

RESEARCH ARTICLE (ORIGINAL) 

## Contributions to the family's adaptation to the onset of a neurocognitive disorder

*Contributos para a adaptação face ao surgimento de uma situação de perturbação neurocognitiva na família*

*Contribuciones a la adaptación ante la aparición de una situación de trastorno neurocognitivo en la familia*

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Among family members, the greater the impact of perceived family relations, the greater the perceived social support ( $r = 0.219$ ;  $n = 104$ ;  $p < 0.05$ ); the greater the emotional impact, the greater the need to seek support ( $r = 0.303$ ;  $n = 104$ ;  $p < 0.01$ ); and the greater the perceived impact on the economic dimension, the greater the need to seek support ( $r = 0.319$ ;  $n = 104$ ;  $p < 0.01$ ).**Conclusion:** The family's functioning, the patient's level of dependence, the education level, the gender, and the degree of kinship seem to influence family adaptation.**Keywords:** family relations; family; dementia; nursing**Resumo****Enquadramento:** A família é o principal recurso da pessoa que adocece, assumindo-se, os seus constituintes, como cuidadores familiares.**Objetivo:** Identificar as variáveis que influenciam o impacto da perturbação neurocognitiva nos familiares e caracterizar os cuidadores de pessoas com PNC.**Metodologia:** Estudo quantitativo, descritivo e correlacional, com 262 familiares de pessoas com perturbação neurocognitiva.**Resultados:** Os cuidadores evidenciam uma associação entre as dimensões impacto emocional ( $r = 0,526$ ;  $n = 102$ ;  $p < 0,01$ ), económica ( $r = 0,292$ ;  $n = 102$ ;  $p < 0,01$ ), procura de suporte ( $r = 0,279$ ;  $n = 102$ ;  $p < 0,01$ ), prestação de cuidados ( $r = 0,375$ ;  $n = 102$ ;  $p < 0,01$ ) com maior sobrecarga percebida. Entre os membros da família, quanto maior o impacto das relações familiares percebidas, maior o suporte social percebido ( $r = 0,219$ ;  $n = 104$ ;  $p < 0,05$ ); quanto maior o impacto emocional, maior a necessidade de procura de suporte ( $r = 0,303$ ;  $n = 104$ ;  $p < 0,01$ ); e quanto maior o impacto percebido na dimensão económica, maior a necessidade de procura de suporte ( $r = 0,319$ ;  $n = 104$ ;  $p < 0,01$ ).**Conclusão:** O grau de funcionalidade da família, a dependência da pessoa cuidada, a escolaridade, o género e o grau de parentesco parecem ter influência na adaptação das famílias.**Palavras-chave:** relações familiares; família; demência; enfermagem**Resumen****Marco contextual:** La familia es el principal recurso de la persona que cae enferma y sus miembros se consideran cuidadores familiares.**Objetivo:** Identificar las variables que influyen en el impacto del trastorno neurocognitivo en los familiares y caracterizar a los cuidadores de personas con PNC.**Metodología:** Estudio cuantitativo, descriptivo y correlacional, con 262 familiares de personas con trastorno neurocognitivo.**Resultados:** Los cuidadores observan una asociación entre las dimensiones impacto emocional ( $r = 0,526$ ,  $n = 102$ ,  $p < 0,01$ ), económica ( $r = 0,292$ ,  $n = 102$ ,  $p < 0,01$ ), búsqueda de apoyo ( $r = 0,279$ ,  $n = 102$ ,  $p < 0,01$ ), prestación de cuidados ( $r = 0,375$ ,  $n = 102$ ,  $p < 0,01$ ) con una mayor carga percibida. Entre los miembros de la familia, cuanto mayor es el impacto de las relaciones familiares percibidas, mayor es el apoyo social percibido ( $r = 0,219$ ,  $n = 104$ ,  $p < 0,05$ ); cuanto mayor es el impacto emocional, mayor es la necesidad de buscar apoyo ( $r = 0,303$ ,  $n = 104$ ,  $p < 0,01$ ), y cuanto mayor es el impacto percibido en la dimensión económica, mayor es la necesidad de buscar apoyo ( $r = 0,319$ ,  $n = 104$ ,  $p < 0,01$ ).**Conclusión:** El grado de funcionalidad de la familia, la dependencia de la persona cuidada, la educación, el género y el grado de parentesco parecen influir en la adaptación de las familias.**Palabras clave:** relaciones familiares; familia; demencia; enfermería**Corresponding author**

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## Introduction

Population aging is associated with the prevalence of chronic and disabling diseases, namely neurocognitive disorders (NCDs). Around 50 million people live with a dementia NCD worldwide, and there are nearly 10 million new cases every year. According to the World Health Organization (2018), Alzheimer's disease contributes to 60-70% of cases. According to the Dementia in Europe Yearbook 2019 (Alzheimer Europe, 2019), around 194,000 people live with a NCD in Portugal, which is the fourth leading cause of death. The costs associated with the exponential increase of NCD cases worldwide are around 700 billion euros with medical treatment, social support, and informal help due to informal caregivers' loss of income and productivity. This study aimed to identify the variables influencing the impact of NCDs on the family and characterize the caregivers of people living with a NCD.

## Background

Despite the decentralizing policy for hospital care in Portugal, access to social and health services is still a complex, slow, and delayed process. Due to the increased aging rate, about 55.3% of people exhibit deterioration in their level of dependence (PORDATA, 2021). Age combined with the level of dependence creates specific needs that are ensured by family caregivers (Melo et al., 2021). Therefore, it is urgent to establish new health policies and social services with solutions accessible to all citizens.

Portugal has an estimated 1.4 million informal caregivers who lack economic, social, and emotional support (Movimento Cuidar dos Cuidadores Informais, 2021). In 2019, the need for the Informal Caregiver Statute was recognized, which addresses the needs of patients and caregivers (Instituto de Segurança Social, 2021). Family caregivers are essential to healthcare systems as they accompany the patient throughout the caring process. However, caregivers providing daily care experience negative impacts, such as depressive symptoms, anxiety, and stress. Caring for a person with a NCD is a complex process because families experience social isolation and ambiguous feelings that compromise their emotional systems. Caregivers need psychoemotional support and more appropriate coping strategies to more effectively solve their problems (Melo et al., 2021).

Changes in the family structure and dynamics imply that families are limited in ensuring adequate health care to their dependent relatives, which is reflected in the increased demand for institutional support. Family members report changes at different levels, such as changes in their housing conditions, daily routines, and personal and work lives. Using situation-specific strategies to understand and cope with the evolution of the disease can minimize the negative impact of care delivery.

Given the challenges of family readaptation caused by the onset of a NCD, nurses need to deepen their knowledge

of the impact/consequences on the family to contribute to developing evidence-based practices. This study aimed to identify the variables influencing the impact of NCDs on the family.

## Research question

Which variables influence the impact of NCDs on the family?

What are the sociodemographic and clinical characteristics of the caregivers of people living with a NCD?

## Methodology

Data were collected between March 2019 and September 2020 through questionnaires applied to the different household members. The health professional of reference and/or researcher provided support in their completion. Households that had a person with a medical diagnosis of NCD and residing in the household were included. Families whose relatives with a NCD lived in residential facilities or nursing homes were excluded. In the different adult day care centers involved, the health professional of reference identified the families that met the inclusion criteria and voluntarily agreed to participate in the study. Participants' autonomy and right to withdraw were ensured through an informed consent form that included the following information: nature of the study, duration, methodology, purpose, and associated risks. The main caregiver and the researcher validated this form. The right to withdraw from the study at any time was clarified by phone or email to the researcher. This study used a non-probability convenience sample of 262 family members who lived with a person with a NCD on a daily basis. Permission was requested and granted for the use of the assessment instruments in this study. The following assessment tools were used: a) For persons with a NCD - Questionnaire with sociodemographic and clinical data; the Mini-Mental State Examination (MMSE) translated and adapted to the Portuguese population by Guerreiro et al. (1994) was used to check for cognitive impairment; the Lawton-Brody Scale was used to assess the level of independence in the performance of instrumental activities of daily living (Araújo et al., 2008); the Barthel Index was used to measure the level of independence in the performance of 10 basic activities of daily living (Araújo et al., 2007); b) For family members - Questionnaire with sociodemographic and clinical data; the Family APGAR score (Portuguese version by Agostinho & Rebelo, 1988); the Satisfaction with Social Support Scale (*Escala de Satisfação do Suporte Social*, ESSS) developed by Ribeiro (1999) to assess the perception of social support based on four domains (satisfaction with friends/friendships, Intimacy, satisfaction with family, and social activities); and the *Questionário de Avaliação Familiar do Impacto da PNC* (QAFIT, Family Assessment Questionnaire of the Impact of the NCD) developed by Silva and Sá (2020) to assess the impact of the NCD on the family; and c)

For primary caregivers - Questionnaire with sociodemographic and clinical data, the Family APGAR Scale, the ESSS, the Zarit Burden Interview adapted and validated by Sequeira (2007) to assess the objective and subjective burden of informal caregivers, and the QAFIT.

Data confidentiality and anonymity were ensured, with the respective coding through sequential numbers of all data obtained. The data collected in this study were processed using descriptive and inferential statistics through the IBM SPSS software, version 25.0. The study received a favorable opinion from the Ethics Committee of a Hospital Institution in the area of Psychiatry in the Northern region (Opinion no. 08 CEASS).

Pearson's and Spearman's correlation coefficients were used (parametric and non-parametric tests, respectively) to study the associations between the different variables after verifying the assumptions described. The significance level was set at  $p \leq 0.05$  (95% CI).

## Results

The results show that 53.3% of people with a NCD were women, aged 43 to 95 years ( $M = 75.4$ ,  $SD = 10.21$ ), 48.6% were married, 47.6% had completed basic education, and 90.5% were retired. Concerning the level of dependence assessed by the Barthel and Lawton-Brody scales, most people with a NCD had a severe level of dependence. As for the MMSE, the mean score was 20.46 ( $SD = 4.78$ ), indicating cognitive impairment in several functional areas, with 36.4% scoring lower than or equal to 15 points. Concerning the caregivers of people living with a NCD, most of them were women (74%), married (76%), who had completed secondary education (30.8%), retired (39.4%), and aged 35 to 89 years ( $M = 60.52$ ,  $SD = 13.76$ ). The most prevalent comorbidities were mental, behavioral, or neurodevelopmental disorders, circulatory system diseases, and musculoskeletal and connective tissue diseases. As for the remaining family members living with the person a NCD, most of them were women (62.7%), married (55.1%), with higher education (33.5%), employed (73.2%), and aged 18 to 84 years ( $M = 49.94$ ,  $SD = 13.72$ ). With regard to the presence of health-related comorbidities, the most prevalent diseases in this group were mental, behavioral, or neurodevelopmental disorders and circulatory system diseases. Concerning family functioning as assessed by the Family APGAR score, 57.6% of families consider themselves highly functional and 42.4% moderately dysfunctional.

The results show differences in the global QAFIT between female caregivers ( $M = 1.76$ ,  $SD = 0.35$ ) and male caregivers [ $M = 1.43$ ,  $SD = 0.41$ ,  $t(100) = 3.95$ ,  $p < 0.001$ ], with a higher global impact among female caregivers. In the family relations dimension between female caregivers ( $M = 1.54$ ,  $SD = 0.69$ ) and male participants ( $M = 1.20$ ,  $SD = 0.62$ ,  $t(100) = 2.19$ ,  $p = 0.031$ ), in the emotional dimension [female gender  $M = 1.78$ ,  $SD = 0.50$  and male gender  $M = 1.49$ ,  $SD = 0.68$ ,  $t(100) = 2.27$ ,  $p = 0.026$ ] and in the support-seeking dimension [female gender  $M = 1.97$ ,  $SD = 0.61$  and male gender  $M = 1.53$ ,  $SD = 0.83$ ,

$t(100) = 2.47$ ,  $p = 0.019$ ]. Regarding the perceived social support, differences were found between female participants ( $M = 43.40$ ,  $SD = 9.62$ ) and male participants [ $M = 47.64$ ,  $SD = 8.12$ ,  $t(100) = -1.99$ ,  $p = 0.049$ ], with the perceived social support being higher in male caregivers. Statistically significant differences were found in the Family APGAR score according to the family members' gender, with female family members ( $M = 7.64$ ,  $SD = 1.92$ ) scoring higher than male family members [ $M = 6.12$ ,  $SD = 2.10$ ,  $t(59) = 3.99$ ,  $p = 0.001$ ].

Statistically significant differences were found in the support-seeking dimension according to the caregiver's education level, indicating that the higher the education level, the higher the support-seeking level. Education levels were compared based on the number of participants per education level (secondary education, technological specialization, and higher education) and the dimensions of the impact of care delivery, the perceived social support, and the functioning of family members. Differences were found in the economic dimension of the impact of care delivery according to the family member's education level. More specifically, differences were found between family members with secondary education and those with higher education, with the former having a higher perception of the impact in this dimension. The same is true with regard to perceived social support.

Concerning the Family APGAR score, statistically significant differences were observed between the employed caregivers ( $M = 5.11$ ,  $SD = 1.50$ ) and the retired caregivers [ $M = 6.32$ ,  $SD = 2.75$ ,  $t(57) = -2.08$ ,  $p = 0.038$ ], the latter with a higher perceived family functioning.

Regarding marital status, differences were found only in the dimensions of the impact on support-seeking between family members who are single ( $M = 1.90$ ,  $SD = 0.69$ ) and those who are married [ $M = 1.53$ ,  $SD = 0.69$ ,  $t(129) = 2.87$ ,  $p = 0.005$ ], with the impact of support-seeking being higher in single family members.

Statistically significant differences were found in the impact of care delivery according to the degree of kinship with the person with a NCD in the dimension of family relations, namely differences between the children's group and the group of participants without a degree of kinship, as well as between the latter and the wife/husband group. There were also differences between the group without a degree of kinship and the daughter-in-law/son-in-law group. The most significant impact in this support-seeking dimension was found in the group of participants without a degree of kinship.

As for patients' level of dependence, differences were found in the dimension support-seeking, with a higher impact on caregivers who care for severely dependent people ( $M = 2.03$ ,  $SD = 0.60$ ) than on those who care for moderately dependent people [ $M = 1.69$ ,  $SD = 0.78$ ,  $t(75) = -2.15$ ,  $p = 0.035$ ]. Among caregivers, differences were found in the total and emotional QAFIT dimensions depending on the level of dependence. The differences in the caregiver group were found between caregivers of totally or severely dependent people and caregivers of mildly dependent people.

Differences were found in the QAFIT dimensions accord-



ing to the level of dependence, namely in total QAFIT. The impact on the family members of a person with a NCD with total or severe dependence is higher than on those family members of a person with mild dependence. Differences were also found in the dimension of family relations between the level of total or severe dependence and mild dependence, where the impact on the family member was higher when the person had severe dependence. In the emotional dimension, the impact of care delivery was higher when the person was moderately dependent.

Table 1 shows a positive, moderate, and statistically significant association between the emotional impact perceived by caregivers (assessed by the QAFIT) and their perceived burden ( $r = 0.526$ ,  $n = 102$ ,  $p < 0.01$ ), suggesting that the higher the emotional impact, the higher the burden. The same is true for the economic and support-seeking

dimensions of the QAFIT, that is, the higher the economic impact perceived by caregivers, the higher their perceived burden ( $r = 0.292$ ,  $n = 102$ ,  $p < 0.01$ ) and need for support-seeking ( $r = 0.279$ ,  $n = 102$ ,  $p < 0.01$ ). A positive and statistically significant association was found between burden and the total QAFIT, suggesting that the higher the impact of care delivery, the higher the perceived burden ( $r = 0.375$ ,  $n = 102$ ,  $p < 0.01$ ). With regard to the Family APGAR scores, a positive, weak, and statistically significant association was found with support-seeking, suggesting that the higher the family's functioning, the higher the need to seek support ( $r = 0.398$ ,  $n = 102$ ,  $p < 0.01$ ). All QAFIT dimensions were moderately, positively, and statistically significantly associated with the instrument's total score, with the highest correlation between the family relations dimension and the total QAFIT score ( $r = 0.650$ ,  $n = 102$ ,  $p < 0.01$ ).

**Table 1**

*Pearson's correlation coefficients for the QAFIT dimensions, social support, and burden of caregivers*

Variables								
Total QAFIT	-							
Family relations	0.650**	-						
Emotional	0.623**	0.052	-					
Economic	0.446**	0.073	0.007	-				
Support-seeking	0.604**	0.206*	0.380**	0.038	-			
Social support	-0.173	-0.127	-0.103	-0.148	0.007	-		
Burden	0.375**	-0.118	0.526**	0.292**	0.279**	-0.162	-	
Family APGAR	0.125	-0.025	0.088	-0.053	0.398**	0.219	-0.235	-
	Total QAFIT	Family relations	Emotional	Economic	Support-seeking	Social support	Burden	Family APGAR

Note. \* $p < 0.05$ ; \*\* $p < 0.01$ .

Table 2 shows a positive, weak, and statistically significant association between the impact of family relations perceived by family members (assessed by the QAFIT) and their perception of social support ( $r = 0.215$ ,  $n = 104$ ,  $p < 0.01$ ), suggesting that the higher the impact of family relationships, the higher the perceived social support. The same is true for the emotional and support-seeking dimensions of the QAFIT, that is, the higher the emotional impact perceived by family members, the higher their need to seek support ( $r = 0.220$ ,  $n = 104$ ,  $p < 0.01$ ). Moreover, the higher the need to seek support, the higher the impact on the economic dimension ( $r = 0.315$ ,  $n = 104$ ,  $p < 0.01$ ). As for the family APGAR scores, a negative,

weak, and statistically significant association was found in the emotional impact dimension, suggesting that the lower the family's functioning, the higher the emotional impact ( $r = -0.10$ ,  $n = 104$ ,  $p < 0.05$ ) and support-seeking ( $r = 0.184$ ,  $n = 104$ ,  $p < 0.05$ ). All QAFIT dimensions have strong, positive, and statistically significant associations with the total QAFIT. The highest correlation was found between the emotional dimension and the total QAFIT score ( $r = 0.704$ ,  $n = 104$ ,  $p < 0.01$ ). A positive and statistically significant association was found between family APGAR and social support ( $r = 0.202$ ,  $n = 104$ ,  $p < 0.05$ ), suggesting that the better the family functioning, the better the perceived social support.

**Table 2**

*Pearson's correlation coefficients for the QAFIT dimensions, social support, and family APGAR scores of family members*

Variables							
Total QAFIT	-						
Family relations	0.570**	-					
Emotional	0.774**	0.209*	-				
Economic	0.612**	0.043	0.235**	-			
Support-seeking	0.511**	-0.001	0.22**	0.315**	-		
Social support	0.070	0.215**	-0.035	-0.032	-0.018	-	
Family APGAR	0.11	0.268**	-0.10*	-0.089	0.184*	0.202*	-
	Total QAFIT	Family relations	Emotional	Economic	Support seeking	Social support	Family APGAR

Note. \* $p < 0.05$ ; \*\* $p < 0.01$ .

Spearman's correlation coefficient was used to analyze the associations between the QAFIT dimensions and the level of dependence. Table 3 shows a positive, weak, and statistically significant association between the total QAFIT score and the level of dependence ( $r = 0.23$ ,  $n = 104$ ,  $p < 0.05$ ), suggesting that the higher the level of dependence, the higher the impact of care delivery on the caregiver of the person with a NCD. Similarly, a positive, weak, and statistically significant association was found among the family members between the total QAFIT score and the level of dependence ( $r = 0.23$ ,

$n = 104$ ,  $p < 0.05$ ), suggesting that the higher the level of dependence, the higher the impact of care delivery on the family member of the person with a NCD. Among family members, a positive, weak-to-moderate, and statistically significant association was found between the dimension of family relations and the level of dependence ( $r = 0.39$ ,  $n = 104$ ,  $p < 0.01$ ), suggesting that the higher the degree of dysfunctionality of the person with a NCD, the higher the impact on the dimension of family relations of the family members of the person with a NCD.

**Table 3**

*Spearman's correlation coefficients for the QAFIT dimensions and the level of dependence assessed by the Barthel Index and the Lawton-Brody Scale (caregivers and family members)*

Variables	Barthel Index	Lawton-Brody Scale	MMSE
<b>Caregivers</b>			
Total QAFIT	-0.06	<b>0.23*</b>	0.07
Family relations	-0.16	0.17	-0.05
Emotional	0.17	0.76	-0.007
Economic	-0.04	0.05	0.006
Support-seeking	0.04	0.18	-0.07
	Barthel Index	Lawton-Brody Scale	MMSE
<b>Family members</b>			
Total QAFIT	<b>0.23*</b>	0.18	-0.18
Family relations	<b>0.39**</b>	0.15	0.12
Emotional	0.12	0.11	-0.05
Economic	-0.02	-0.02	-0.15
Support-seeking	0.01	0.21	-0.06
	Barthel Index	Lawton-Brody Scale	MMSE

Note. \* $p < 0.05$ ; \*\* $p < 0.01$ .

## Discussion

People with a NCD have a mean age of 75 years, are predominantly women (53.3%), married (48.6%), with basic education (47.6%), and mostly retired (90.5%). Most have severe dependence and cognitive impairment in several functional areas, with a mean score of 20.461 in the MMSE.

The caregivers of people with a NCD are mostly women (74.0%), married (76.0%), with secondary education (30.8%), retired (39.4%), and a mean age of 60 years. As regards the presence of comorbidities, mental, behavioral, or neurodevelopmental disorders, circulatory system diseases, and musculoskeletal system or connective tissue diseases were the most prevalent. The profile of caregivers is in line with the study published by Carvalho et al. (2019) as one of the facilitating factors for them to assume the role of caregivers. The family members who live with the person with a NCD are women (62.7%), married (55.1%), with higher education (33.5%), employed (73.2%), and with a mean age of 49.94 years. With regard to the presence of health-related comorbidities, mental, behavioral, or neurodevelopmental disorders and circulatory system diseases are the most prevalent diseases in this group.

According to the survey developed by the *Movimento Cuidar dos Cuidadores* Informais (Caring for Informal Caregivers Movement, 2021), there is a lack of economic, social, and emotional support. The majority of respondents (85.5%) need more financial support, 71% need more support in terms of care delivery, 68.5% need more professional support, 64% need more psychological support, and 49% need more legal support. The long-term dependence of a person with a NCD may trigger situations of stress and personal, family, and social imbalance experienced in different ways by caregivers and other family members. The main caregiver is responsible for daily care, appointments, treatments, and managing finances, assets, information, and family relations. From an emotional point of view, it is not easy for the caregiver to delegate the functions they have assumed throughout the illness process. Caregivers usually do not expose their feelings, thoughts, anguishes, and needs, avoiding dialogue with the person with a NCD to escape the reality they are experiencing and think about the future. According to the study by Mattos and Kovács (2020), the experience of caring for a relative allows valuing the simplest acts and gestures in different daily activities. The feelings of pride, search for meaning, closer relationship, and promotion of self-esteem are mediators in the caring process, providing emotional regulation and acceptance of the situation. In this study, the Family APGAR scores on the family's functioning revealed that 44.6% of the families considered themselves highly functional and 48.2% moderately dysfunctional. These results show that the higher the family's functioning, the higher the need to seek support for the caregivers. However, the results of the remaining family members show that the lower the family's degree of functioning, the higher the emotional impact. Intervention with caregivers requires a thorough assessment of the needs of both patients and family mem-

bers. Therefore, caregivers and family members should be provided with the knowledge necessary to understand the evolution of the disease and strategies to cope with maladjusted behaviors using multidisciplinary teams and community resources (Abreu, 2020).

One-third of the families use the available community resources, even when the level of dependence is high. This lack of demand increases isolation and physical and emotional burdens (Ordem dos Psicólogos Portugueses, 2020). The lack of knowledge about the available responses is a factor pointed out by caregivers for not using them. It is also important to reflect on the communication between health professionals, patients, and their families; however, intra-family communication is a means of support for the family experiencing a disease. Intra-family communication should allow sharing goals and expectations, clarifying thoughts, emotions, and feelings, and resolving family conflicts. At the social level, providing care to a person with a NCD increases family conflicts and decreases social support and interaction (Ordem dos Psicólogos Portugueses, 2020). The results show the importance of obtaining social support, highlighting coping strategies such as problem-solving and social support. The least used strategy was the acceptance of responsibility. In the same study, the least used strategy was the search for spiritual support. Figueiredo et al. (2020) found that the most commonly used strategies to cope with a chronic illness were reframing, that is, the ability to redefine the stressful events to adopt a more positive view of the situation and restructure their functions and roles; passive evaluation, that is, the family's acceptance of the stressful events; and obtaining social support, including the family's commitment to obtaining support from friends, neighbors, or extended family. According to Carvalho et al. (2019), caregivers display feelings of fear and uncertainty about the possible institutionalization of the person with a NCD. It is important to strengthen the acquisition of new strategies that empower the informal caregiver and contribute to keeping the patient in the community. An adequate level of literacy leads to more positive health outcomes and more appropriate use of the available health services/resources (Vaz, 2020). Therefore, lower literacy levels are associated with more hospitalizations, poor treatment adherence, and even increased mortality (Vaz, 2020). Information resources, multidisciplinary social support, and advice provided to caregivers at home through information and communication technologies (ICTs) can have a positive impact on different types of caregivers. The implementation of support programs using ICTs has positive outcomes in terms of accessibility, availability, and cost-effectiveness (Landeiro et al., 2017). Informal care should be associated with rewarding dimensions that allow for a more positive perception of the situation, as well as the acquisition of more adaptive and functional strategies, thus improving the relationship with the patient. This study should be applied to a larger sample of caregivers and family members who live with the patient on a daily basis to understand the consequences of caregiving and design the most appropriate nursing interventions to meet their needs.

## Conclusion

These data provided a better understanding of the families' adaptation to the onset of a NCD in one of the household members. The family's functioning, the patient's level of dependence, education level, gender, and the degree of kinship seem to influence family adaptation. The search for social support by people with higher education levels improves family functioning and reduces emotional repercussions. However, the more dysfunctional the person with a NCD, the more compromised the family relations. Household members cope in different ways with the needs arising from the illness process. To minimize the impact on the families, more appropriate strategies should be defined in collaboration with health professionals, thus raising the awareness of society and policy-makers of the importance of families in the provision of informal care. Further studies should be conducted to assess the family caregivers' profile and characterize the impact of the caring process on the household members.

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