Validation of Questionnaire to Assess the Impact of Dementia on the Family

Validação do questionário de avaliação do impacto da demência na família

Validación de encuesta de evaluación del impacto de la demencia en la familia

ABSTRACT
Objective: To validate a questionnaire to assess the impact of dementia on one of the household members. Methods: Methodological study. The instrument was designed based on literature review, expert opinion, and researchers’ experience and then applied to a non-probability convenience sample consisting of 262 family members who live daily with a person with dementia. The construct validity was studied by exploratory factor analysis, principal components method, with varimax rotation of the items. Results: An instrument with 30 items was obtained, distributed in four dimensions: “Emotional dimension,” “Economic dimension,” “Family relations dimension,” and “Support-seeking dimension.” Factor analysis revealed a total explained variance of 54.96% and a total Cronbach’s alpha of .899. Conclusions: The instrument presents high internal consistency, grouped into four dimensions, all closely related to the family’s adaptation to the onset of dementia in one of its members.

Descriptors: Dementia; Family Relations; Validation Study; Nursing; Factor Analysis.

RESUMEN
Objetivo: Validar un cuestionario de evaluación del impacto de la demencia en uno de los miembros del agregado familiar. Métodos: Estudio metodológico. El instrumento fue construido, con base en la revisión de la literatura, opinión de peritos y en la experiencia de los investigadores. Fue aplicado a una amostra no probabilística de conveniencia constituida por 262 familiares de personas que coabitam diariamente con a persona con demencia. La validez de constructo fue estudiada por análisis factorial exploratorio, método de componentes principales, con rotación varimax de los ítems. Resultados: Se obtuvo un instrumento con 30 ítems distribuidos por cuatro dimensiones: “Dimensión emocional,” “Dimensión económica,” “Dimensión relaciones familiares” y “Dimensión procura de suporte.” A análisis fatorial reveló una variancia explicada total de 54,96% y un alfa de Cronbach total de .899. Conclusões: El instrumento presenta una consistencia interna elevada agrupando-se em quatro dimensões, todas elas intimamente ligadas à adaptação da família ao aparecimento da demência num dos seus membros.

Descritores: Demência; Relações Familiares; Estudo de Validação; Enfermagem; Análise Fatorial.

Mafalda Sofia Gomes Oliveira da Silva
ORCID: 0000-0002-2509-5566

Luis Octavio de Sá
ORCID: 0000-0001-9687-413X

Sandra Sofia Barbosa Pinto de Almeida
ORCID: 0000-0002-1874-0432

Ana Catarina Rodrigues da Silva Reis
ORCID: 0000-0002-0986-6092

1Escola Superior de Saúde Jean Piaget. Vila Nova de Gaia, Portugal.
2Universidade Católica Portuguesa, Instituto de Ciências da Saúde. Porto, Portugal.
3Escola Superior de Saúde Santa Maria. Porto, Portugal.

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Corresponding author:
Mafalda Sofia Gomes Oliveira da Silva
E-mail: mafaldassilva@hotmail.com

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INTRODUCTION

According to the Organization for Economic Co-operation and Development (OECD) Report\(^1\), there are about 47.5 million people with dementia worldwide, and this figure could reach 75.6 million by 2030 and 135.5 million by 2050.

The World Health Organization\(^2\) reports that Alzheimer's dementia represents about 60% to 70% of cases. Dependence combined with behavioral problems such as delirium, hallucinations, aggressiveness, disinhibition, or other neuropsychiatric symptoms leads to profound changes in family dynamics\(^3\), which makes it necessary to assess the person's needs in order to plan and develop specific and appropriate interventions for each family.

The family is a social construction representing a collective way of acting and thinking, which evolves over time according to the organization and functioning of society\(^4\). It is considered a basic support unit for continuity of care, bearing the responsibility of caring for members who have lost the ability to maintain an independent life.

However, there is a high risk of psychological, physical, and social morbidity among family members, compromising the ability to deal with the sick person when they live in the same house\(^5\). Family transitions, such as the decrease in the number of people in the household, its geographical distribution, and the participation of women in the labor activity, are frequent events in western society, with negative consequences for the family network\(^6\), making this phenomenon very complex.

Lack of capacity to deal with the needs and the overload experienced daily by the family members tend to worsen with the evolution of the condition. That is a worrisome situation due to this caring relationship’s objective and subjective impacts.

The reorganization between the caregiver, the ill person, and the family members is essential to identify and maximize the skills and personal resources needed to minimize the consequences of the onset of dementia. The repercussions felt by the different household members can be perceived in diverse ways and in various spheres: physical, psychological, social, economic, and relational dynamics\(^7\).

In this sense, it is essential to implement new forms of assistance that allow the maintenance of the quality of life of the different family members and the ill person to minimize physical and psychological vulnerability\(^8\). However, few studies address the consequences of this disease, the adaptation process, and the use of health resources by the different family members besides the primary caregiver.

Families should be integrated into nursing care planning to identify their needs and thus facilitate the family transition and adaptation process. Care delivery is assumed to be executed by the closest people, from neighbors, friends, and family members, which adds difficulties underlying the new role of caregiver.

The use of assessment instruments in clinical practice allows for a better understanding of the more subjective phenomena arising from the care process and constitutes an added value to support clinical decision-making in nursing\(^9\). Data regarding a situation of vulnerability are generated and provide multidisciplinary teams with improvements in communication processes, with a direct impact on the priority and logistics of care and the dimensionality of time\(^10\). For health professionals to objectively identify the needs on the physical, psychological, and spiritual levels of the sick person and their families, they need assessment tools that provide a more objective, rigorous evaluation and that systematize the provision of care. The interest of a practice supported by instruments focuses on identifying the primary skills and presenting, guiding, and establishing\(^10\) the provision of nursing care.

OBJECTIVE

Validate a questionnaire to assess the impact of dementia on a household member.

METHODS

Ethical aspects

The research guaranteed participants’ autonomy and right of refusal, at any time and without any prejudice, through telephone contact or e-mail to the investigator. The study principles were assured in the informed consent form, signed by the researcher and the primary caregiver/family member, containing information about the study’s nature, duration, methodology, purposes, and risks.

Authorizations were requested and granted, also via e-mail, to the respective authors to use the assessment instruments adopted in this study and to ensure data confidentiality and anonymity, with the respective coding of all information obtained. The clinical oversight of a Psychiatry hospital in the North Region, to formalize the data collection, received a request for compliance with the ethical requirements of the study, and the Ethics Committee granted a favorable opinion.

Design, period, and place of study

That is a methodological study. The dimensions that make up the Questionnaire to Assess the Impact of Dementia on the Family, built and validated by the researchers, were designed based on the literature review\(^11\), which allowed the conceptual framework of the researcher’s experience, and on the Delphi study\(^12\) carried out in previous stages of a more extensive study.

Data collection occurred between March 2019 to September 2020 with the questionnaire’s distribution and application to different household members up to the 4th degree of kinship and, whenever necessary, to fill in, they counted with the support of a reference health professional and/or researcher.

Population or sample; criteria of inclusion and exclusion

The sample was non-probability by convenience, consisting of 262 family members who live daily with a sick person with dementia, including families responsible for a person with a medical diagnosis of dementia living in the home. The study excluded people with dementia institutionalized in residential facilities for older people.
Study protocol

In the different Day Care Centers involved, the health professional of reference identified the families that met the inclusion and exclusion criteria and voluntarily agreed to participate in the study. The Questionnaire to assess the impact of dementia on the family was applied to the primary caregiver and family members living with the person with dementia.

Analysis of results

The decision to use parametric and non-parametric statistical tests to analyze the differences in the impact caused by the onset of dementia on different household members was intended to favor the achievement of the study objectives. The first step is to verify the assumptions inherent to the tests; depending on the verification of the assumptions and whenever the necessary conditions for the use of parametric statistics were not met (normal distribution, n less than 30, investigated variable with an ordinal or nominal level of measurement) non-parametric tests are used. To test the construct validity of the instrument, we applied principal component analysis (PCA), with varimax rotation of the items, using the Kaiser-Meyer-Olkin (KMO) test and Bartlett’s Test of Sphericity (BTS) as requirements to confirm the adequacy of the sample for factor analysis. For the factor analysis to be credible, the following assumptions were adopted: eigenvalues > 1, exclusion of items whose factor saturation in the dimension was lower than .30, and application of the discontinuity principle.

For data treatment, descriptive and inferential statistics were used with the help of the software Statistical Package for the Social Sciences, version 25.

RESULTS

A KMO value of .777 was obtained, and Bartlett’s test of sphericity reached a value of 4647.483 (p<.001), which is considered a good level.

Subsequently, exploratory factor analysis was performed to study the principal components. The PCA revealed the presence of four components with eigenvalues greater than 1, which explained 54.96% of the total variance, being factor 1 (Family Relationships) the one with the highest contribution. The items defining a factor were considered when their values (loadings) were equal or greater than .30, with values equal to or greater than .71 being excellent, .63 very good, .55 good, .45 reasonable, and .32 poor. However, we must include the minimum acceptable value in the choice. The theoretical design of this instrument was made up of six dimensions: “Economic Dimension,” “Emotional Dimension,” “Family Relations Dimension,” “Information and Health Care Seeking Dimension,” “Social Dimension,” and “Spiritual Dimension,” which forced an analysis along these lines. However, it was observed that the level of reliability decreased, which is why the factor model of four dimensions was chosen: “Family Relationships Dimension,” “Emotional Dimension,” “Economic Dimension,” and “Support-seeking Dimension.” The “Information and Health Care Seeking Dimension” was renamed to the “Support-seeking Dimension,” taking into consideration the set of items that best characterize it. Based on the factor analysis, 30 items were excluded since they were not sensitive to what we intended to assess and did not obtain saturation in any dimension.

Then, it was created an instrument with 30 items and the internal consistency, evaluated by Cronbach’s alpha of .899, was considered good. It was verified that this division obtained by factor analysis suggests a construct with rational significance (Table 1). All factors have high factorial loadings.

Factor 1 defines the Family Relations dimension with nine items that best characterize it. They are items 1, 2, 3, 4, 5, 6, 7, 8, and 9, which together explain 19.799% of the total variance. Factor 2 includes ten items that characterize the Emotional dimension, which, by a weighting factor, are distributed as follows: items 10, 11, 12, 13, 14, 15, 16, 17, 18, and 19; together, they explain 16.83% of the total variance. Factor 3 characterizes the Economic dimension and integrates six items that, by weight, are listed as follows: items 20, 21, 22, 23, 24, and 25, which explain 11.388% of the total variance. Finally, factor 5 includes the items of the dimension Support-seeking, which, by weight, are arranged as follows: items 26, 27, 28, 29, and 30, with an explained variance of 7.089%. The instrument’s internal consistency coefficients were calculated for each dimension, considering the previously performed PCA. The results will be presented in Table 2.

Table 1 – Factor Analysis of the Questionnaire to Assess the Impact of Dementia on the Family

| Components | Family Relations | Emotional | Economic | Support-seeking |
|------------|-----------------|-----------|----------|-----------------|
| 1. I easily cope with memory loss. | .728 | | | |
| 2. I deal easily with physical and verbal aggression. | .772 | | | |
| 3. I easily cope with mental confusion/disorientation | .796 | | | |
| 4. I easily deal with inappropriate sexual behavior. | .610 | | | |
| 5. I deal easily with evading behaviors. | .755 | | | |
| 6. I easily cope with neglectful self-care behaviors. | .781 | | | |
| 7. I deal easily with impulsive behavior. | .805 | | | |
| 8. I easily cope with changes in pacing. | .726 | | | |
| 9. I deal easily with frustration behavior. | .683 | | | |
| 10. I feel exhausted due to the daily contact with the sick person. | | | | .576 |
| 11. I feel irritated constantly. | | | | .685 |
| 12. I have frequent insomnia. | | | | .716 |
| 13. I have trouble concentrating. | | | | .774 |
| 14. I wonder if he/she understands what is going on. | | | | .497 |
| 15. I think a lot about the time I spent with the person without illness. | | | | .578 |

To be continued
By the analysis of Table 2, we notice the presence of significant values of the degree of reliability (>0.60), being that the Dimension “Support-seeking” presents a lower value (0.678) but is adequate. Theoretically, the “Family Relations” dimension included eight items, but after testing the PCA, it now includes nine items. The analysis results of internal consistency of the nine items, with the correlations of each item with the total of its fitting subscale (corrected coefficient) and the alpha value of each dimension if that same item were excluded. We also integrated the mean and standard deviation for each item.

Table 2 – Internal consistency coefficients for each dimension in family members of people with dementia

| Dimension       | Items                                                                 | M    | SD   | Corrected item-total correlation | Cronbach’s alpha if item deleted |
|-----------------|----------------------------------------------------------------------|------|------|----------------------------------|---------------------------------|
| Family Relations| I easily deal with physical and verbal aggression.                    | 1.40 | .925 | .715                             | .884                            |
|                 | I easily cope with mental confusion/disorientation.                  | 1.58 | .875 | .736                             | .883                            |
|                 | I easily cope with memory loss.                                      | 1.60 | .873 | .645                             | .890                            |
|                 | I easily deal with inappropriate sexual behavior.                    | 1.12 | .972 | .707                             | .897                            |
|                 | I easily deal with evasion behavior.                                 | 1.20 | .905 | .681                             | .883                            |
|                 | I deal easily deal with neglectful self-care behaviors.              | 1.36 | .882 | .722                             | .884                            |
|                 | I deal easily with impulsive behavior.                               | 1.52 | .934 | .731                             | .883                            |
|                 | I handle pacing changes easily.                                      | 1.58 | .992 | .642                             | .890                            |
|                 | I deal easily with frustration behavior.                             | 1.72 | .917 | .580                             | .895                            |
| Emotional       | I think a lot about the time I spent with the person without the disease. | 1.75 | .984 | .519                             | .835                            |
|                 | I have frequent insomnia.                                            | 1.54 | .921 | .624                             | .825                            |
|                 | I wonder if he/she understands what is going on.                    | 1.86 | .915 | .452                             | .849                            |
|                 | I feel lonely.                                                       | 1.49 | .995 | .713                             | .816                            |
|                 | I feel irritated constantly.                                         | 1.70 | .842 | .604                             | .828                            |
|                 | I have trouble concentrating.                                       | 1.47 | .904 | .664                             | .822                            |
|                 | I feel exhausted due to the daily contact with the sick person.      | 1.89 | .832 | .487                             | .837                            |
|                 | I feel sad.                                                         | 1.33 | 1.031 | .633                             | .824                            |
|                 | I have feelings of anger and frustration.                           | 1.33 | .995 | .462                             | .840                            |
|                 | I wonder about the meaning of companionship.                         | 1.22 | .998 | .325                             | .853                            |
| Economic        | I consider that there has been a reduction in family income.         | 1.94 | .910 | .659                             | .865                            |
|                 | I consider that there has been an increase in the medication expenses. | 2.01 | .934 | .667                             | .864                            |
|                 | I consider that there has been an increase in expenses for hiring health professionals for care at home. | 1.55 | 1.109 | .701                             | .859                            |
|                 | I consider that there has been an increase in spending on clinical equipment. | 1.44 | 1.087 | .742                             | .851                            |
|                 | I consider that there was an increase in travel expenses.           | 1.85 | .955 | .752                             | .850                            |
|                 | The disease caused increased spending on structural changes in the residence. | 1.54 | 1.025 | .628                             | .870                            |

Cronbach’s alpha of the dimension

Table 1 (continued)

To be continued
For the set of nine items in the “Family Relations” Dimension, the internal consistency coefficients ranged from .883 to .895. Based on these results, the conclusion was that these nine items contribute significantly to assessing the impact of dementia on family relations. No items were eliminated at this stage. The overall alpha of the subscale is .899, which gives it good internal consistency since it is higher than the values considered critical and required for this type of scale (alpha= .70).

In the “Emotional” dimension, the internal consistency values for the set of ten items ranged from .816 to .853. These results indicate that these ten items contribute significantly to assessing the impact of dementia in the “Emotional” dimension. Considering previous literature on variables that may influence caregiving, such as burden, spirituality, social support, degree of dependence, among others(14), we believed that the spiritual dimension would present itself as an essential coping tool throughout the caregiving process. However, item 68 (“I wonder about the meaning of companionship”) was integrated into the “Emotional Dimension” since it achieved more saturation in this dimension. The overall Cronbach’s alpha of the subscale is .846, which gives it good internal consistency.

In the “Economic” Dimension, the internal consistency values for the set of six items ranged from .850 to .870, expressing a significant contribution to evaluating the economic impact of dementia on the family. No items were eliminated at this stage. The overall alpha of the subscale is .881, which gives it good internal consistency since it is higher than the values considered critical and required for this type of scale (alpha= .70).

In the “Support-seeking” Dimension, the internal consistency values for the set of five items ranged from .555 to .714. This result demonstrates that these items contribute significantly to assessing the need for support-seeking in families taking care of someone with dementia. No items were eliminated at this stage. The overall alpha of the subscale is .678, which gives it adequate internal consistency since it is close to the values considered critical and required for this type of scale (alpha= .70).

DISCUSSION

Considering the PCA, it was possible to identify “Family relations,” “Emotional,” “Economic,” and “Support-seeking” dimensions after the exclusion of 38 items from the instrument. We tested the item’s internal consistency for the discovered dimensions through the Cronbach’s alpha of each one, which allowed us to assess their adequacy and psychometric quality. That is a relevant aspect when the intention is to measure a specific latent phenomenon. Based on the dimensions “Family relations,” “Emotional,” “Economic,” and “Support-seeking,” significant values of reliability (> .60) were found to be present, with the dimension “Support-seeking” showing a lower value (.678), although adequate. The Questionnaire presented good validity and reliability indicators, confirmed by the results of the exploratory factor analysis, through principal components, the validity of the discriminant convergent of α.

Regarding the “Family Relations,” “Support-seeking,” and “Economic” dimensions, the literature points out that different family members, when faced with the onset of an illness in one of their relatives, use different coping strategies to adapt to the changes resulting from the situation.

Study(11) shows that the most used strategies when a chronic illness arises are: reframing, that is, the ability to redefine the stressful events to adopt a more positive view of the situation and to restructure one’s functions and roles; passive evaluation, that is, the family’s acceptance of the stressful events; and obtaining social support, amplifying the ability to obtain support from friends, neighbors or family.

According to authors(16), caregivers show feelings of fear and uncertainty when facing the possibility of integrating a person with dementia into an institution, which expresses the importance of new strategies that empower the informal caregiver for the different daily needs and that contribute to the maintenance of the ill person in the community. This study also reinforces the importance of training, experience sharing, social resources, and specialized services focused on the ill person and caregivers. An adequate level of literacy is known to contribute to more positive health outcomes and more appropriate use of existing health services/resources(16). Conversely, lower literacy levels are associated with more hospitalizations, poor adherence to treatment regimens, and increased mortality(18).

Thus, there is an urgent need for healthcare professionals to understand how families cope with and adjust to the onset of dementia to improve the support, training, and skills of informal caregivers. These measures should be part of daily health care and social support routine.

From a cultural point of view, the family is responsible for providing care to the ill person in Portugal. Informal caregivers should be seen either as partners or customers throughout the care process. As customers, they need regular care, and, as partners, they take action as informal caregivers, who should receive training to provide the best care, also acting as agents in the readaptation and reintegration processes of people with dementia(17).
Dementia is a public health problem with a multifactorial origin, resulting in high costs to society and the family. For this reason, one of the most impacted dimensions is the "Economic," in line with the results of other studies\(^\text{18-19}\), which also highlighted the economic problems as one of the significant challenges for informal caregivers.

Research\(^\text{20}\) found that caring for a family member with dementia directly impacts family caregivers since they accompany the aging process. In the results of this study, we can see that the more significant the emotional impact, the greater the burden. The same is true regarding the economic impact felt by the caregiver, which increases not only the perception of burden but also the need to look for support.

Authors\(^\text{21}\) have concluded that the cost of a residential care stay for a person with dementia can be more expensive, about 1.2 times more than for people without dementia. More subjective aspects such as the close relationship, the unavailability of the caregiver, and family issues for the continuity of care needed at home are more relevant than the functional capacity of the ill person itself\(^\text{20}\). In this sense, the proximity relations established between specialized services and caregivers and the economic support can promote or prolong the permanence of people with dementia in their homes.

The onset of these diseases has implications for the life of the sick person and their entire social support network\(^\text{21}\). A study\(^\text{22}\) alerted to the social repercussions on the health and well-being of formal and informal caregivers. The development of the caring process goes through the experiences of the family caregiver, the family reality, and the orientations provided by multidisciplinary teams and support groups\(^\text{23}\). In the family members of this study, it was possible to observe that the more significant the impact of family relationships, the greater the need to search for social support. Likewise, when the emotional impact is more significant, the need to seek support and the impact of the "Economic" dimension becomes greater.

In the social domain, the care provided to people with dementia is related to increased family conflicts, diminished support, and social interaction\(^\text{17}\). A study\(^\text{18}\) reinforces the importance of informational/integration support, psychosocial care, and articulation with organizations for a more effective readaptation to the new reality and needs reduction.

In this aspect, this study's results are similar to another\(^\text{24}\), which verified the possibility that the provision of daily care to the person with dementia may trigger physical, psychological, social, and financial problems, in addition to significant family changes. It was observed that the higher the level of dependence, the more significant the impact of caring on caregivers and family members of the person with dementia. It was also verified that, in family members, when the degree of the dysfunctionality of the person with dementia is higher, the greater the impact on the family relations dimension. It is noteworthy that, according to the degree of dependence of the person with dementia, different responses are required in the social/assistance and health spheres and legal protection measures that regulate and ensure the rights of the person cared for and the caregiver.

Thus, caregivers should have access and knowledge of the network of services/access mechanisms available in the community that provide the development/acquisition of caregiver skills, which are essential in providing quality care. The challenges arising from the action of caring modify the family dynamics and increase the caregiver's burden\(^\text{25}\). Family caregivers experience several types of physical, psychological, emotional, social, and financial overload, which tend to worsen with the lack of daily resources necessities, especially in household aid for hygiene or food care\(^\text{26}\). Some can experience this situation with affection, spirituality, and family members' support\(^\text{25}\). The caregiver's feelings of stress or overload are influenced by multiple factors such as the type of disease and the older person's degree of dependence\(^\text{26}\).

It is estimated that about 40% of caregivers worldwide experience a burden, primarily women who care for their parents, spouses, or children\(^\text{27}\). In this same study, Portugal was one of the countries evaluated with resources in a sample of 3849, presenting a response rate of 57.3%, identifying 15% of caregivers. As expected, the financial burden is lower in this group (15.1%) than in another identified in underdeveloped countries (44.1%). No significant changes were found in the dimensions of burden evaluated, such as emotional, time, and embarrassment.

Research\(^\text{28}\) shows that daily measures can mitigate stress, such as meditation, yoga practices, religiosity, and a positive relationship between family and caregiver. It is expected that the provision of care results in economic hardship\(^\text{29}\). In this study, this dimension also appeared in practice, associated with the provision of caretaking to caregivers and relatives of the person with dementia.

**Study limitations**

The study showed exciting results but had some limitations. Although the instrument helps assess the impact of the onset of dementia on the family, it should be applied to a larger sample of family members who live daily with the ill person in order to provide a better understanding of these repercussions, as well as to assist in the planning and execution of nursing care provided to the different family members.

**Contributions to the field of Nursing**

With this study, we hope to have contributed to the continuity of scientific research in this field by adopting appropriate and experimental methodologies that allow health professionals to define better and systematically assess the strategies developed with the different family members. Assessment tools are an added value for identifying needs, formulating diagnoses, and implementing nursing interventions targeted at the different family members.

**CONCLUSIONS**

The Questionnaire allows us to assess the impact caused by dementia on the family. The result of the data's factor analysis was an instrument with 30 items, divided into four dimensions: "Family relations," "Emotional," "Economic," and "Support-seeking."
The instrument has a good level of validity and reliability, with alpha values higher than .70 overall, except in the "Support-seeking dimension." It is a valid and reliable instrument to assess the impact of the onset of dementia in the family.

Furthermore, it is a vital tool to help nurses in elaborating nursing diagnoses and implementing more adequate programs and strategies that aim to minimize the needs of the different members of the household and the sick person, thus improving the quality of life for all.

SUPPLEMENTARY MATERIAL

Silva M, Sá L, Marques G. The impact of neurocognitive disorder in the family: a scoping review. Rev Paul Enferm. 2019 Ag 30(4): 1-14. doi:10.33159/25959484 /

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