

Self-esteem of cancer patients' caregivers with reduced functional capacity

Autoestima dos cuidadores de doentes oncológicos com capacidade funcional reduzida
Autoestima de los cuidadores de pacientes oncológicos con capacidad funcional reducida

Natália Stanko Moreira¹
 Cristina Silva Sousa¹
 Vanessa de Brito Poveda¹
 Ruth Natalia Teresa Turrini¹

1. Universidade de São Paulo.
 São Paulo - SP, Brazil.

ABSTRACT

Objective: To evaluate the caregivers' self-esteem of cancer patients with reduced functional capacity. **Methods:** This is a cross sectional study, conducted in a large oncology public hospital. We used a convenience sample consisted of 90 primary caregivers of cancer patients with functional capacity (Karnofsky) between 20 and 50. We collected data about demographic characteristics, the responsibility involved in the care and self-esteem was assessed by the Scale to Measure the Feeling of Self-Esteem of Dela Coleta. Data were analyzed using the Mann-Whitney test and Kruskal-Wallis test, with 5% significance level. **Results:** The majority of caregivers was women, with a partner, low income and maintained family relationships with the patient and had an average self-esteem. Self-esteem was significantly associated to family income ($p = 0.002$). **Conclusion:** The self-esteem of caregivers of cancer patients is influenced by the conditions of life, especially financial.

Keywords: Caregivers; Neoplasms; Self-concept; Oncology nursing.

RESUMO

Objetivo: Avaliar a autoestima de cuidadores de doentes oncológicos com capacidade funcional reduzida. **Métodos:** Trata-se de estudo do tipo transversal, realizado em um hospital público, de grande porte, especializado em oncologia. Utilizou-se uma amostra por conveniência composta por 90 cuidadores principais de doentes com câncer com capacidade funcional (Karnofsky) entre 20 e 50. Foram coletados dados sócio-demográficos, sobre os encargos envolvidos no cuidar e a autoestima foi avaliada pela Escala para Medida do Sentimento de Autoestima de Dela Coleta. Os dados foram analisados pelo teste de Mann-Whitney e de Kurskall-Wallis, com nível de significância de 5%. **Resultados:** A maioria dos cuidadores eram mulheres, com companheiros, com baixa renda mensal, mantinham relações familiares com o doente e apresentavam média autoestima. A autoestima foi associada de forma estatisticamente significante apenas com a renda familiar ($p = 0,002$). **Conclusão:** A autoestima dos cuidadores de pacientes oncológicos é influenciada pelas condições de vida, especialmente as financeiras.

Palavras-chave: Cuidadores; Neoplasias; Autoimagem; Enfermagem oncológica.

RESUMEN

Objetivo: Evaluar la autoestima de los cuidadores de pacientes oncológicos con capacidad funcional reducida. **Métodos:** Estudio transversal, realizado en un hospital público especializado en Oncología. Se utilizó una muestra de conveniencia compuesta por 90 cuidadores de pacientes con cáncer con la capacidad funcional (Karnofsky) entre 20 y 50. Fueron colectados datos socio-demográficos sobre los encargos necesarios en la atención y la autoestima se evaluó mediante la Escala para Medida del Sentimiento de Autoestima. Los datos fueron analizados mediante la prueba de Mann-Whitney y Kruskal-Wallis, con significación del 5%. **Resultados:** La mayoría de los cuidadores eran mujeres, con un compañero, el ingreso mensual era bajo, mantenían relaciones familiares con el paciente y tenían una autoestima mediana. La autoestima se asoció de forma estadísticamente significativa sólo a los ingresos familiares ($p = 0,002$). **Conclusión:** La autoestima de los cuidadores de pacientes con cáncer está influenciada por las condiciones de vida, especialmente financieras.

Palabras-clave: Cuidadores; Neoplasia; Autoimagen; Enfermería Oncológica.

Corresponding author:
 Cristina Silva Sousa.
 E-mail: thicoteco@bol.com.br

Submitted on 05/16/2014.
 Accepted on 04/15/2015.

DOI: 10.5935/1414-8145.20150043

INTRODUCTION

Cancer has an important position in chronic diseases, with mortality increasing every year. Estimates from the National Cancer Institute (INCA) showed 580,000 new cases of cancer for 2014, being also a valid forecast for 2015¹.

Patients in their final stage are often weak and dependent, and signs such as pain, mental confusion, difficulty breathing, eating and mobility are commonly reported². During this period, patients need care provided by health services and assistance in their daily living activities, which requires the action of professional or family caregivers to assist their basic needs and to follow physician prescription.

In cases where the caregiver is a family member, changes in appearance, the functional skills and social and family roles generate an impact on the caregiver, usually being negative. Aware of the patient's family needs, the caregiver can rethink about their future and their life goals. Take caregiver position means learning to deal with the threats and fear of new symptoms, hospitalizations and limitations³.

In general, these caregivers feel overwhelmed with their new function, experiencing the feeling of anxiety, physical and emotional exhaustion, which they cannot unlink⁴. They may present financial difficulties because the increased costs of the patient or abandonment of work to play this caring function³.

The main caregivers also experience high emotional demands and charges, learning to deal with the feelings of the patient and his family, as family conflicts can be exacerbated by the disease situation, and leisure activities become rare or nonexistent⁴⁻⁶.

Thus, the self-esteem of the caregivers may be affected, considering the self-esteem as the view that the individual has of himself⁷. The feelings experienced about a terminal patient can reflect on the actions of their caregivers. The demand generated by the care is inversely related to the self-esteem of caregivers of parents with cancer⁸.

Self-esteem is a personal concept that can affect different aspects of life in individuals. Due to the dedication given to the patient, caregivers often do not prioritize actions of their personal needs, generating problems in their lives. In the context in which they live, caregivers of patients with advanced stage cancer, evaluating self-esteem may allow the construction of nursing interventions to improve their quality of life.

In this sense, this study aimed to evaluate the self-esteem of caregivers of cancer patients with reduced functional capacity.

METHOD

Cross-sectional study, exploratory, conducted with a convenience sample consisted of 90 primary caregivers of patients

with cancer and functional capacity (Karnofsky) between 20 and 50, who were 18 years old or older with communication skills and understanding preserved.

Data collection was carried out between October 2008 and July 2009 in oncology wards and palliative care in a large public hospital, specialized in oncology in São Paulo.

Patients in advanced stages of the disease and reduced functional capacity were identified by consulting the chart, which were also collected socio-demographic variables (age and marital status) and those related to the disease (primary tumor site, tumor stage, functional capacity, time between the date of diagnosis and the date of the interview).

The functional capacity of patients was characterized using the Karnofsky Scale, seeking to indicate the individual's well-being from their functional capacity, that is the ability to perform activities of daily life. Their score ranges from 0 to 100, where 100 indicates full health and zero indicates death⁹.

After identification of patients with Karnofsky below 50 recorded in the chart, their caregivers who accompanied the patient with cancer were approached in the waiting room for outpatient care. The researcher was close to caregivers when necessary, to carry out the reading of the instruments, in order to overcome problems of understanding or reading difficulties.

Caregivers answered the characterization form that addressed aspects related to socio-demographic data and charges involved in care. This instrument contained information such as age, education, gender, religion, marital status, family income, number of children, disease, relationship with the patient, occupation, if they received help to care for the patient, time providing care to the patient, if they had other occupations and leisure activities.

Caregivers were evaluated using the Scale to Measure the Feelings of Self-Esteem of Dela Coleta¹⁰, composed of fifteen questions. When answering this scale, the individual must agree or disagree with each statement, adding a final score corresponding to their self-esteem score, ranged from zero to 15 points, when each positive self-esteem answer one point is assigned, and zero for negative answers. The higher the score, the higher the individual's self-esteem feeling.

In the Scale to Measure the Feelings of Self-esteem, scores from zero to five points indicate low self-esteem; from six to 10 points, an average self-esteem, and from 11 to 15 points 10 represent high self-esteem¹⁰.

In data analysis, absolute and relative frequencies were used. Associations between self-esteem score and qualitative variables were analyzed using the Mann-Whitney test (for comparisons between two subgroups) and the Kruskal-Wallis test (for comparisons between more than two subgroups), with a significance level of 5%. The reliability of the scale was measured by Cronbach's alpha coefficient.

This study was approved by the Institutional Review Board of the Hospital wherein the fieldwork was developed (Protocol number 0644/08). Caregivers who met the inclusion criteria and agreed to participate were informed about the research objectives, the assurance of anonymity, freedom to participate in the research, and signed the Consent Informed Term in two copies.

RESULTS

Sociodemographic characteristics of the caregivers

Among the 90 caregivers analyzed, they were aged from 18 to 81 years old with a predominance of females, representing 84.4% of the sample. In religion, 50% were Catholic, followed by 27.8% of Evangelicals; 12.2% reported not having religion; and 10% had another religion. Children were most of the main caregivers (40%); followed by spouses (38.9%) and individuals with other kinship in 21.1% of cases. Care time ranged from one to 144 months. In this period, 78.8% of caregivers said they did not have any leisure activities.

Most caregivers (75.5%) had a partner and 45.6% had two to three children; 24.5% do not have children; 20% had one child and 10% had four or more children.

More than half had monthly income up to 2.9 minimum wage. Regards to occupation, 43.3% had other activities besides taking care of the patient, such as working, house chores and caring for children and 56.7% did not have other activities in addition to patient's care.

Self-esteem evaluation of the caregivers

The average score of self-esteem obtained by the main caregivers of cancer patients with reduced functional capacity was 10.8 points. The minimum score was three points and a maximum of 15 points, with a median of 10.6. The scale Cronbach's alpha was 0.729.

There was no statistical connection between patient's characteristics and the self-esteem score of caregivers (Table 1).

Table 2 illustrates the self-esteem scores and the characterization of caregivers, according to gender, age, education, marital status, family income, current occupation, religion, number of children, relationship with the patient and practice of leisure activities.

There was a statistically significant association between self-esteem and family income ($p = 0.002$), showing that individuals with lower income have lower self-esteem scores than the other.

The phrases of the Scale to Measure the Feelings of Self-esteem that contributed significantly to the lowest scores were: "there are things in me that I would change if it were possible" (67.8%), "so far I almost could not accomplish what I had planned for me" (55.6%), "I need recognition and approval of my

actions" (45.5%), "I usually have the feeling that there is nothing I can do right" (35.6%), "I would like to find a person who could solve my problems" (35.6%), "I certainly feel useless at times" (30%) (Table 3).

DISCUSSION

Most caregivers included in this study were women, with a partner and low monthly income, maintained family relationships with the patient and by the average scores, it was observed that caregivers had average self-esteem, with a statistically significant association only in family income, that is, the lower the income, the lower the self-esteem.

Previous investigations showed the role of women and the family relationship of the caregiver with the chronically patient, as well as highlighted the characteristics of the disease and the patient not being related to low scores of self-esteem among caregivers^{8,11}. This was also evidenced by this study.

The socio-demographic characteristics of caregivers are directly related to global feelings of self-esteem. Against this claim, a study that examined the psychosocial consequences for adult daughters, caregivers of elderly parents, with up to sixty days of diagnosis of cancer identified high scores of self-esteem and more likely to score higher in women with other occupations, beyond patient care, as regular work and care of children, daughters or granddaughters⁸.

However, in a recent research, the characteristics associated with caregivers, such as belonging to the female gender, being single, less educated and with low income were related to higher overwhelm¹². Thus, the possibility of the caregiver to be inserted in the marketplace work and preserve his individuality could contribute positively to self-esteem.

A meta-analysis study that described the different cancer effects on caregivers' well-being, indicated that the caregiver stress can lead to disturbances and changes in the health of the physical caregiver. Interventions with caregivers can reduce these negative effects and improve the coping skills of caregivers, knowledge and quality of life¹³.

It is interest to point out that the results of this study suggest a relationship between the practice of leisure activities and the self-esteem score, where people with lower scores perform less leisure activities, possibly by the time required to meet the patient's needs. This can create a negative impact on interpersonal relationships and partially comes against the evidence demonstrated by a longitudinal study¹⁴ that analyzed 163 caregivers, and concluded that generally, high levels of overload experienced by caregivers of patients with lung cancer have an impact on their psychological well-being and quality of life.

Self-esteem is related to the overload on informal caregivers of cancer patients, suggesting the need for psychological support and participation of other family members in care¹⁵.

Table 1. Self-esteem of caregivers according to socio-demographic characteristics and morbidity of patients with reduced functional capacity. São Paulo, 2010

Patients' characteristics	n (%)	Average (SD)	Self-esteem of caregivers scale		p
			Median	Variation	
Gender					
Female	46 (51.1)	10.4 (3.3)	13	3-15	0.471*
Male	44 (48.9)	11.1 (2.5)	12	3-15	
Age					
25-50	16 (17.8)	10.9 (3.3)	12	3-14	0.512*
51-90	74 (82.2)	10.7 (2.9)	11	3-15	
Marital status					
With partner	68 (75.6)	10.8 (2.9)	11.5	3-15	0.928*
Without partner	22 (24.4)	10.7 (3.2)	11.5	4-15	
Tumor place^a					
Gastrointestinal tract	32 (35.5)	10.6 (3.3)	12	3-15	0.983**
Head and neck	15 (16.7)	10.7 (3.0)	11	4-15	
Urologic	13 (14.5)	11.3 (2.3)	12	8-15	
Other places ^b	30 (33.3)	10.7 (2.9)	12	3-15	
Time of diagnosis (n = 83)					
1-12 months	41 (49.4)	10.95 (2.75)	12	3-14	0.952*
13-468 months	43 (50.6)	10.95 (3.13)	11.5	3-15	
Karnofsky					
50	29 (32.3)	10.34 (3.35)	11	3-14	0.813**
40	49 (54.5)	10.94 (2.48)	11	4-15	
30	11 (12.2)	11 (3.78)	13	3-15	
20	1 (1.1)	12 (0)	12	12	

* Mann-Whitney test; ** Kurskall-Wallis test; ^a Brazil. Ministry of Health. Secretary of Health Care. National Cancer Institute. TNM: classification of malignant tumors/translation of Ana Lúcia Amaral Eisenberg. 6 ed. - Rio de Janeiro: INCA, 2004; ^b Bone and soft part tumors, gynecological, lung and pleura, breast, skin, ophthalmic and lymphomas.

This aspect becomes more important to be noted that in a study analyzing 179 caregivers of terminal patients found that 77.0% of them showed significant distress, more than 76.0% showed anxiety and 77.4% depression, where self-esteem of caregivers and the workload were strong distress predictors¹⁶, that is, caregivers need support.

Information on the main negative answers to certain items of the scale show that self-esteem has its own component of the individual, that is, how he is perceived as a human being and as the protagonist of his story. Some statements could refer to the ability to cope everyday obstacles and perceived impotence in death and the need to alleviate the suffering of the other.

In this scenario, health professionals stand out for their ability to ensure better conditions for caregivers and patients, since assisting caregivers in developing effective coping strategies

can reduce the overload associated with the care of the patient, resulting in physical and psychological protection, which will favor better care to the patient¹⁷.

With increasing longevity of the population, incidence of patients with chronic and degenerative diseases and the need for caregivers is increased, which often are also family members, and with this is a growing demand for health actions that provide reception to this subject.

CONCLUSION

It was concluded that the analyzed caregivers had average self-esteem, noting the high emotional demand that caregivers of cancer patients with reduced functional capacity can receive from the patient and their families.

Table 2. Self-esteem of caregivers according to socio-demographic characteristics. São Paulo, 2010

Variables of caregivers	N (%)	Self-esteem scale			p
		Average (SD)	Median	Variation	
Gender					
Female	76 (84.4)	10.63 (2.95)	11	3-15	0.129**
Male	14 (15.6)	11.57 (2.73)	12.5	5-14	
Age					
25 to 50	55 (61.1)	10.4 (3.11)	11	3-15	0.200**
51 to 90	35 (38.9)	11.37 (2.54)	12	5-15	
Education					
0 to 8 years	42 (46.7)	10.76 (2.74)	11	4-15	0.726*
9 to 16 years	48 (53.3)	10.79 (3.1)	12	5-15	
Marital Status					
With partner	68 (75.6)	10.79 (2.87)	11.5	3-15	0.928*
Without partner	22 (24.4)	10.73 (3.16)	11.5	4-15	
Family income (MW^a)					
Up to 2.9 MW	46 (51.1)	9.89 (2.94)	11	4-14	0.002*
3 to 24.1 MW	44 (48.9)	11.7 (2.63)	12	3-15	
Current occupation					
Yes	39 (43.3)	10.72 (2.89)	11	3-15	0.770*
No	51 (56.7)	10.82 (2.98)	12	3-15	
Receiving help					
Yes	55 (61.1)	10.75 (2.92)	11	3-15	0.838*
No	35 (38.9)	10.83 (2.97)	12	3-15	
Religion					
Catholic	45 (50)	10.64 (2.96)	11	3-15	0.880**
Evangelic	25 (27.8)	10.56 (3.02)	11	3-15	
Others	20 (22.2)	11.35	12	4-15	
Number of children					
0 to 1	18 (20)	10.44 (3.65)	11	4-15	0.827*
2 to 5	72 (80)	10.86 (2.74)	12	3-15	
Relationship with the patient					
Children	37 (41.1)	10.97 (2.92)	11	3-15	0.808**
Spouses	32 (35.6)	10.84 (2.83)	12	3-15	
Others	21 (23.3)	10.33 (3.18)	11	4-14	
Time of care (months) n = 89					
1 to 36 months	76 (85.4)	10.71 (3.01)	11.5	3-15	0.523*
36 to 144 months	13 (14.6)	11.38 (2.43)	12	6-14	
Leisure activities					
Yes	19 (21.1)	12 (1.91)	12	7-15	0.061*
No	71 (78.9)	10.45 (3.07)	11	3-15	

* Mann-Whitney test; ** Kurskall-Wallis test; ^a Current minimum wage (MW) of R\$ 465.00.

Table 3. Answers ratio scored negatively (zero) in the Scale to Measure the Feelings of Self-Esteem. São Paulo, 2010

Phrases	N (%)
1. I usually have the feeling that there is nothing I can do right.	32 (35.6)
2. I often think I'm a worthiness person.	10 (11.1)
3. I constantly wish to be someone else.	15 (16.7)
4. I give up easily the things I'm doing.	20 (22.2)
5. I am happy as I am.	20 (22.2)
6. My family understands me.	20 (22.2)
7. I am able to do things as most people are.	9 (10.0)
8. Usually, I am satisfied with myself.	24 (26.7)
9. I would like to find a person who could solve my problems.	32 (35.6)
10. So far I almost could not accomplish what I had planned for me.	50 (55.6)
11. There is something in me that I would change if possible.	61 (67.8)
12. I need recognition and approval of my actions.	41 (45.5)
13. On the whole, I feel that I am a loser.	8 (8.9)
14. I certainly feel useless at times.	27 (30.0)
15. I would be a different person than I am.	23 (25.6)

There was a statistically significant association between income and self-esteem of caregivers of cancer patients, that is, the lower the income, the lower the self-esteem.

Despite the limitations of the present study regarding the generalization of the results, by the research design and sample type, the research shows the nursing staff to several aspects that must be worked with caregivers and possible family members of cancer patients which can impact on the quality of the care provided.

In this way, for the care of cancer patients with reduced functional capacity being implemented in full, the nursing team must be attentive to all its dimensions, including the physical, social and emotional aspects of caregivers, building with the caregiver measures that assist in dealing with feelings and situations that compromise their physical and psychological well-being.

It is suggested the development of research with interventionist focus for health promotion and quality of life for this profile of caregivers. The study has limitations to have used a convenience sample and restricted its collection to caregivers of patients treated in public hospitals because they generally have low income and the caregiver is often a family member.

REFERENCES

1. Instituto Nacional de Câncer José Alencar Gomes da Silva - INCA. Coordenação Geral de Ações Estratégicas. Coordenação de Prevenção e Vigilância. Estimativas 2014 - Incidência de Câncer no Brasil. Rio de Janeiro: INCA; 2014 [Acesso em 2015 abril 10]. Disponível em: <http://www.inca.gov.br/estimativa/2014/>.
2. Seow H, Barbera L, Sutradhar R, Howell D, Dudgeon D, Atzema C, et al. Trajectory of performance status and symptom scores for patients with cancer during the last six months of life. *J Clin Oncology*. 2011;29(9):1151-8.
3. Barros SMM, Andrade MAC, Siqueira FAA. Caring for a family member with cancer: contributions from a systematic family therapy. *Pensando Fam*. 2013;17(2):96-110.
4. Manoel MF, Teston EF, Waidman MAP, Decesaro MN, Marcon SS. The Family relationship and the burden level on Family caregivers. *Esc Anna Nery*. 2013;17(2):346-53.
5. Braz E, Ciosak SI. O tornar-se cuidadora na senescência. *Esc Anna Nery*. 2009;13(2):372-7.
6. Oliveira WT, Antunes F, Inoue L, Reis LM, Araujo CRMA, Marcon SS. Vivência do cuidador familiar na prática do cuidado domiciliar ao donete crônico dependente. *Cienc. cuid. saude*. 2012;11(1):129-37.
7. Freire T, Tavares D. Influence of self-esteem and emotion regulation in subjective and psychological well-being of adolescents: contributions to clinical psychology. *Rev Psiq Clin*. 2011; 38(5):184-8.
8. Raveis VH, Bachner YG, Karus DG. Examining the social context in the caregiving experience: correlats of Global Self-Steem among adult daughter caregivers to an older parent with cancer. *J Aging Health*. 2009;21(7):1016-39.
9. Karnofsky DA, Burchenal JH. The clinical evaluation of chemotherapeutic agents in cancer. In: McLeod CM ed. Evaluation of chemotherapeutic agents. New York (EUA): Columbia University Press; 1949; 191-205p.
10. Dela Coleta JÁ, Dela Coleta MF. Escalas para medida de atitude e outras variáveis psicossociais. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da USP; 1996.
11. Alptekin S, Gönüllü G, Yücel İ, Yarış F. Characteristics and quality of life analysis of caregivers of cancer patients. *Med Oncol*. 2010;27(3):607-17.
12. Park CH, Shin DW, Choi JY, Kang J, Baek YJ, Mo HN, et al. Determinants of the burden and positivity of family caregivers of terminally ill cancer patients in Korea. *Psychooncology*. 2012;21(3):282-90.

13. Northouse L, Williams A-L, Given B, McCorkie R. Psychosocial care for family caregivers of patients with cancer. *J Clin Oncology*. 2012;30(11):1227-34.
14. Grant M, Sun V, Fujinami R, Sidhu R, Otis-Green S, Juarez G, et al. Family caregiver burden, skills preparedness, and quality of life in non-small cell lung cancer. *Oncol Nurs Forum*. 2013;40(4):337-46.
15. Adejumo A. Influence of social support, depression, and self-esteem on burden of care among caregivers of oncology patients. *World Hosp Health Serv*. 2009;45(3):19-21.
16. Costa-Requena G, Cristófol R, Cañete J. Caregivers' morbidity in palliative care unit: predicting by gender, age, burden and self-esteem. *Support Care Cancer*. 2012;20(7):1465-70.
17. Guedes AC, Pereira MG. Burden, Coping, Physical Symptoms and Psychological Morbidity in Caregivers of Functionally Dependent Family Members. *Rev. Latino-Am. Enfermagem*. 2013;21(4):935-40.