

Quality of life of caregivers of patients with gastrointestinal cancer: relationship of sex, age, and stage of the cancer patients

Qualidade de vida de cuidadores de pacientes com câncer gastrointestinal: relação de sexo, idade e estágio dos pacientes com câncer

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ABSTRACT

Introduction: The caregivers of cancer patients may experience changes in their routine that affect their quality of life. The aim of the study was to identify the domains that compromise the quality of life (QoL) of the caregivers of patients with gastrointestinal cancer (GIC). **Methods:** A descriptive, observational study with caregivers of patients diagnosed with GIC during chemotherapy therapy was done. The caregivers answered 2 questionnaires, SF-36 (short form health survey 36) and CBS (caregiver burden scale). **Results:** 100 caregivers of 100 patients with GIC were included. The mean age of the patients was 62.2 ± 13 years. Most of them had colorectal cancer (66%), ECOG 0-1 (87%) and stage II/III (81%) disease. Among caregivers, 81% had less than 60 years old and 76% were female. According to the SF-36, lower levels were observed in the emotional, physical aspects and vitality and the best average in functional capacity. Regarding the CBS instrument, the general strain domain and disappointment was the more affected. Stage or ECOG was not associated to the caregivers QOL or burden. High schooling level of the patients was associated with a better quality of life and less burden of the caregivers. Ageing caregivers had a worst QoL and an increased burden. **Conclusion:** Most of caregivers were women and youngsters, and had a worst quality of life in emotional role, physical aspects and vitality, and an increased burden in general strain and disappointment.

Keywords: Caregivers; Quality of life; Gastrointestinal cancer.

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RESUMO

Introdução: Os cuidadores de pacientes com câncer podem vivenciar mudanças em seu cotidiano que afetam sua qualidade de vida. O objetivo do estudo foi identificar os domínios que comprometem a qualidade de vida (QV) dos cuidadores de pacientes com câncer gastrointestinal (CG). **Métodos:** Foi realizado um estudo descritivo e observacional com cuidadores de pacientes com diagnóstico de CG durante o tratamento quimioterápico. Os cuidadores responderam a 2 questionários, SF-36 (*short form health survey 36*) e CBS (*caregiver burden scale*). **Resultados:** 100 cuidadores de 100 pacientes com CG foram incluídos. A média de idade dos pacientes foi de 62,2±13 anos. A maioria deles tinha câncer colorretal (66%), ECOG 0-1 (87%) e doença em estágio II/III (81%). Entre os cuidadores, 81% tinham menos de 60 anos e 76% eram do sexo feminino. De acordo com o SF-36, foram observados níveis inferiores nos aspectos emocionais, físicos e vitalidade, e a melhor média na capacidade funcional. Em relação ao instrumento CBS, o domínio de desgaste geral e decepção foi o mais afetado. Estágio ou ECOG não foram associados à QV ou sobrecarga do cuidador. A alta escolaridade dos pacientes foi associada a uma melhor qualidade de vida e menor sobrecarga dos cuidadores. Cuidadores idosos tiveram pior QV e sobrecarga aumentada. **Conclusão:** A maioria dos cuidadores eram mulheres e jovens, e apresentaram pior qualidade de vida no papel emocional, aspectos físicos e vitalidade, e aumento da sobrecarga no desgaste geral e decepção.

Palavras-chave: Cuidadores; Qualidade de vida; Câncer gastrointestinal.

INTRODUCTION

Gastrointestinal cancer is a common cause of cancer, being colorectal and gastric cancer the 3rd and the 5th cause of cancer worldwide,^[1] and the 2nd and 5th cause of cancer, respectively in Brazil.^[2]

Patients with advanced disease (metastatic or locally advanced) are candidates of chemotherapy treatment. Their routine is hard; they had to go to the oncologist frequently, to do blood tests, CT or MRI scans and infusion chemotherapy, often intravenous. Adverse effects as anorexia, fatigue, nausea, vomiting, and diarrhea occur in most chemotherapies' treatment. These changes in their routine make them need a caregiver that have an important role in the management of the patients, mainly in advanced stages.

However, the involvement of the caregivers in the patient treatment affects their own health causing physic and mental disturbances. The time and effort spent with the cancer's patients, increase the risk of morbidities, decrease the social life, and can compromise their quality of life. Some researchers observed that mental distress^[3] is more severe than physical disturbance. The time spent with the patients also decrease the possibility of the individual to work, thereby reducing family income. The deterioration of health-related quality of life increases when they take care of terminal cancer patients.^[4,5]

Questionnaires of quality of life was studied to quantify the changes in different domains in caregivers. The knowledge of their burden may help the professional team to introduce a special support program to decrease the impact of the patient in their mental and health quality of life.

The SF-36 (short form health survey 36) is a generic measure of quality of life (QoL) in a variety of diseases to evaluate outcomes with 36 questions in 8 domains that study mental and physical health. It was validated in Brazil by Ciconelli et al. (1999)^[6] in patients with rheumatoid arthritis.

The CBS (caregiver burden scale) is an instrument used to evaluate general aspects of quality of life related mental and emotional health in caregivers of patients with chronic disease and cancer. After description by Oremark in 1988, this questionnaire had been modified by Elmstahl et al, in 1996^[7] and validated in Brazil by Medeiros et al. (1998).^[8]

The aim of the study was to identify the quality of life of the caregivers of gastrointestinal cancer patients on chemotherapy using the short form health survey 36 and the caregiver burden scale and compare these alterations with sex, age, stage, and ECOG of the cancer patients.

METHODS

A descriptive observational study was carried out with informal (non-paid) caregivers that are closest to the patient with gastrointestinal cancer on chemotherapy with or without radiotherapy at the outpatient's oncology of gastrointestinal tumor at the Hospital Sao Paulo, from the Federal University of Sao Paulo.

The study was approved by the ethical committee of the university (CEP UNIFESP) CAAE No. 04338518.2.0000.5505. All the caregivers with more than 18 years were informed about the study and after signing the informed consent form, answered 2 questionnaires, the SF-36 and the CBS.

The questionnaires had been answered in a private space without the presence of the patient by the same interviewer.

Epidemiological data such as sex, age, marital status, educational level, and comorbidities of the patients and caregivers was collected. Tumor location, ECOG and stage was collected from medical records.

The SF-36 is a questionnaire of quality of life, largely used to evaluate health and mental status in medical outcomes with 36 questions. It includes 8 domains to assess: functional capacity, role physically, bodily pain, general health, vitality, social functioning, role emotional, and general health perceptions. It has been answered by self-administration or with the help of the same nurse. The SF-36 score ranges from 0 (lowest) to 100 (highest QoL level). Although there is not a consensus about the cut off, values ≤ 50 are considered an impaired quality of life.

The CBS is an instrument used to evaluate general aspects of quality of life related mental and emotional health with 22 questions, distributed in 5 domains: general strain (8 questions), isolation (3 questions), disappointment (5 questions), emotional involvement (3 questions), and environment (3 questions). Each question had four alternatives (not at all, seldom, sometimes, or often). The score from each domain is found by the mean arithmetic of the scores and the global score is calculated by the mean arithmetic of all the 4 domains. Higher scores indicate greater impact on quality of life. CBS values between 0-19 points were considered minimal burden and between 20-88 points were considered high burden.

Statistical analysis

The exploratory analysis of the data included descriptive statistics, mean, median, standard deviation, minimum and maximum values for numerical variables and number, and proportion for categorical variables. The comparison of ordinal variables (domains of quality of life and domains of burden) between the two independent groups was performed using the Mann-Whitney test. Patients and caregivers were treated as joint distributions to find relationships between the ordered pairs (patient and caregiver). The comparison of numerical variables between them was performed using the Student's t-test for paired samples and categorical variables, using the McNemar test. Statistical analysis was performed using IBM SPSS Statistics software version 24 (IBM Corporation, NY, U.S.). Values of $p < 0.05$ were considered significant.

RESULTS

A hundred caregivers that take care of 100 patients with gastrointestinal cancer were included. The mean age of the patients was 62.2 ± 13.0 years old, most of them had ≥ 60 years old (67%), were male (52%) and single, divorced, or widowed (60%). Among the patients, 66 had colorectal cancer, 11 esophageal cancer, 10 gastric cancer, 9 pancreatic cancer, and 4 had hepatocellular carcinomas. Most of the patients had stage III (50%), 31% stage II and 19% stage IV, 89% were on chemotherapy treatment and 11% on chemotherapy plus radiotherapy. 59% had ECOG 0 and 28% ECOG 1. (Table 1)

Table 1. Characteristics of the cancer patients and of the caregivers

Characteristics	Cancer patients N=100 N (%)	Caregivers N=100 N (%)	p
Mean age (years)	62.2 \pm 13.0	38.8 \pm 14.3	<0.001
Age, n (%)			
<60 years	33 (33)	81 (81)	<0.001
≥ 60 years	67 (67)	19 (19)	
Gender, n (%)			
Male	52 (52)	24 (22.6)	<0.001
Female	48 (48)	76 (77.4)	
Educational stage n (%)			
Elementary school	47 (47)	15 (15)	<0.001
High school/University level	53 (53)	85 (85)	
Marital stage n (%)			
Not married/widower/divorced	60 (60)	74 (74)	<0.001
Married	40 (40)	26 (26)	
Co-morbidities, n (%)			
Yes	79 (79)	72 (72)	0.310
No	21 (21)	28 (28)	

Note. Categorical variables are described in number (percentage)

In contrast among the caregivers 81% had less than 60 years old, the mean age was 38.8 ± 14.3 years old and were female (76%). Regarding education, 85% had college or high school, 74% were married. 41% were daughter/son, 33% were wives, and 10% were brothers. (Table 1)

The comorbidities mentioned by the caregivers were also arterial hypertension and diabetes, but 28% of the caregivers did not have any disease. The frequency of youngers, females, and a higher schooling grade in the group of caregivers were significantly different compared to the patients ($p < 0.001$). (Table 1)

The SF-36 showed a lower (< 50) level in emotional aspects (14.7), physical aspects (26.8), and vitality (35.9). The best average value was obtained in functional capacity (80.9). (Table 2)

Comparing the results obtained in the SF36 most affected according to specific parameters of the cancer patients, we did not find differences between quality of life of the caregivers and age of the patients. Emotional role ($p = 0.018$) was worst in caregivers of women patients and caregivers of patients with lower schooling had worst QoL in vitality ($p = 0.002$) (Table 3).

Caregivers of married patients had a better QoL in vitality ($p = 0.006$). No difference was observed among the domains and stage or ECOG of the cancer patients.

Ageing caregivers (≥ 60 years) had a worst QoL on general health (47.2 ± 6.1 vs. 54.8 ± 17.9 ; $p = 0.017$). No difference was observed between the sex of the caregivers and the different domains.

In relation to CBS, it was observed that the domain general strain (mean=20, average of 11-31) and disappointment (mean=15, average 5-20) had the highest score, indicating a higher burden. The other domains had a mean and an average less than 20. (Table 4)

Ageing caregivers had a higher burden on the disappointment domain (16.5 ± 4.0 vs. 14.8 ± 3.1 , $p = 0.018$). Caregivers not married had also an increases burden in this domain (16.5 ± 2.7 vs. 14.7 ± 3.4 , $p = 0.019$)

We did not find a difference on general strain or disappointment in the caregivers and sex, age, marital stage, schooling level, stage disease or ECOG of the patients. (Table 5)

Table 2. Short form health survey of the caregivers studied.

Domains	Mean	SD	Median
Functional capacity	80.9	24.6	95.0
Role physically	26.8	37.5	0
Bodily Pain	53.3	21.9	51.0
General health	53.3	16.6	52.0
Vitality	35.9	27.9	21.0
Social functioning	51.3	24.1	50.0
Role emotional	14.7	31.9	0
Mental health	61.0	20.8	62.0

SD: standard deviation

Table 3. Short Form Health Survey 36 (SF-36) and according to the age, gender, schooling and marital stage of the patients

		Short Form Health Survey 36		
		Mean \pm SD		
Variables		Role Physically	Vitality	Role emotional
Age	<60 years	21.2 \pm 38.1	29.9 \pm 24.1	9.1 \pm 25.4
	≥ 60 years	29.5 \pm 37.2	38.8 \pm 22.0	17.4 \pm 34.5
	P value	0.154	0.171	0.216
Gender	Female	28.7 \pm 12.5	39.4 \pm 29.7	8.3 \pm 27.9
	Male	25.0 \pm 40.5	32.6 \pm 26.0	20.5 \pm 34.4
	P value	0.239	0.409	0.018
Educational Stage	Elementary	22.9 \pm 32.1	27.1 \pm 22.4	12.8 \pm 29.9
	College/Uni	30.2 \pm 41.7	43.6 \pm 30.1	16.3 \pm 33.7
	P value	0.603	0.002	0.668
Marital Stage	Married	23.1 \pm 35.9	42.3 \pm 28.3	15.8 \pm 31.1
	No M, W, D	29.2 \pm 38.6	31.6 \pm 26.9	13.9 \pm 32.6
	P value	0.402	0.006	0.554

College/Uni: College or University level; No M: no married, W: widower, D: divorced

Table 4. *Caregiver Burden Scale* of the caregivers studied.

Domains	Mean	SD	Median
General strain	20.0	5.58	20.0
Isolation	8.5	1.65	8.5
Disappointment	15.0	3.37	15.0
Emotional involvement	4.0	2.50	4.0
Environment	9.0	1.81	9.0

Table 5. Caregiver burden Scale according to the age, gender, schooling, marital stage, ECOG and stage of the patients

Variables		General Strain mean±SD	Disappointment mean±SD
Age	<60 years	20.3 ± 6.2	15.9 ± 3.3
	≥60 years	21.1 ± 5.2	14.8 ± 3.3
	P value	0.793	0.109
Gender	Female	19.9 ± 5.7	15.1 ± 2.9
	Male	21.7 ± 5.3	15.3 ± 3.7
	P value	0.078	0.457
Schooling	Elementary	21.7 ± 5.9	15.5 ± 3.4
	College/Uni	20.6 ± 5.2	14.8 ± 3.3
	P value	0.081	0.325
Marital stage	Married	21.9 ± 5.6	15.8 ± 3.1
	No M, W, D	20.2 ± 5.4	14.8 ± 3.4
	P value	0.135	0.134
Stage	II	20.3 ± 5.4	15.5 ± 2.0
	III-IV	21.1 ± 5.6	15.0 ± 3.8
	P value	0.570	0.865
ECOG	0	20.6 ± 5.7	15.5 ± 3.2
	1-2	21.2 ± 5.3	14.7 ± 3.4
	P value	0.633	0.312

College/Uni: College or University level; No M: no married, W: widower, D: divorced

DISCUSSION

The quality of life of the patients with cancer on chemotherapy and radiotherapy treatment requires constant attention of the multidisciplinary team. This attention needs to include the informal caregiver that was chosen by the patient and his family. Although there is a high number of studies on patient's quality of life, few of them have been done to access the impact of the disease in the caregivers of patients with gastrointestinal cancer. These patients had, in addition to the common side effects of the chemotherapy, some specific requirements as the preparation of the diet by nasogastric tube, difficulty of digestion after gastrointestinal resection or the care of colostomy.^[9]

The caregivers included, as already described in other studies, are younger, females, and daughters of the patients.^[9-12] We also found that the caregivers had a higher schooling level that is remarkably important suggesting that these subjects had a better condition to understand the medical instructions and follow the treatment of the cancer patients.

Wieldraaijer et al. (2018),^[13] described that most of the patients were retired and lived with a relative. Almost 70% had a comorbidity being most frequently cardiovascular disease (45%), arthrosis (16%) or diabetes (15%).^[13] In our study, most of the patients also lived with a relative and had a similar percentual of comorbidities.

Emotional role, physically role and vitality were the 3 dimensions most affected in the SF-36 with an index less than 50 considered the cutoff by some authors. The best score was found on functional activity (80.9) and mental health (61). Santo et al. (2011),^[14] found similar results for these domains, a mean score of 83 for functional capacity and 61.3 for mental health.

The domain emotional role had the worst index of quality of life. Take care of a patient with cancer cause anxiety symptoms. Some authors have reported a higher intensity of anxiety among the caregivers done due to the perception of cancer diagnosis and cancer progression.^[10,11,14]

Depression had been associated with some life aspects of the caregivers as gender, time spent with the caregivers, quality of sleeping, social and financial support, time spent with the caregiving and the presence of chronic disease. These aspects had been studied among caregivers of chronic disease.^[15]

Caregivers of females had a worst quality of life. The women are commonly the ones that take care of the routine of the house. In their absence, caregivers must assume this activity. We did not find a correlation between emotional role of the caregivers and age. Litzelman et al. (2016),^[16] described that caregivers of elderly patients are frequently older, but generally had a good performance.

We did not find a worst emotional role compared to the stage or ECOG, probably because most of the patients had ECOG 0-1. Our patients were able to perform their daily activities and have not weakness that could limit mobility. Another explanation is that caregivers also believed that they had to satisfy the patient at the expense of their own needs.^[12,13,14] According to the clinical stage, another Brazilian study did not find a higher emotional distress in caregivers of lung cancer patients compared to the clinical stage and believed that these finds might be related to the tendency of caregivers to underestimate their perception of anxiety.^[17] These authors described a worsening in quality of life of the caregivers in all domains of the SF-36 in patients with poor quality of life.^[17]

Involving the informal caregivers as a member of the treatment team, it is important to optimize the health of the patients. The health of the patient can improve when the caregiver has a better quality of life.^[14]

This domain of vitality was most affected in caregivers of females, not married and patients with lower school level. Caregivers of females and patients that had not a partner had probably an increase of routine activities and patients with lower scholaryty needs more attention to understand and adhere to treatment. Vrettos et al. (2012),^[18] described a lower score in married caregivers that were mainly spouses, which live in the same house of the patient.

We observed that caregivers with more than 60 years had worse quality of life by SF-36 in the domain of general health independent of the age of the patient.

Most of these caregivers take care of ageing patients and both had physical weakness and a higher index of comorbidities.

The burden level of most of our caregivers by the CBS was less than 20, probably because most of the patients is on adjuvant treatment, had stage II or III disease and ECOG 0-1. The mean level of general strain was 20, but some of them had a higher index. Tiredness due to the increase of responsibilities, to the time spent with the patient and to the loss of time for himself on entertainment or in the treatment of their own health may cause an increase burden level of the general strain. These aspects can also increase the level of disappointment, which was the second cause of higher burden although only some caregivers had an index of 20.

Caregivers of children with cancer, published by Santo et al. (2011),^[14] also identified a higher burden in the domains of disappointment and general strain. The author's report that a great emotional, physical, and financial burden can affects the caregivers. We did not find an emotional burden among the caregivers.

Elderly caregivers had a higher level of burden in disappointment, that can be explained by the fact that ageing subjects become more emotionally involved when taking care of patients with cancer.^[19,20]

Our study has some limitations because it involves a small number of patients with different tumors in the digestive system and in different clinical stages in a single research center. In addition, the study was carried out in a public hospital; where patients had a low income that probably cause a higher impact on quality of life. The higher burden of the caregivers was not compared to the income of the patients.

Despite the limitations, our results showed the fundamental importance of taking care not only of the cancer patient in the gastrointestinal tract, but also of the informal caregiver.

The knowledge of the caregiver's quality of life and burden during the treatment of cancer patients at any stage or ECOG are very important support for caregivers by the multidisciplinary team (social worker, nursing, and psychology) could contribute to a better quality of life for patients and caregivers.

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