Chapter 50

Burden in caregivers of patients with functional dependence and its relation to spirituality

https://doi.org/10.56238/colleinternhealthscienv1-050

Emanuely Andreoli de Siqueira
Lucas Mateus Campos Bueno
Mariana Moskado Batista de Almeida
Ana Júlia Rodrigues de Oliveira
Igor Calixto da Silva
Beatriz da Silva
Jussara Eliana Utida
Camila Costa de Araújo Pellizari
Joyce Karla Machado da Silva

1 INTRODUCTION

Functional dependence is characterized by the limitation that the individual has to perform their activities of daily living, whether basic or complex, making it necessary a person to assist in performing these tasks (NARDI; SAWADA; SANTOS, 2013).

Caregivers are the people who assume the role and take responsibility for assisting in the activities that the person cannot perform independently, offering continuous assistance in activities that require different levels of effort and having functions such as helping with feeding, locomotion, personal hygiene, and other daily tasks (GRANERO et al., 2019; D'AMEN, SOCCI, & SANTINI, 2021).

The execution of this role brings with it positive and negative aspects, and these negative aspects can result in a psychological and physical overload, due to the fatigue and difficulties encountered and the need to prioritize the patient's needs (NARDI; SAWADA; SANTOS, 2013; SANTOS et al., 2017).

Faced with the negative aspects arising from the act of caring, spirituality can provide hope and confidence to this population, since it involves aspects about the meaning of life and living, and can bring a sense of peace and purpose to perform their craft with less impact, since it is not limited to types of beliefs or practices (DELGADO-GUAY, et al., 2012; PANSINI et al, 2017).

Thus, it becomes essential to understand the burden and spirituality of caregivers, in order to contribute to health professionals' goals and behaviors for this population.

2 METHODOLOGY

This is a cross-sectional descriptive study approved by the Research Ethics Committee under CAAE 38803320.6.0000.8123, which evaluated caregivers of patients seen at the Physical Therapy School Clinic

of the Universidade Estadual do Norte do Paraná. The data were collected from November 2021 to May 2022.

The caregivers were invited to participate in the research on the day and time when the patient was undergoing physical therapy. At the first moment, the Informed Consent Form (ICF) was presented, explaining the entire research and the questionnaires used.

The study was composed of the Informal Caregiver Burden Assessment Questionnaire, which was used to assess physical, social, and emotional burden. It consists of 32 items and a numerical scale ranging from 1 to 5. The total score ranges from 32 to 160 points, in which higher values indicate greater burden (MONTEIRO; MAZIN; DANTAS, 2015).

The Abbreviated Religious/Spiritual Coping scale (CRE-Brief) was used to evaluate the dimension of spirituality and how caregivers deal with daily stressful factors. It is composed of 49 items, of which, 34 are positive items (CRE-p: strategies that provide a beneficial effect to the practitioner) and 15 are negative items (CRE-n: strategies that provide harmful consequences to the practitioner) (PANSINI et al, 2017).

In addition to these questionnaires, the sociodemographic profile form adapted from Trigueiro et al (2011) was also used to collect basic data from each caregiver.

3 RESULTS AND DISCUSSION

The study was composed of 26 caregivers of patients with functional dependence. Of these, 21 (80.7%) were female and 5 (19.2%) were male, with ages ranging from 28 to 71 years, of which, 16 (61.5%) were from 41 to 59 years old, 8 (30.7%) were from 18 to 40 years old, and only 2 (7.69%) were older than 60 years old, which was also evidenced in the study of Rangel et al. (2019), in which a large part of the sample was younger than 60 years old. In the study by Gaioli et al. (2012) there was also a predominance of women as caregivers, which evidences a greater tendency of women in the caregiving task. All caregivers were related to the patient, being 13 (50%) mother, 7 (26.9%) husband, 4 (15.3%) son and 2 (7.69%) grandmother/grandfather. In the study by Rangel et al. (2019), most of the caregivers are the sons (as), which was not observed in the present study, since most of the sample are mothers of the patients. Of the 26 caregivers, 24 (92.3%) reside with the patient and only 2 (7.69%) do not live with the patient, which is also possible to observe in the study of Gaioli et al. (2012), in which more than half of the sample participants reside with the patient.

Among the assessed domains of burden presented in table 1, the positive aspects such as efficacy and control mechanisms and satisfaction with the caregiver role and with the family member obtained a median of 5.0 in an interval from 1 to 5 in both domains, suggesting that the caregivers show satisfaction with their role and present facilitating aspects for this practice and, in the study by Monteiro et al, showed that there is a correlation between burden and satisfaction with the role and with the family member. The item family support obtained a median of 4.0 between the minimum and maximum interval, indicating that

the caregivers have the support of the family, which was not observed in the study by Pedrosa et al (2021), in which the lowest scores of burden were concentrated in this item.

Table 1. Overload evaluation

Informal caregiver burden (QASCI)	**Minimum**	**Maximum**	**Median**	**Mean ± SD**
Emotional overload (4-20)	1	5	1,0 (2,63)	2,17±1,52
Implications for personal life (11-55)	1	5	1,0 (3,00)	2,26±1,53
Financial Overload (2-10)	1	5	2,0 (3,50)	2,51±1,60
Reactions to demands (5-25)	1	5	1,0 (0,00)	1,53±1,17
Effectiveness and control mechanisms (3-15)	1	5	5,0 (0,00)	4,52±1,06
Family support (2-10)	1	5	4,0 (2,00)	3,75±1,37
Satisfaction with the caregiver role and with the family member (5-25)	1	5	5,0 (0,00)	4,69±0,88

Regarding spirituality, it was observed that caregivers use CRE-p more than CRE-n, showing that they believe that spirituality is a positive factor in coping with stress and everyday situations, according to Table 2. According to Iseselo et al (2016) and Ram et al (2020), religious coping is seen as the only means of encouragement and hope to this population and that caregivers use a mix of coping strategies including religious coping.

Table 2. Spirituality Assessment

Abbreviated Religious/Spiritual Coping Scale (CRE-Brief)	**Minimum**	**Maximum**	**Median**	**Mean ± SD**
CRE- Positive	1	5	4,0 (1,0)	3,53±1,02
CRE- Negative	1	4	1,0 (2,0)	1,73±0,98

In the correlation analysis shown in table 3, it can be seen that financial burden is most related to CRE-n (r=0.4, p=0.03), which is characterized by caregiver discontent with spirituality or religious beliefs.

Family support is inversely related to CRE-n (r=-0.4, p=0.04) as well as in efficacy and control mechanisms and satisfaction with the caregiver role, demonstrating that these are factors that benefit caregivers and generate less dissatisfaction regarding spirituality and personal beliefs.

Table 3. Correlation between CRE-positive and CRE-negative with overload.

CRE- Positive	*r*	*p*
Emotional overload	0,1	0,45
Implications for personal life	0,0	0,78
Financial Overload	0,1	0,35
Reactions to demands	-0,1	0,93
Effectiveness and Control Mechanisms	0,1	0,93
Family Support	0,0	1,0
Satisfaction with the caregiver role and with the family member	0,3	0,06
CRE- Negative		
Emotional overload	0,2	0,19

Implications for personal life	0,2	0,18
Financial Overload	0,4	0,03*
Reactions to demands	0,2	0,17
Effectiveness and Control Mechanisms	-0,2	0,16
Family Support	-0,4	0,04*
Satisfaction with the caregiver role and with the family member	-0,0	0,79

Note: Pearson's correlation test. *Indicates statistically significant values ($p \leq 0.05$).

4 FINAL CONSIDERATIONS

It was possible to notice that most of the caregivers are female, live with the patient, and have some degree of kinship with the patient.

According to the aspects evaluated of burden, it was noted that the caregivers have good family support, show satisfaction with the role they have, and present aspects that facilitate continuing to face the problems that arise from the performance of this role. Regarding spirituality, it was possible to conclude that the caregivers use more positive beliefs, showing that religious coping is a coping strategy and that it is seen as a positive factor by the caregivers, indicating that spirituality and religion are a source of support.

It is also concluded that the caregiver's spirituality and religious beliefs indicate a relationship with burden, in which financial burden is most related to NERC and family support is inversely related to NERC.

Thus, it was possible to characterize the burden and spirituality of caregivers of patients with functional dependence and to observe the relationship between these two factors; however, more studies are needed to investigate this association.

REFERENCES

DELGUADO-GUAY, M. O.; PARSONS, H. A.; HUI, D.; CRUZ, M. G. D. L.; THORNEY, S.; BRUERA, E. Spirituality, Religiosity, and Spiritual Pain Among Caregivers of Petients with Advanced Cancer. **American Journal of Hospice & Palliative medicine**. n. 30, v. 5, p. 455-461. 2012.

D'AMEN, B.; SOCCI, M.; SANTINI, S. Intergenerational caring: a systematic literature review on young and young adult caregivers of older people. **Bmc Geriatrics**, v. 21, n. 1, p. 1-7, 5 fev. 2021.

GAIOLI, C. C. L. O.; FUREGATO, A. R. F.; SANTOS, J. L. F. Perfil de Cuidadores de Idosos com Doença de Alzheimer Associado à Resiliência. **Contexto Enferm**, 2012.

GRANERO, G. S.; SANTOS, A. S.; SOUSA, K. C. R.; CINTRA, C. P.; CASEMIRO, M. C.; GARCIA, L. A. A.; BOMFIM, I. H. F. B. Sobrecarga de Cuidadores Familiares de Idosos com Depressão: Estratégias de Intervenções. **REFACS (online)**. v. 7, n.4, p. 491-502. 2019.

ISESELO, M. K. KAJULA, L. YAHYA-MALIMA, K. I. The psychosocial problems of families caring for relatives with mental illnesses and their coping strategies: a qualitative urban based study in Dar es Salaam, Tanzania. BMC Psiquiatria, 2016.

MONTEIRO, E. A; MAZIN, S. C; DANTAS, R. A. S. Questionário de Avaliação de Sobrecarga do Cuidador Informal: Validação para o Brasil. **Rev Bras Enfer**, v.68 n.3, p. 64-70. 2015.

NARDI, E. F. R.; SAWADA, N. O.; SANTOS, J. L. F. Associação entre a incapacidade funcional do idoso e a sobrecarga do cuidador familiar. **Revista Latino-Am. Enfermagem**. v. 21, p. 5. set.-out. 2013.

PANZINI, R. G.; MOSQUEIRO, B. P.; ZIMPEL, R. R.; BANDEIRA, D. R.; ROCHA, N. S.; FLECK, M. P. Qualidade de vida e espiritualidade. **International Review of Psychiatry**. v.29: n.3, p.263-282, 2017.

PEDROSA, A. O.; ROCHA, D. M.; OLIVEIRA, A. C.; SANTOS, A. M. R.; FIGUEIREDO, M. L. F.; NOGUEIRA, L. T. Indicadores e fatores associados à sobrecarga em cuidadores informais de pacientes em radioterapia. **Acta Paul Enferm**, 2021.

RANGEL, R. L.; SANTOS, L. B.; SANTANA, E. S.; MARINHO, M. S.; CHAVES, R. N.; REIS, L. A. Avaliação da Sobrecarga do Cuidador Familiar de Idosos com Dependência Funcional. **Revista Aten. Saúde**. São Caetano do Sul, v. 17, n. 60, p.11-18, abr/jun 2019.

RAO, P.; Grover S.; Chakrabarti S. Coping with caregiving stress among caregivers of patients with schizophrenia. **Asian J Psychiatr**. Julho, 2020.

SANTOS, T. V; YAMADA, A. S; CARDOSO, F. M.. FERRO, F. A. R.; ANDRADE, K. F.; GONÇALVES, L. F. Overload assessment imposed on primary caregivers of patients with cerebral palsy. **Revista Amazônia Science & Health**, 2017.

TRIGUEIRO, L. C. L.; LUCENA, N. M. G.; ARAGÃO, P. O. R.; Lemos, M. T. M.; Perfil sociodemográfico e índice de qualidade de vida de cuidadores de pessoas com deficiência física. **Revista Fisioterapia e Pesquisa**. São Paulo, v.18, n.3, p. 223-7, jul/set. 2011.