Original Article

Association of spirituality, quality of life and depression in family members of older adults with dementia

Associação da espiritualidade, qualidade de vida e depressão em familiares de idosos com demências

Relación entre la espiritualidad, calidad de vida y depresión en familiares de adultos mayores con demencias

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Abstract

Objective: To associate spirituality with the quality of life and depression of family caregivers and understand the family dynamics when there is a member with dementia at home.

Methods: Mixed method study with a sequential exploratory strategy. The following instruments were used in the quantitative phase: the socio-contextual questionnaire, World Health Organization Quality of Life – BREF, Beck Depression Inventory and World Health Organization Quality of Life – spirituality, religiousness and personal beliefs. In the qualitative phase, 35 participants responded to a semi-structured interview. The two phases were performed online by means of the Google Forms and Meet platform.

Results: The sample consisted of 100 participants, of which 83% were female aged between 18 and 76 years. In the correlation between WHOQOL-BREF, WHOQOL-SRPB and BDI, the results showed that the lower the depression score, the higher the spirituality and quality of life scores. Three categories emerged from results of the interviews: Family reorganization in the care for the person with dementia; Spirituality and its implications for coping with dementia; Spirituality and support network as a health protection factor for the family caregiver.

Conclusion: Spirituality was as an important coping factor for family caregivers of older adults with dementia, and a factor that reduces the risk of depression and improves quality of life.

Resumo

Objetivo: Associar a espiritualidade com a qualidade de vida e a depressão de cuidadores familiares e compreender a dinâmica familiar quando há um integrante com demência no domicílio.

Métodos: Estudo misto, com estratégia sequencial exploratória. Na etapa quantitativa, foram usados os instrumentos questionário sóciocontextual, *World Health Organization Quality of Life – BREF*, Inventário de Depressão de Beck e *World Health Organization Quality of Life – spirituality, religiousness and personal beliefs*. Na etapa qualitativa, 35 participantes responderam a uma entrevista semiestruturada. As duas etapas foram *on-line* na plataforma *Google Forms* e *Meet*.

Resultados: A amostra foi composta de 100 participantes, dos quais 83% eram do sexo feminino com idade entre 18 e 76 anos. Na correlação entre WHOQOL-BREF, WHOQOL-SRPB e BDI os resultados evidenciaram que quanto menor o escore de depressão, maiores os escores de espiritualidade e qualidade de vida. Dos resultados das entrevistas emergiram três categorias: Reorganização familiar na promoção do cuidado à pessoa com demência; Espiritualidade e suas implicações no enfrentamento da demência; Espiritualidade e rede de apoio como fator de proteção à saúde do cuidador familiar.

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Conflicts of interest: none to declare.

Conclusão: A espiritualidade configurou-se como importante fator de enfrentamento para os cuidadores familiares de idosos com demência, bem como um fator redutor do risco de depressão e de melhora da qualidade de vida.

Resumen

Objetivo: Relacionar la espiritualidad con la calidad de vida y la depresión de cuidadores familiares y comprender la dinámica familiar cuando hay un integrante con demencia en el domicilio.

Métodos: Estudio mixto, con estrategia secuencial exploratoria. En la etapa cuantitativa, se usaron los siguientes instrumentos: cuestionario socio-contextual, *World* Health Organization Quality of Life – BREF, Inventario de Depresión de Beck y *World* Health Organization Quality of Life – *spirituality, religiousness and personal beliefs*. En la etapa cualitativa, 35 participantes respondieron a una entrevista semiestructurada. Las dos etapas fueron virtuales en la plataforma *Google Forms* y *Meet*.

Resultados: La muestra fue compuesta por 100 participantes, de los cuales el 83 % era de sexo femenino, de entre 18 y 76 años. En la correlación entre WHOQOL-BREF, WHOQOL-SRPB y BDI, los resultados demostraron que cuanto menor era la puntuación de depresión, mayor era la puntuación de espiritualidad y calidad de vida. A partir de los resultados de las entrevistas, surgieron tres categorías: Reorganización familiar en la promoción del cuidado a personas con demencia, Espiritualidad y sus consecuencias en el afrontamiento a la demencia, Espiritualidad y red de apoyo como factor de protección de la salud del cuidador familiar.

Conclusión: La espiritualidad se configuró como un importante factor de afrontamiento para los cuidadores familiares de adultos mayores con demencia, así como un factor reductor del riesgo de depresión y de mejora de la calidad de vida.

Introduction

According to the World Health Organization (WHO), one in five people will be over 60 years old by 2050.[1] The number of people living with dementia is expected to increase from 55 million to 139 million by 2050.[2] The most common type is Alzheimer's disease, which will affect 75 million people worldwide in 2030 and 132 million in 2050.[3]

Aging has important implications for family dynamics, especially in maintaining the quality of life and health of the older adult population and preserving their permanence with the family, especially when there is a member with dementia.[4]

Dementia is defined as a progressive cognitive disorder that leads to the loss of independent function.[5] In addition to other damages, cognitive and motor deficits from dementia influence the difficulty in performing Activities of Daily Living and the ability to manage the environment, making older adults increasingly dependent on their family members.[5] The health care needed by older adults with dementia brings changes to the family's way of life and in family roles, including what each one is, how is seen and what is expected of each one.[6]

The family is a dynamic system that contains other interrelated subsystems and plays important roles in society, such as affection, education, socialization and the reproductive function. As a system, the family contributes to build solutions that integrate its subsystems, influencing the understanding of care and the health-disease process.[7]

The family experience of having a member affected by dementia undergoes changes in relationships and in their dynamics, involving feelings and emotions. For this reason, the family caregiver becomes vulnerable to overload, which is a potential promoter of stress, anxiety, depression, fear, suffering and communication difficulties, and can evolve to a process of disruption of the family balance.[8-10]

With the advancement of dementia, the family structure has to be reorganized.[10] In this sense, some strategies can contribute to the recovery of family balance in the face of all care difficulties; the support provided by spirituality stands out.[11]

Spirituality is defined by the WHO as a set of emotions and convictions of a non-material nature, assuming there is more than can be perceived or fully understood, referring the individual to issues such as the purpose and meaning of life.[12] It is the search for meaning of life through concepts that transcend the tangible and manifests in the life of human beings according to age, religion, culture and health status.[13] Spirituality is an integral part of those who provide care and has a beneficial character in health and quality of life.[13] In this sense, this factor is a source of strength and support to deal with the reality of family caregivers of older adults with dementia, as well as inspiration for feelings of gratitude and satisfaction.

In the search for coping strategies in the care situation, the family caregiver of the older adult with dementia finds technical-scientific and emotional support in the nursing team, as nursing is the sci-

ence of care and helps in the physical and spiritual wellbeing of people.[14]

Historically, the spiritual dimension has been present in professional nursing practice since Florence Nightingale. It has changed from a tendency to see spirituality linked to religion to reflections of ethical, bioethical and philosophical nature, in addition to the attempt to understand the spirituality phenomena of patients and nurses themselves.[15]

Although the focus of this study was not to investigate the role of nursing, its importance to the comprehensive care of family caregivers of older adults with dementia is noteworthy. Nursing professionals are able to identify the difficulties of family caregivers in the care provided to older adults with dementia and implement specific interventions, taking into account the entire family context. They can also encourage family caregivers to take care of themselves, seeking strategies and mechanisms to maintain their good quality of life and mental health, for example, with therapy, practice of sports and connection with their spirituality.

There is a gap in studies relating to spirituality, quality of life and depression of family caregivers of older adults with dementia, seeking to understand the difficulties, limitations of care and perceptions of these family caregivers. This investigation is important by considering that family caregivers of older adults with dementia need attention from health professionals, as they are at a higher risk of illness due to care overload and emotional and physical exhaustion.

The aim of this study is to associate spirituality with the quality of life and depression of family caregivers and to understand the family dynamics when there is a member with dementia at home.

Methods

This is a mixed method study with a sequential exploratory strategy. Descriptive and analytical design was used in the quantitative phase, and data collection was performed through web forms sent via e-mail. In the qualitative phase, data were collected after completing the instruments of the quantitative phase in online interviews via Google Meet, in compliance with recommendations of physical distancing because of the 2019 coronavirus disease pandemic.

The study was conducted in different municipalities in Brazil through dissemination in digital media, social networks and the webpage of the Universidade Federal de São Paulo (Unifesp). Data collection was performed online and lasted between March and October, 2020. The sample consisted of 100 family members with at least one family member diagnosed with dementia, over 18 years of age and with technological resources (internet access). In the qualitative phase, 35 family caregivers who participated in the first phase were randomly invited.

In the quantitative phase, the following instruments validated in Brazil were applied: a socio-contextual questionnaire for characterization of the sample and of social, economic and health data;[16] the World Health Organization Quality of Life – BREF (WHOQOL-BREF) to assess personal issues, emotional wellbeing and disabilities, considering the physical (7 to 35 points), psychological (6 to 30 points), social relationships (3 to 15 points) and environment (8 to 40 points) domains. The higher the score, the better the quality of life.[17]

The following instruments were also used: Beck Depression Inventory (BDI) to investigate signs of depression through self-perception in a score ranging from 0 to 63 points - the higher the score, the greater the degree of depression (no depression, mild, moderate and severe);[18] the World Health Organization Quality of Life and Spirituality, Religiousness and Personal Beliefs (WHOQOL-SRPB) to investigate spiritual, religious and personal beliefs that affect quality of life in eight facets, including physical, psychological, social relationships and environment issues in scores ranging between 4 and 20 – the higher the score, the better the quality of life.[19]

The Statistical Package for the Social Sciences (SPSS), version 21.0, was used in statistical analyzes. Frequency and percentage were calculated for descriptive analysis of categorical variables. Mean, standard deviation, median, minimum and maxi-

mum were calculated for continuous variables. The scores of spirituality domains were compared with quality of life and depression domains; and scores of spirituality domains, of quality of life and depression domains were compared with continuous socio-contextual variables using Spearman's correlation coefficient. The scores of spirituality, quality of life and depression domains were compared with the categorical socio-contextual variables using the Mann-Whitney test (two categories) and the Kruskal-Wallis test (three or more categories). A significance level of 5% was used (p value <0.05). For the crossings, given the low frequency, some variables had their categories grouped.

In the qualitative phase, interviews were conducted by researchers with expertise in family intervention. Participants met the researchers before the interview, and were informed about the project.

Data were collected through a semi-structured online interview with audio recording authorized by participants for future transcription of the content, based on the following guiding question: How did spirituality contribute to cope with Alzheimer's disease or other dementia of your relative?"

Data resulting from interview transcripts underwent content analysis based on Bardin's thematic analysis using the MAXQDA.2020 software.[20,21] Categories and subcategories were created based on the open coding of data, that is, the topics addressed by interviewees were selected and their speech excerpts were coded.[21] Subsequently, axial and selective coding were performed, and it was possible to create code-themes using the MAXMaps tool, generating the following categories from the coding tree: Family reorganization in the care of the person with dementia; Spirituality and its implications for coping with dementia; Spirituality and support network as a health protection factor for the family caregiver.

After the analyses, results were coordinated in order to answer the objectives by means of information that allowed us to understand the phenomenon of how the family uses spirituality in coping with the care of older adults with dementia.

The study was approved by the Research Ethics Committee of the Universidade Federal de São Paulo (Unifesp) under number 3.924.288. Participants received instructions and clarifications about the study objectives in the online Informed Consent form. In order to guarantee anonymity, interviewees gave a name that characterized their family, and within the family name theme, fictitious names were chosen for participants (Certificate of Presentation of Ethical Appreciation: 27544819.3.0000.5505).

Results

The sample consisted of 100 participants, of which 83% were female, aged between 18 and 76 years, 50% were married, 50% had complete higher education, 51% were employed and 61% had children. When asked about their health status, 84% self-rated themselves as healthy and 54% as having no health problems. The average time of knowledge of the main caregiver about the diagnosis of dementia of their older adult relative was 7.4 years, and 66.3% reported having only one family member with dementia. In the eight facets of the WHOQOL-SRPB, mean values were: 15.71 for Spiritual connection; 17.06 for Meaning & purpose in life; 16.04 for Experiences of awe & wonder; 15.15 for Wholeness & integration; 16.36 for Spiritual strength; 14.81 for Inner peace; 15.63 for Hope & optimism; 16.62 for Faith. In the four domains of the WHOQOL-BREF, mean values were: 70.24 for physical domain; 67.34 for psychological; 65.57 for social relationships; 65.34 for environment. In the BDI, the mean total score was 9.56 points; 79% were categorized with no depression, 9% with mild depression, 6% with moderate depression and 6% with severe depression. From the correlation of continuous variables by BDI score, WHOQOL-SRPB facets and WHOQOL-BREF domains, the older the age, the lower the BDI score (zero to 39 points) and the higher the Wholeness & integration score (five to 20 points) and Inner peace (five to 20 points). The greater the number of children (zero to five), the higher the score for Inner strength (four to 20 points), Hope/optimism (four to 20 points) and Faith (four to 20 points). By correlating the total score of the BDI with the WHOQOL-SRPB facets

and the WHOQOL-BREF domains (Table 1), it was found that the lower the total score of the BDI, the higher the scores of the WHOQOL-SRPB and WHOQOL-BREF scales.

Table 1. Correlation between data from the Beck Depression Inventory, the facets of the World Health Organization Quality of Life and Spirituality, Religiousness and Personal Beliefs and the World Health Organization Quality of Life – BREF

Correlations	Total score (BDI)
Spiritual connection	
R	-0.21
p-value	0.0338
n	100
Meaning &purpose in life	
R	-0.35
p-value	0.0004
n	100
Experiences of awe & wonder	
R	-0.42
p-value	<0.0001
n	100
Wholeness & integration	
R	-0.59
p-value	<0.0001
n	100
Spiritual strength	
R	-0.45
p-value	<0.0001
n	100
Inner peace	
R	-0.70
p-value	<0.0001
n	100
Hope & optimism	
R	-0.59
p-value	<0.0001
n	100
Faith	
R	-0.41
p-value	<0.0001
n	100
Physical domain	
R	-0.56
p-value	<0.0001
n	99
Psychological domain	
R	-0.76
p-value	<0.0001
n	99
Social relationships	
R	-0.57
p-value	<0.0001
n	99
Environment	
R	-0.63
p-value	<0.0001
n	99

Spearman's correlation coefficient; BDI - Beck Depression Inventory

In qualitative results of the 35 interviews, the grouping of the final codes in the MAXMaps tool generated three categories and subcodes related to the family organization of care for the person with dementia in the family and spirituality as a coping strategy in care. The most significant codes that responded to the study objectives were extracted.

Family reorganization in the care of the person with dementia

Dementia promoted significant changes in the family of most participants. The repercussions on the family were both positive and negative: reorganization of tasks, approximation and distancing in relationships, attributions of responsibility and care, overload of the main caregiver, conflicts and readjustment of roles.

> *On the weekend everyone forgets that Mom has to receive a visit or that I need to get some air... There are five of us... For them this is not a priority, and I cannot understand how they manage to do it. (Abalone, F. Mar)*

> *We realized that this situation of my mother created a bit of distancing within the family. Because nobody wants this burden. (Estímulo, F. Espiritualizada)*

For some interviewees, the role of primary caregiver of the older adult with dementia was a choice of their own, as a way of repaying the care received throughout their lives.

> *I don't see it as an option, it's something simple and I don't see it as a duty. It's intrinsic, she's part of me! I can't think of abandoning her... It was my decision that she would live with me. (Paciência, F. Persistência)*

For other interviewees, the restructuring of family dynamics and the decision to choose the main family caregiver were joint decisions.

> *I had to divide myself between her and my children and my husband... So for me, it was more*

convenient to bring her to my house... With my retirement I also suffered, I retired to be with my mother. (Carinho, F. Linda)

It was a joint decision because they didn't want to take (mother), so I'm bringing (her home). (Energia, F. Fogo)

Spirituality and its implications in coping with dementia

Most family members interviewed reported that spirituality was essential in maintaining the family's socio-emotional balance, reducing conflicts, coping with dementia and in self-knowledge.

There is no denying that with all conflicts we have between sisters, brothers-in-law, nephews, if it weren't for spirituality, we wouldn't have gone through all this... Spirituality is what has united the family the most. (Abalone, F. Mar)

I already felt more shaken having to talk about it, there was a time when I cried a lot, it has already changed with the support of spirituality, by knowing myself and accepting. (Ânimo, F. Fogo)

Spirituality favored strengthening, understanding, acceptance, support and tranquility in the family nucleus.

I've learned many things in spiritism... It makes me feel good, gives me comfort and encouragement. I believe in this life everything happens for a reason, it is to learn something, experience something, to have some new experience. It gives me comfort. (Companheirismo, F. Encontro)

Spirituality is a key point for our mental health, because it makes us understand and manage our feelings, it is not easy to go through all this. Without understanding why am I going through this, I would be an angry, distressed person with depression, maybe with panic syndrome, maybe I wouldn't be able to take care of him (father). (Cuidado, F. Apoio)

For the family, spirituality helps to promote care to the extent that belief was a motivation in the face of challenges and coexistence.

It helped me a lot holding on to faith, praying alone and with her (mother), doing the gospel at the center. The (formal) caregivers were also very religious, they helped me a lot, it gave me a lot of strength. (Estranheza, F. Esquisita)

Spirituality and support network as a health protection factor for the family caregiver

Some of the main caregivers reported changes in quality of life and mental health, in addition to restrictions on self-care, sleep and personal life, factors that make it difficult to cope with the disease although mitigated by spirituality.

It's hard to take care of myself, even less nowadays! I used to go to the gym three, four times a week, and I haven't step foot in the gym for a year. I go to therapy every week because I said I need it, otherwise my head will go crazy. It's complicated, sometimes it makes me a little guilty. (Paciência, F. Persistência)

Spirituality is the union of good and bad experiences. It is also a warning to think about you tomorrow, to think about quality of life... (Esforço, F. Força)

Tiredness and exhaustion are part of it, but the strength of spirituality, we receive every day. (Companheirismo, F. Acolhimento)

Cases of depression and feelings of exhaustion and guilt before the family with the responsibility of caring for the older adult were also reported.

Just talking about this subject makes me cry. Today, even taking medication for depression, I'm still very delicate. It's the weight of responsibility. (Carinho, F. Linda)

I don't feel bad about taking care of my mother, but it is exhausting, it makes me tired, I feel ter-

rible sometimes. I'm not going to say I deal with it well, it revolts me, it makes me angry, but I have to live, think better and take care of my mother! I'm not happy to be taking care of my mother 24 hours a day. (Unidade, F. Unida)

Family members brought up the importance of the family, social and health support network as a protective factor for the primary caregiver's mental health in improving quality of life.

I go to therapy every week, because my life has changed a lot. I had total and absolute freedom, I lived alone and today I live alone with my dependent mother. (Paciência, F. Persistência)

My great-aunt (nurse) came to help and provide care. Each one did what they could, and everyone here always helped. All people around us helped us. (Intimidade, F. Ligação)

The family and health support network also promoted union and relief from the burden of care.

I really appreciate this support I have from my husband! My children help me. So at this time I am very touched, because I never imagined I would need so many people to take care of an older person. (Carinho, F. Linda)

We hired a nurse, at night my sister stayed and on weekends my brothers. It wasn't heavy for anyone, it was worrisome! (Força, F. Religiosa)

We can handle the situation well, we take very good care of him, I have a (formal) caregiver. We feel good, because we have resources to take care of him, material and spiritual. (Cuidado, F. Apoio)

My network is the Day Center (private), she (mother) spends 5 days a week there, during this period I can do other things and when my brothers come here, they help me to take to the doctor and dentist. (Resguardo, F. Discrição)

I have help three times a week from a (formal) caregiver, my brother helps a lot with the financial part because he can't be there anymore. My sister stays when she can, helps out on weekends and I go somewhere. (Companheirismo, F. Encontro)

Discussion

The results of socio-contextual data demonstrate that most family caregivers are female, married, with children. Culturally, in Brazil, the care for an older adult family member is the responsibility of women, who occupy the roles of wives, sisters, daughters or granddaughters.[22]

As a historical and social construction, women are taught from childhood to care for their families. Caring for the older adult is added to all women's working hours, increasing the emotional and physical burden, with the possibility of leading to illness and social isolation.[22,23] In this study, 83% of the main caregivers were women, and most reported having left personal life, health care and leisure in second place; some also mentioned abandoning their professional careers. The provision of care can make family relationships and friendships, leisure and religious practices difficult. Therefore, the support network is essential so the main family caregiver does not fall ill (mentally and physically) and maintains the personal routine as much as possible.[24]

The diagnosis of dementia brings changes that can be unfavorable in the lives of family members, since the care process develops from the experiences of the main caregiver and is incorporated from the family reality and the older adult's needs, but, in general, it is a process of great difficulties and changes.[25,26] In this study, the results showed that 66.6% of participants were experiencing dementia for the first time. Family caregivers reported having had their lives completely changed after the diagnosis or after living together with the older adult, as their routine, concerns and actions turned to care.

Regarding the main caregiver, 21% of the sample had depression, ranging from mild to severe. In the interviews, some participants mentioned emotional changes and used therapy, physical activity, social and family support network as coping strategies. Studies show that these strategies reduce the

risk of social isolation and depression, reduce the level of anxiety and help to promote wellbeing.[26] In this aspect, the creation of public policies that integrate the family as a unit of care becomes relevant, aiming to reduce the burden and depression levels of the main caregiver.[27]

Another relevant data that emerged from this study refers to having children as a positive factor for reducing the burden of care, because this has the potential to promote care and mutual help. According to reports, this factor reduces the burden on the main caregiver, because children participate in the division of responsibility for care and provide emotional support. A study emphasizes that the affective relationship between grandparents and grandchildren favors the future care relationship between them, including grandchildren in the division of care and making them informal caregivers to help the main caregiver.[28]

When analyzing the BDI, the WHOQOL-SRPB and the WHOQOL-BREF, it was found that family caregivers had lower levels of depression and better quality of life indices when their ties were associated to spirituality. The emotional and physical burden of family members of older adults with dementia affects their social and personal lives, as well as their own health, but the practice of spirituality and its values are strengthening for physical and emotional wellbeing, for coping with difficulties and for the self-perception of better quality of life.[13,18,23] Iin 93% of respondents, spirituality was configured as an important individual and family coping factor that supports emotional aspects and gives meaning to life.[29]

The correlation between WHOQOL-SRPB and WHOQOL-BREF with socio-contextual data showed spirituality as an efficient factor for maintaining quality of life and better self-assessment of one's own health.[30] According to a study in line with the WHO concepts of spirituality and quality of life, spirituality can be a dimension of mental health, a protective factor of health and an indicative vector of quality of life.[31] Respondents reported that spiritual practices and rites help the family to feel well physically and emotionally, in the reduction of conflicts and maintainance of relationships. In this sense, ecumenical spirituality[32] (linked to religion or not), which strengthens family beliefs and human values, such as mercy, respect and fraternal love, also influences their relationships and care promotion, helping the mental health of the main caregiver and in family life.[33]

The results of interviews showed spirituality as an effective strengthening and coping factor for maintaining the socio-emotional balance of the family, as it helps to promote care and attenuate feelings and conflicts arising from the coexistence of care. This corroborates study data, which emphasize that values and beliefs motivate and give meaning to actions of family members, who perform their new role guided by their spirituality.[31]

Other reports emphasize that spirituality attenuates their personal difficulties, as it helps them to deal with their challenges, feelings and frustrations in seeing their family member in need of basic care. Many family members mentioned having to learn to deal with feelings of anguish, concern and abdication, as they began to dedicate all their free time to the older adult. A study shows that the greater the dependence of the family member on Activities of Daily Living, the greater the time spent on care, the deprivation of personal life and abdication for the main caregiver's wellbeing.[34] In this sense, the support of the nursing professional is important to plan and reorganize the care routine; to find, together with the family member, possible support networks (family or social); to identify potentialities to be developed in the older adult, seeking their autonomy, and to develop strategies that help in the main caregiver's coping.[14,35]

Professional follow-up and support were also cited by family members as important coping strategies. Therefore, nursing has a fundamental role in providing care and services to these families, acting as an important technical-scientific professional support network for the guidance of these family members. Their performance can be effective in encouraging the participation of other family members in the care process, encouraging the autonomy and potential of the older adult, in addition to including the family as a unit of care, as in most cases, they put their health in second place.[14,33,35]

The questionnaires used proved to be easy to apply, enabling the characterization of the sample, assessment and measurement of quality of life and investigation of signs of depression and how spiritual/religious/personal beliefs contribute to family relationships and the promotion of care. The interviews brought an understanding of the reality and dynamics of the family with an older adult with dementia at home.

As the study was limited to the punctual speech of a small number of families, the findings and follow-up within a period cannot be generalized, and the apprehension of the family dynamics is unfeasible.

Conclusion

Spirituality proved to be an important coping and strengthening factor for the family caregiver in the face of difficulties encountered and the emotional and physical exhaustion triggered by caring for the person with dementia. The self-perception of health for wellbeing can be linked to the practice of spirituality that helps to maintain the good mental health of family caregivers of older adults with dementia, reducing the risk of developing depression. The family and social support network, as well as specialized professional care contribute to reduce physical and emotional overload and the risks of depression, enabling an improvement in the quality of life of the main caregiver. Another contribution of the study was its possible use by health professionals as a support in humanized and expanded care of individuals to their families. New studies investigating spirituality as a coping factor for families facing the care of a dependent older adult with dementia/Alzheimer's disease are needed.

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Collaborations

Barreto LV, Cruz MGS, Okuno MFP and Horta ALM contributed to the project design, data analysis and interpretation, article writing, relevant critical review of the intellectual content and approval of the final version to be published.

References

1. Organização Mundial da Saúde (OMS). Resumo. Relatório mundial de envelhecimento e saúde. Genebra: OMS; 2015 [citado 2022 Fev 15]. Disponível em: https://sbgg.org.br/wp-content/uploads/2015/10/OMS-ENVELHECIMENTO-2015-port.pdf
2. Organização Pan-Americana da Saúde (OPAS). Mundo não está conseguindo enfrentar desafio da demência. Washington: OPAS; 2021 [citado 2022 Fev 15]. Disponível em: https://www.paho.org/pt/noticias/2-9-2021-mundo-nao-esta-conseguindo-enfrentar-desafio-da-demencia
3. Canal Saúde. OMS: número de pessoas afetadas por demência triplicará no mundo até 2050. Rio de Janeiro: Fundação Oswaldo Cruz; 2017 [citado 2022 Fev 15]. Disponível em: https://www.canalsaude.fiocruz.br/noticias/noticiaAberta/oms-numero-de-pessoas-afetadas-por-demencia-triplicara-no-mundo-ate-2050-2017-12-12
4. Ferreira LN, Feitosa AN, Silva ML, Ferreira MF, Araújo WA, Toledo MA, et al. Envelhecimento e qualidade de vida em idosos da Atenção Básica de Saúde. Rev Bras Educ Saúde. 2018;8(1):9-14.
5. Radue R, Walaszek A, Asthana S. Neuropsychiatric symptoms in dementia. Handb Clin Neurol. 2019;167:437–54.
6. Walsh F. Processos normativos da família: diversidade e complexidade. 4th ed. Porto Alegre: Artmed; 2016. 608 p.
7. Saad M, Masiero D, Battistella LR. Espiritualidade baseada em evidências. Acta Fisiátrica. 2001;8(3):107–12.
8. Rangel RL, Santos LB, Santana EL, Marinho MS, Chaves RN, Reis LA. Avaliação da sobrecarga do cuidador familiar de idosos com dependência funcional. Rev Atenção Saúde. 2019;17(60):11-8.
9. Tramonti F, Bonfiglio L, Bongioanni P, Belviso C, Fanciullacci C, Rossi B, et al. Caregiver burden and family functioning in different neurological diseases. Psychol Health Med. 2019;24(1):27–34.
10. Silva CF. Relacionamento intergeracional entre idosos e adultos jovens da mesma família: caracterização e repercussões [tese]. Pernambuco: Universidade Católica de Pernambuco; 2019.
11. Kamada M, Augusto JV, Silva CM, Silva PM, Fonseca AP. O papel da espiritualidade no enfrentamento da doença de Alzheimer. Rev Soc Bras Clin Med. 2019;17(1):21–4.
12. World Health Organization (WHO). WHOQOL and Spirituality, Religiousness and Personal Beliefs (SRPB). Department of mental health. Geneva: WHO; 1998 [cited 2022 Apr 17]. Available from: https://apps.who.int/iris/handle/10665/70897
13. Dias FA, Pereira ER, Silva EM, Medeiros AY. Espiritualidade e saúde: uma reflexão crítica sobre a vida simbólica. Research. Soc Dev. 2020;9(5):e52953113.
14. Coelho NH. Grau de dependência do idoso com Alzheimer, carga do familiar cuidador e papel da enfermagem. Cogitare; 2020. p. 46.

15. Brandão JL, Gomes AM, Mota DB, Thiengo PC, Fleury ML, Dib RV, et al. Spirituality and religiosity in the context of comprehensive care: reflections on comprehensive health and nursing care. Res Soc Dev. 2020;9(10):e5499108780.

16. Creswell JW. Projeto de pesquisa: métodos qualitativo, quantitativo e misto. 2a ed. Porto Alegre: Art Med. 2007. 264 p.

17. Kluthcovsky AC, Kluthcovsky FA. O WHOQOL-bref, um instrumento para avaliar qualidade de vida: uma revisão sistemática. Rev Psiquiatr. 2009;31(3 Supl):1-12.

18. Paranhos ME, Argimon II, Werlang BS. Propriedade psicométricas do Inventário de Depressão de Beck-II em adolescentes. Aval Psicol. 2010;9(3):383–92.

19. Panzini RG, Rocha NS, Bandeira DR, Fleck MP. Qualidade de vida e espiritualidade. Arch Clin Psychiatry. 2007;34(1):105–15.

20. Bardin L. Análise de conteúdo. Tradução Reto LA, Pinheiro A. 70th ed. São Paulo: Editora Edições; 2011. 280 p.

21. Kuckartz U. Qualitative text analysis: a guide to methods, practice & using software. Nova York: SAGE Publications Ltd; 2014. 192 p.

22. Ferreira CR, Isaac L, Ximenes VS. Cuidador de idosos: um assunto de mulher? Estud Interdiscip Psicol. 2018;9(1):108–25.

23. Mendes PN, Figueiredo ML, Santos AM, Fernandes MA, Fonseca RS. Sobrecargas física, emocional e social dos cuidadores informais de idosos. Acta Paul Enferm. 2019;32(1):87–94.

24. Carvalho EB, Neri AL. Uso do tempo por cuidadores familiares de idosos com demência. Rev Bras Enferm. 2018;71(2):948–59.

25. Cesário LM, Chariglione IP. A percepção de familiares cuidadores frente às mudanças ocorridas após um diagnóstico de demência. Rev Bras Geriatr Gerontol. 2018;21(6):768–80.

26. Garcia CR, Cipolli GC, Santos JP, Freitas LP, Braz MC, Falcão DV. cuidadores familiares de idosos com a doença de alzheimer. Rev Kairó Gerontol. 2017;20(1):409-26.

27. Schuck LM, Antoni CD. Resiliência e Vulnerabilidade nos sistemas ecológicos: Envelhecimento e Políticas Públicas. Psicol Teor Pesqui. 2018;34:e3442.

28. Reis AR. Quando os netos se tornam cuidadores dos avós [dissertação]. Portugual: Instituto Politécnico de Viana do Castelo; 2018.

29. Oliveira SG, Sartor SF, Morais ES, Maya NF, Gervini CM, Morales CP. Spirituality, religiosity and terminality: possible topics in homecare visits carried out with family caregivers. Rev Enferm UFPI. 2017;6(2):69–73.

30. Pereira CR, Sobral GL, Maia GL, Bedor CN. A espiritualidade enquanto estratégia de enfrentamento para o cuidador familiar frente a terminalidade. Rev NUPEM. 2020;12(25):124–33.

31. Tonil R. Atas do espírito: a Organização Mundial da Saúde e suas formas de instituir a espiritualidade. Anuário Antropológico. 2017;42(2):267–99.

32. Netto P. Os mortos não morrem. São Paulo: Elevação; 2018. 528 p.

33. Couto AM, Caldas CP, Castro EA. Cuidador familiar de idosos e o cuidado cultural na assistência de Enfermagem. Rev Bras Enferm. 2018;71(3):959–66.

34. Carvalho EB, Neri AL. Padrões de uso do tempo em cuidadores familiares de idosos com demências. Rev Bras Geriatr Gerontol. 2019;22(1):e180143.

35. Lima KB, Tavares IC, Souza AR, Silva LC, Souza LA, Sousa AT, et al. O enfermeiro como educador frente aos aspectos emocionais do familiar que cuida do portador de Alzheimer. Rev Eletr Acervo Saúde. 2021;13(2):e5918.