine the health needs of partner and child caregivers of older adults with dementia, including the barriers they face in meeting their needs.	Thematic Analysis	24 caregivers (12 spouses, 12 children)	Semi-structured interviews.	10

The behavioral disturbances of the elderly with dementia also interfered with family relationships, generating physical and emotional wear and tear for the caregiver and requiring patience, understanding, and the need for constant supervision from the family.¹²⁻¹⁴ Another point that affected interpersonal relationships was the impairment of communication between caregivers and the elderly. This generated a sense of distress in the caregivers.¹⁷ The replacement of satisfying conversations with repetitive questions and delusional speech was reported by caregivers as one of the most challenging experiences they faced.¹⁸ "He is no longer the man he was. You lose your husband. When I come home full

of stories, I don't tell them. It takes a long time to explain. Your language and understanding are severely affected."^{13:664}

The loss of the relative who developed dementia leads to the precariousness of social relationships previously maintained by the caregiver individually or together with their partner.¹⁶ Feelings of isolation, entrapment, lack of personal space and independence were expressed when caregivers compared their past with the present showing a solitary act of caring:^{12,14,17.}

I just don't do anything at the moment, I just don't... I would love to have a job, I would love to see my friends more,

which I don't do anymore. Some days I don't shower, which is horrible – well, I'm exhausted by the time shower time comes – and then I go to bed.... I am simply too tired to do anything, and I am sick of the 'how is your mother?' when I talk to my friends. I don't want to talk about it. And then I get upset and cry and think 'oh God'. And then I kind of think, 'no, I don't want to see anybody because I'm just miserable. So it's easier to stay away from everybody.'^{16:11}

I lost my partner in life. Retirement and not being able to do things that would be part of retirement. And you meet friends, and they talk about their trip to Japan and their trip to China and America, and what they're going to do next year, and you know that none of that is an option. And even doing things alone; when you have time for personal things, you are alone.^{16:11}

The sense of isolation, powerlessness, and weariness was reinforced as a consequence of an accumulation of activity coupled with a lack of cooperation from other family members.^{12,15} “In my opinion, from the middle of last year until now, I say I am emotionally exhausted.... You're really dealing with the formal pragmatic side, rather than your own side; yes, you don't have time to go to a therapist.”^{16:10}

Acceptance of the caregiving role was mentioned as an inevitable part of life, and for some caregivers, caregiving was seen as an expected career.^{17–18} However, for some respondents, the title of caregiver was conferred only on professionals, and spouses' self-identification as caregivers was not advocated.¹⁹ A preference for preserving their family role was highlighted, although caregiving was reported as a job or service. The fear of losing their role as family members and of no longer being considered a spouse, a child, and of being recognized only as a caregiver could be observed. The family member did not want to be named as a caregiver in the formal sense or did not imagine themselves in this role, which is conflicting as observed in these accounts, “I never thought that [being described as a caregiver] means that I just started the job and that's it.”^{18:1187}

“[...] I'm going to be a good husband and not a caregiver.”^{19:124}

Limitations and unknowns in dementia caregiving

Family caregivers' knowledge about dementia is limited, generating difficulties in understanding the progression of the disease and leading to care unprepared for its peculiarities. Consequently, there are reports of stress and conflictive behaviors.^{12,15}

It's worse than children, because children you shout and threaten, and they end up doing what you want. She doesn't. Sometimes I say things she shouldn't do. Sometimes I say some things that she shouldn't do, and I get angry and then I feel remorse. I say, 'Let's go to bed,' I put her in the bedroom, turn around, and before I know it, she is already behind me.^{12:305}

Performing inappropriate or futile activities with the elderly that further frustrated the caregiver was described by some of them.¹² They believed, for example, that with effort, cognitive losses could be restored, as illustrated in this line:

This business of me forcing her memory. [...]. It's complicated when you see a person who was a Portuguese teacher today not knowing how to write, read or even count. For me this is very complicated. Because of this, I force her head, make her spell words, make her do math [...]. I do it because of my difficulty to face a person like her becoming like that.^{12:305}

Functional alterations such as incontinence and excessive salivation were among the reasons given by caregivers to limit themselves and family members with dementia from participating in social events. Restrictions in offering liquids and solid foods were even reported, despite being requested by the elderly, in order to reduce the frequency of fecal or urinary habits.¹⁵

Forced isolation was used as a way to deal with behavioral problems at specific times, such as when receiving visitors. Another way of providing behavioral control adopted by the caregivers was the administration of higher than prescribed doses of medication. Such practice was also done with the intention of facilitating a few hours of rest, or a night's sleep for themselves.¹⁵ “The medication wasn't working... so we take more and change it again... let's sleep a little bit.”^{15:1662}

“It's a last resort (placement in a long-term care facility)”^{18:1187}

Overload is evident in the routine of family caregivers, and the use of temporary or long-stay services could be considered alternatives for work reduction. Caregivers expressed physical and emotional exhaustion, lack of temporary and shared care, and absence of community support services.^{15,18} The desire for help and relief was expressed by some caregivers in the face of the burden and complexity of caregiving as can be observed in these narratives:

Around 2 o'clock, she goes to sleep. By then I have to feed her and take her to bed. Then I will have an hour and a half of rest in the afternoon. After 5 o'clock, again, a lot of things will happen. Shopping and other things... I have to get everything ready for the next day. At 7:30 she has to be fed and at 8 o'clock she has to be taken to bed. When she goes to bed, I can't leave her, can I? That is the routine. How can I go to a doctor and learn these things? Is there someone? Where is there someone who can relieve me?^{15:1662}

The main thing I do is get her dressed. Put her to bed. I have to use the elevator. I get her out of bed and put on her clothes. Then I have to feed her and give her all the medicines. She takes about 15, 16 different kinds of medications. It's too much to handle without help.^{14:46}

The desire to relieve the psychophysiological demands of caregiving were expressed by a considerable number of caregivers, ranging from having privacy to read a book, to using regular support for care.¹⁹ However, the time off from the care routine was not always seen as an opportunity for relaxation; many saw this time as an opportunity to perform tasks: “Yes! It was wonderful when I was alone for a whole day. Even if I didn’t go out shopping, I tinkered in the garden, in the car, or with anything, and I felt free.”^{19:1186}

Fear was reported when respite care was considered a more practical way to caregiving needs, as an example the fear of dependence on these services; of being worse spouses; of annoying their partners; or of making the situation worse. In some circumstances, feelings of guilt and anxiety emerged when this kind of “respite” from caregiving was enjoyed:^{18,20} “I wouldn’t take her to a nursing home if it were possible, if we could take care of her here. This is our home [cries].”^{20:123}

Although respite care was perceived as a sensible solution in the face of the need for help, caregivers often did not seek this “relief.” Feelings of loyalty and obligation to the care recipient emerged in the face of this reluctance.^{13,18} In this context, an emotional paradox between finding it ‘painful’ to see their family member taken to a “day care center” and a sense of happiness for the hours of freedom was revealed:¹⁸ “[...] I felt free like a bird.”^{18:1191}

Feelings of commitment and determination were demonstrated by caregivers, both in coping with personal difficulties and to resist institutionalization.^{13,18–19} Marital commitment or filial piety with respect to parents were motivators of the desire for the person with dementia to live at home as long as possible, demonstrating feelings of love and togetherness and revealing the meaning of caregiving for spousal caregivers:^{16,19} “We were so good with each other. So there was no way I could do anything other than be good to her and take care of her. [...] Why should I change because this person is sick?”^{19:123}

Pride in caregiving and the belief of their care being better than other people’s care was also demonstrated by family members, “What could a nursing home do that I can’t? The only difference is that they get paid and I don’t.”^{14:45}

The ability to withstand psychological overload was described as almost unlimited. However, when there was physical overload on the caregiver, the determination to cope suddenly ceased.¹⁹ Institutionalization was then approached as a last resort: “It’s a last resort (placement in a long-term care facility). I don’t want to separate from her until I really can’t stand it, until it’s impossible to avoid.”^{18:1187}

On the other hand, some family members show resistance to institutionalization even in extreme situations.^{18,20} The death at home of the elderly person with dementia, named as “the bitter end” was one such circumstance: “I hope she dies at home or on the ward...but she is not going to an institution.”^{18:1192}

DISCUSSION

The frailty process in the elderly is related to physiological aging and it is common to observe slowing, forgetting words and storage locations of certain objects. However, cognitive decline associated with functional decline may have a pathological origin.^{2,5,6} Forgetfulness, progressive worsening, and difficulty in performing ABVD were perceived by family caregivers and reported in their speeches.^{12–13} However, in some cases, dementia was only suspected in extreme cases, demonstrating the need for earlier cognitive assessment.¹² The lack of awareness and understanding about dementia remains, revealing barriers to diagnosis and care, impacting physically, psychologically, and economically on caregivers, families, and society.^{1,6,12,15} Thus, the importance of cognitive screening and early diagnosis is highlighted, to enable the treatment of symptoms and delay disease progression with the use of medications and non-pharmacological therapies.³

As dementia progresses, it is expected the progressive loss of autonomy of the elderly, cognitive and functional decline that eventually compromise the quality of life, physical, mental and social health of the caregiver.^{3,6,21} In this context, upon diagnosis, family members should be properly welcomed and made aware of the evolution of the disease, minimizing the insecurity and fear reported by those they care for. Proper guidance can also facilitate the adjustments in the family dynamics that eventually culminate in the indispensability of integral and continuous care. The lack of time for oneself, the physical and emotional stress experienced while caring for a family member with dementia are reported complaints that generate reflections about the need for emotional and social support.^{3,12,13,15} Strategies to promote the caregiver’s mental health should be priority actions, aiming at the caregiver’s well-being. The caregiver should feel supported throughout the entire caregiving journey, and the state can also help him/her through psychological support, group activities with others who share similar experiences, physical and leisure activities.^{3,21}

The emotional involvement between the family caregiver and the elderly is explicit, with mourning being a feeling reported when the loss of memories and personality due to dementia was identified.^{13,14,17} Changes in mental abilities, mood and behavior, identified during the progression of the disease, are often misunderstood by caregivers.^{12,15} Thus, it is important that the health care team support the deconstruction of preconceptions and guide family caregivers so that they know how to recognize and manage the signs and symptoms of dementia.

The lack of knowledge about the disease also impacts care planning, generating inappropriate care that leads to overload.^{12,13,15} As observed in the caregivers’ statements, pharmacological management is preferable to non-pharmacological when facing challenging behaviors.¹³ Therefore, health professionals must understand the daily experience of this caregiver, without

judgments, understanding his or her difficulties and limitations, creating a professional bond that provides holistic and integral care. The proposal of interventions aimed not only at developing specific competences in the context of dementia, but also strategies that provide self-care, stress management, and emotional overload are relevant for the well-being of caregivers and, consequently, for the elderly.^{3,21} Encouraging the search for support networks, such as family members, friends, formal caregivers, temporary or long-term care should be offered as options, showing caregivers that caring does not have to be lonely.

The last alternative approached by the caregivers was institutionalization, and the resistance to its realization even in extreme situations raises the need to adopt a new meaning for this act. Institutionalization should be understood as a “new” aid option for those who need or want it; not as a “lack of option” or “abandonment”. The care of the elderly with dementia, which includes their institutionalization when necessary, should be shared by family, society, and the state. Therefore, the creation of public policies that support, assist, and guide family caregivers of older adults with dementia should be promoted, given the current and future demands of society.²¹

CONCLUDING REMARKS

The lack of knowledge about dementia made it impossible to plan adequate care and intensified the caregivers’ burden.^{12,13,15} Feelings of grief and tension emerged revealing a lonely and distressing caregiving.^{13–14} However, feelings of pride and loyalty also emerged along with resistance to the institutionalization of the elderly.^{13,18,20} This duality of feelings reveals the complexity of caring for family members with dementia.

Considering that family caregivers are fundamental parts in the care of elderly patients with dementia, it is necessary that the actions of health professionals also be directed to them.²¹ Public policies that involve and help caregivers are relevant in order to provide their physical and mental well-being, which indirectly impacts care receivers.

Thus, the results obtained in this study are important to help health care professionals in the provision of care for the elderly with dementia and their families, and also to provide subsidies for the creation of more humanized public policies that consider the integrality of care.

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