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Follow-up of Gastrectomized Patients due to Gastric Cancer in a Cancer Center of Bogota, Colombia

Theme: Chronic care

Contribution to the discipline: Description of perceived burden and state of performance in patients with cancer who have gone through oncology therapy constitute a fundamental element to generate evidence-based indicators that guide follow-up plans from the experience reported by the participants once they leave the hospital institutions.

ABSTRACT

Objective: To determine the perceived burden and functional status of gastric cancer patients with gastrectomy in a center of cancer in Bogota (Colombia) between 2013 and 2016. **Materials and methods:** Retrospective description of patients intervened by gastrectomy distributed in three groups: Patients with gastrectomy from 1 to 12 months of surgical intervention, 13 to 14 months and 25 to 36 months. For this, it was used the disease burden perception instrument and the Karnofsky scale. **Results:** 127 patients were included. 63 from 1 to 12 months, 43 from 13 to 24 months, and 21 from 25 to 36 months of intervention. Gastric adenocarcinoma of intestinal pattern stage III and II predominate. More than 50 % of the patients required total gastrectomy and received adjuvant chemotherapy. The majority of participants performed regular activities with mild signs and symptoms, presented low overall perceived burden and functional performance without statistically significant differences between groups. Patients from 1 to 12 months of intervention reported greater levels of physical discomfort. **Conclusions:** In patients with gastrectomy for gastric cancer, physical symptoms persist such as emotional disturbances, economic difficulties and limitations in the work role, findings to be included in follow-up programs.

KEYWORDS (SOURCE: DeCS)

Stomach neoplasms; stomach cancer; gastrectomy; cost of illness, follow-up studies; nursing oncology.

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Seguimiento de pacientes gastrectomizados por cáncer gástrico en un centro oncológico de Bogotá, Colombia

RESUMEN

Objetivo: evaluar el seguimiento de pacientes gastrectomizados por cáncer gástrico en un centro de oncología en Bogotá, entre 2013 y 2016, y determinar el estado funcional y la percepción de la carga de enfermedad. **Material y métodos:** descripción retrospectiva de pacientes intervenidos por gastrectomía, distribuidos en tres grupos: de 1 a 12 meses de seguimiento luego de la intervención, de 13 a 14 meses, y de 25 a 36 meses. Se utilizó un instrumento de percepción de carga de enfermedad crónica validado y la escala de Karnofsky. **Resultados:** se incluyeron 127 pacientes: 63 a un año, 43 a 2 años y 21 a 3 años. Predomina el adenocarcinoma gástrico de patrón intestinal. Más del 50 % requirió gastrectomía total, más quimioterapia adyuvante, y estaba en estadios II y III. La mayoría realiza actividad normal con signos y síntomas leves, con una carga de enfermedad percibida global baja y un estado funcional sin diferencias significativas entre los grupos. Los pacientes con seguimiento de 1 a 12 meses reportaron un mayor malestar físico. **Conclusiones:** en pacientes gastrectomizados por cáncer gástrico, persisten síntomas físicos, alteraciones emocionales, dificultades económicas y limitación en el rol laboral, hallazgos por ser incluidos en los programas de seguimiento.

PALABRAS CLAVE (FUENTE: DeCS)

Neoplasias gástricas; cáncer de estómago; gastrectomía; costo de enfermedad; estudios de seguimiento; enfermería oncológica.

Seguimento de pacientes gastrectomizados por câncer gástrico em um centro de oncológico em Bogotá, Colômbia

RESUMO

Objetivo: Avaliar o seguimento de pacientes gastrectomizados emum centro de referêncianacidade de Bogotá entre 2013 e 2016, determinando o status funcional e a percepção da carga da doença. **Material e métodos:** Descriçãoretrospropectiva dos pacientes intervencionados por gastrectomiadistribuídosemtrês grupos, que têm entre 1 a 12 meses de intervençãocirúrgica, 13 a 14 meses e 25 a 36 meses. Utilizamos o instrumento de percepção da carga de doençascrônicas, desenhado, avaliado e a escala de Karnofsky. **Resultados:** 127 pacientes foramacompanhados por gastrectomia por câncer gástrico; 63 emum ano, 43 em 2 anos e 21em 36 meses. Do ponto de vista histopatológico, predomina o adenocarcinoma gástrico intestinal. Mais de 50 % necessitaram de gastrectomia total, além de quimioterapia adjuvante e corresponderamaosestágios II e III. A maioria dos pacientes commonitorizaçãoactividade normal realizada sinais e sintomas leves comumabaixa carga global percebida e um estado funcional, semdiferenças significativas entre os grupos namonitorização de doentesacompanhados durante 1 a 12 meses relatados maisdesconforto físico. **Conclusões:** Nos pacientes gastrectomizados por câncer gástrico, a percepção de sobrecarga da doença é baixa. Alguns sintomas físicos persistem, disturbios emocionais e dificuldades econômicas, bem como limitação no papel do trabalho, achados a serem considerados no desenvolvimento de programas de acompanhamento.

PALAVRAS-CHAVE (FONTE: DeCS)

Neoplasias gástricas; cancro do estômago; gastrectomia; efeitos psicosociais da doença; seguimentos; enfermagem oncológica.

Introduction

Every year, globally, over one million de new cases of gastric cancer occur, and close to 850 000 people die. Estimates predict a two-fold increase of cases and deaths in men and women (1). In Colombia, according to GLOBOCAN 2018, there were 7419 new cases of gastric cancer, figures ranking this disease as third in frequency and as the first cause of mortality (1). Surgical techniques and perioperative management have improved in recent decades. Survival five years after the curative resection for patients with locally advanced disease is from 20 % to 30 % (2). Gastrectomy — a highly complex surgery, with important consequences for the patient from the nutritional, functional, and emotional points of view — is the principal effective curative option in treating gastric cancer. There are body changes that imply adaptation and preparation to return to daily activities, a situation that reflects the impact and burden for patients during follow-up (2, 3).

Within the 10-year plan for cancer control in Colombia 2012-2020, improving the quality of life with implementation of social support service and follow-up to patients and caregivers are strategic action lines (4).

Studies have explored mortality, quality of life, survival rates, and postsurgical complications in patients with gastric cancer (5-11). Often, health problems are evaluated in terms of mortality, but this indicator fails by not considering the time lost due to disability and other non-fatal health results. The distribution of health resources is made based on the indicator of mortality, but leaves out the weight generated by morbidity (12). This last aspect of perceived burden of the disease has not been evaluated in the follow-up of patients gastrectomized due to gastric cancer.

Perceived burden refers to the additional effort that implies satisfying the needs of the person with a chronic condition. It includes three dimensions: Psychological and spiritual suffering, general and physical discomfort, and sociocultural and family alteration (judgment a person makes upon the impact and burden represented by the health condition on family and social roles). Each situation associated with the additional effort is measured in terms of frequency (13).

The description of this burden contributes important knowledge on the patient's performance after surgery, bearing in mind psychological and spiritual aspects, general discomfort, and physical discomfort, as well as the sociocultural and family alteration (13). In literature, few approaches describe perceived burden due to disease and the state of performance in those who have undergone gastrectomy.

It should be highlighted that this situation has not been explored as research by nursing, thus, the lack of evidence-based indicators that guide follow-up planes from experiences reported by patients, once they are discharged from hospital institutions.

The aim of this study was to determine the perceived burden and functional state of patients with gastric cancer after undergoing gastrectomy in a reference cancer center. After the surgical intervention, three groups were monitored: 1) from 1 to 12 months, 2) from 13 to 24 months, and 3) from 25 to 36 months by applying a functional scale (Karnofsky) and an instrument for perception of disease burden.

Materials and Methods

Cross-sectional, descriptive retrospective study, which included 127 adults (>18 years) with diagnosis of gastric adenocarcinoma, subjected to gastrectomy between 2013 and 2016. The follow-up was organized in three groups: 1) from 1 to 12 months after the surgical intervention; 2) from 13 to 24 months after the intervention; and 3) from 25 to 36 months after intervention.

The study included participants with or without adjuvant treatment, and with capacity to communicate verbally. After reviewing the clinical histories, 175 subjects possibly eligible were identified; excluding 16 due to death, 9 for not having gastric adenocarcinoma, 18 due to wrong phone number, and 5 who wished not to participate in the study. A final intentional sample of 127 patients was acquired, distributed thus: 63 to group 1, 43 to group 2, and 21 to group 3. Participants were reached via telephone and through consultation at the gastroenterology service, where informed consent was obtained and questionnaires were distributed to be filled out. Application of the scales was carried out in person in the external gastroenterology consultation service. The average time to apply the scales was 20 min, with a minimum of 18 and a maximum of 45 min.

A file was filled out for sociodemographic characterization, and the instrument of perception of chronic disease burden was developed and validated within the Colombian context (13), from

the theory of symptom management (14). This instrument has 48 items that explore three dimensions of burden: Psychological and spiritual; discomfort and physical discomfort; and sociocultural and family alteration. Participants indicated the frequency of the discomfort from a Likert-type scale, from 1 (absence of the problem) to 4 (maximum problem). Scale reliability was at 0.89 (Cronbach's alpha).

Additionally, Karnofsky's scale was applied, which consists in a self-report report of the physical capabilities of the patient. In oncology, it is used to evaluate the performance level: A score of 100 % indicates the individual can perform normal activities and that there is decrease in the state of performance (15).

The analysis was conducted by using the Statistical Package for Social Sciences (SPSS). Measures of central tendency and dispersion were calculated to determine the perceived burden, distribution of frequencies, percentages, sociodemographic profile and state of performance. Comparison of the groups in perceived burden and in each of the dimensions was carried out through nonparametric tests, like the Kruskal-Wallis test. Institutional research and ethics committees endorsed this work.

Results

Characteristics of the participants

Intestinal pattern gastric adenocarcinoma and stages II and III prevailed within the three groups. Over 50 % of the patients required total gastrectomy and received adjuvant chemotherapy. Regarding age, a mean from 60 to 62.5 years was identified. In patients with follow-up from 1 to 12 months after surgical intervention, and in those from 13 to 24 months, the highest occurrence of disease was in males. Low schooling, the household as principal occupation, married, socioeconomic level 2 (stratum) prevailed in the three groups (Table 1).

Table 1. Profile of patients gastrectomized due to gastric cancer

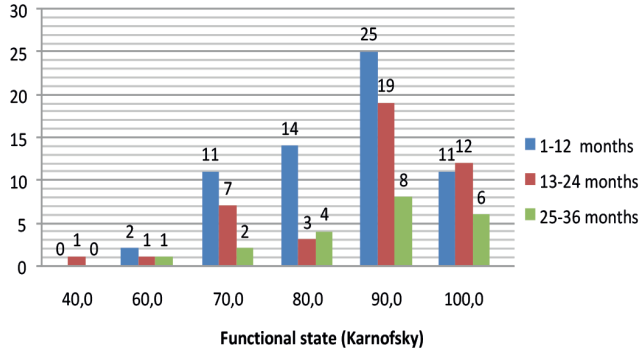
Variables		Gastrectomized gastric cancer intervention groups		
		1 to 12 months	13 to 24 months	25 to 36 months
		n = 63 (%)	n = 43 (%)	n = 21 (%)
Type of gastrectomy	Subtotal gastrectomy	34.9	44.2	42.9
	Total gastrectomy	65.1	55.8	57.1
Adenocarcinoma type	Intestinal	55.6	74.4	71.4
	Diffuse	25.4	16.3	23.8
	Mix	19.0	9.3	4.8
Stage	in situ cancer (0)	14.3	9.3	4.8
	IA-IB	17.5	9.3	14.3
	II (IIA-IIB)	28.6	34.9	42.9
	III (IIIA-IIIB)	34.9	41.9	33.3
	IV	4.8	4.7	4.8
Adjuvant treatments	Received chemotherapy	54.0	69.8	76.2
	Received radiotherapy	23.8	48.8	52.4
	Current chemotherapy treatment	41.3	16.3	9.5
	Current radiotherapy treatment	12.7	0.0	0.0
Age group	18 to 35 years	3.2	4.7	0.0
	36 to 59 years	39.7	41.9	42.9
	60 to 75 years	39.7	46.5	38.1
	76 and over	17.5	9.3	14.3
Sex	Female	41.3	39.5	47.6
	Male	58.7	60.5	52.4
Schooling	Illiterate	7.9	9.3	0.0
	High school	22.2	30.2	33.3
	Graduate	0.0	2.3	0.0
	Primary	55.6	46.5	42.9
	Technical	6.3	2.3	9.5
	Complete university	7.9	9.3	14.3
Marital status	Married	46.0	48.8	42.9
	Separated	9.5	9.3	4.8
	Single	14.3	16.3	19.0
	Common-law	25.4	16.3	23.8
	Widow (er)	4.8	9.3	9.5
Occupation	Employed	11.1	7.0	0.0
	Home	41.3	44.2	47.6
	None	34.9	34.9	33.3
	Independent work	12.7	14.0	19.0
Socioeconomic level	1	11.1	11.6	9.5
	2	68.3	55.8	38.1
	3	20.6	32.6	57.1
Age	Mean (SD)	62.5 (11.1)	61.8 (11.9)	60.04 (12.4)

Source: Own elaboration.

A. Functional state (Karnofsky scale)

In relation with to the functional state in the three groups, most scored > 90, that is, perform normal activities, with slight signs and symptoms of disease. In the group from 1 to 12 months, 36 patients of 63 scored > 90. In the group from 25 to 36 months after surgical intervention, 31 patients of 43 had scores > 90, while in the group with greater follow-up 14 of 21 scored > 90 (Figure 1).

Figure 1. Functional state (Karnofsky) of patients gastrectomized and on follow-up by months from intervention



Source: Own elaboration.

B- Application of the instrument: Perception of chronic disease burden: Three dimensions of burden: Psychological and spiritual discomfort and physical discomfort and sociocultural and family alteration.

The dimension of *spiritual and emotional burden* (possible scores: 15 - 60) tends to be low in the three groups and has no statistically significant differences among the groups (Figure 2a).

The dimensions of general discomfort and physical discomfort (possible scores: 19 - 76) and sociocultural and family alteration (possible scores: 14 - 56) tend to be low, and no statistically significant differences were found among the groups (Table 2, Figures 2b and 2c).

The global disease burden perceived (possible scores: 48 - 192) tends to be low in the three groups, and statistically significant differences were not found either (Figure 2d).

Table 2. Dimensions of disease burden in the follow-up of patients gastrectomized due to gastric cancer

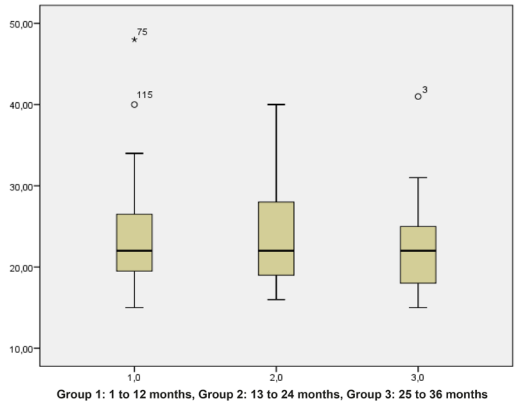
Group	Statistic	Spiritual and social burden	Physical discomfort	Sociocultural and family alteration	Global burden perceived
1-12 months of intervention	Median	23.4	36	20.74	80.23
	SD	6.21	8.4	5.69	17.29
13-24 months of intervention	Median	23.5	33.9	19.83	77.3
	SD	5.9	8.7	5.03	16.22
25-36 months of intervention	Median	22.33	34.05	19.04	75.42
	SD	6.1	7.89	5.4	17.18
Statistical significance (p value)		0.64	0.23	0.17	0.42

SD: Standard deviation of statistical significance $p < 0.005$.

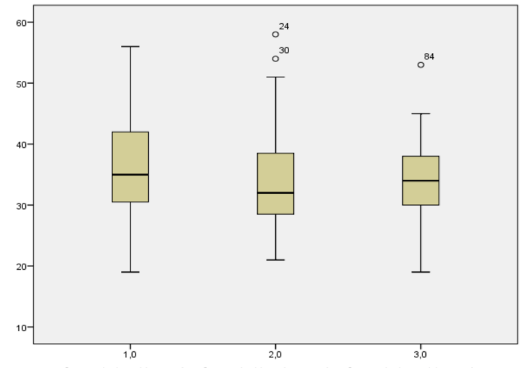
Source: Own elaboration.

Figure 2. Burden in patients with gastric cancer gastrectomized

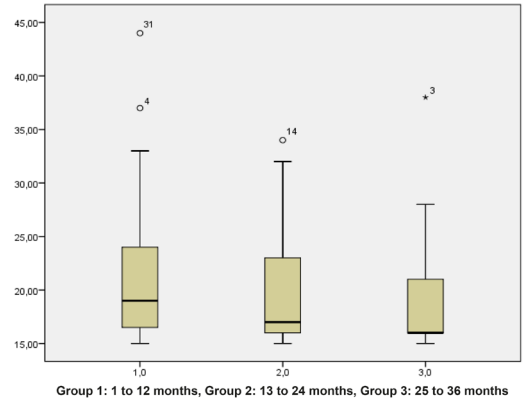
2a. Emotional suffering by intervention groups



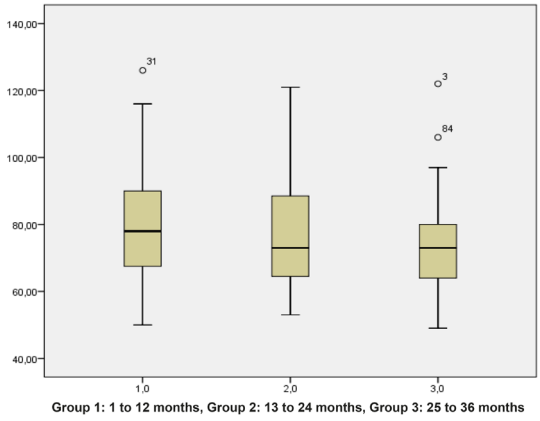
2b. Physical discomfort by intervention groups



2c. Sociocultural and family alteration by intervention groups



2d. Total burden perceived by intervention groups



Source: Own elaboration.

In terms of spiritual and emotional burden, the most-frequent symptoms in the three groups were sadness, anguish, uncertainty, fear, and melancholy. With respect to physical discomfort, the most-frequent discomfort in the three groups were weakness, distress, diarrhea, changes in appetite, pain, fatigue, cramps, sleep alterations, and weight loss. The group from 1 to 12 months of follow-up reports a greater frequency of these annoyances compared to the others. Regarding the burden of sociocultural and family alteration, the three groups highlight economic difficulty and alterations in work role.

Upon analyzing the items individually, statistically significant changes are only identified for anxiety, anguish, weight loss, and alteration of the work role. Values reported in the group from 1 to 12 months are the highest (Table 3).

Table 3. Perceived burden in the follow-up of patients gastrectomized due to gastric cancer

	Perceived burden	Group 01	Group 02	Group 03	P value
Spiritual and emotional burden	Neglect	1.270	1.233	1.333	0.74
	Anxiety	1.698	1.605	1.286	0.03
	Anguish	1.968	1.628	1.571	0.01
	Low self-esteem	1.492	1.442	1.333	0.67
	Distrust	1.238	1.163	1.048	0.17
	Despair	1.571	1.581	1.667	0.98
	Guilt	1.254	1.302	1.048	0.13
	Uncertainty	1.905	1.884	1.905	0.98
	Lability	1.762	1.791	1.762	0.99
	Melancholy	1.921	2.209	2.000	0.31
	Sadness	2.079	2.302	2.333	0.35
	Loss of identity	1.032	1.163	1.095	0.38
	Fear	1.762	1.767	1.667	0.74
	Shame	1.190	1.163	1.095	0.6
	Deficit of cognitive capacity	1.349	1.326	1.190	0.59
Physical discomfort	Distress	2.413	2.070	2.143	0.15
	Cutaneous alterations	1.778	1.884	1.667	0.49
	Alteration in daily life activities	2.111	1.791	1.857	0.24
	Alteration of motor functionality	1.730	1.860	1.667	0.6
	Alteration of sensitivity	1.254	1.256	1.190	0.87
	Weakness	2.413	2.233	2.286	0.43
	Disfigurement	1.683	1.581	1.333	0.38
	Deterioration of verbal communication	1.159	1.070	1.000	0.22
	Sexual dysfunction	1.349	1.628	1.286	0.29
	Pain	2.286	2.186	2.238	0.6
	Fatigue	2.206	2.023	2.190	0.32
	Alterations in balance	1.778	1.767	2.000	0.4
	Sleep alterations	2.159	2.070	2.095	0.83
	Changes in appetite	2.413	2.070	2.000	0.55
	Diarrhea	2.317	2.209	2.000	0.44
	Urinary discomfort	1.254	1.302	1.571	0.36
	Respiratory discomfort	1.270	1.302	1.333	0.97
	Cramps	2.016	1.860	2.238	0.2
	Weight loss	2.413	1.791	1.952	0.008

	Perceived burden	Group 01	Group 02	Group 03	P value
Sociocultural and family alteration	Social isolation	1.365	1.256	1.381	0.73
	Alteration of family dynamics	1.333	1.326	1.333	0.72
	Alteration of the family role	1.238	1.209	1.190	0.95
	Alteration of the work role	1.952	1.651	1.286	0.03
	Affectation of a caregiver	1.317	1.233	1.143	0.76
	Economic dependence	1.619	1.488	1.190	0.12
	Economic difficulty	2.175	2.372	2.190	0.48
	Deterioration of social interaction	1.540	1.419	1.429	0.6
	Discrimination	1.095	1.093	1.143	0.87
	Cultural confrontation	1.159	1.023	1.048	0.42
	Stigmatization	1.159	1.140	1.095	0.98
	Architectural exclusion	1.032	1.047	1.000	0.43
	Loss of social status	1.143	1.209	1.095	0.58
	Subjection	1.175	1.047	1.095	0.26

Statistical significance: $p<0.005$

Source: Own elaboration.

Discussion

The study reflects the gastric cancer profile in Colombia: Most patients are older adults (in the sixth decade of life), with advanced stages and intestinal adenocarcinomas (16-18). The disease occurs more in men than in women.

The majority of patients can perform normal activities, data agreeing with findings in literature (19-21). However, the group with follow-up from 1 to 12 months, after gastrectomy, has a higher affectation of the state of performance against the other two, probably because they are in the initial phase of surgery adaptation (post-gastrectomy) and receive adjuvant treatments, like chemotherapy and radiotherapy.

Patients from the three groups have low perceived disease burden, an observation that differs from other studies in which it tends to be high with alterations in quality of life (6-9). It is possible that those surviving cancer, usually report positive aspects in their quality of life and a lower burden of symptoms because they experience change with respect to their wellbeing, given a positive oncological evolution of their disease, as reported by other authors (22, 23).

In spiritual and emotional burden, the findings for the three groups tend to be low; however, sadness, anguish, uncertainty, fear, and melancholy persist. Information available is limited on alterations of this type in outpatients who remain disease-free during some time after diagnosis or treatment. Han *et al.* (23) found that the prevalence of mood alterations in patients with stomach cancer, who were disease-free during at least one year was 43.9 %, a high rate with respect to other cancer survivors. Several factors are associated with these alterations, confirming their multidimensional nature; it is possible that these patients in follow-up, after surgery, have greater difficulty to perform their habitual work and, consequently, less income and high economic burden (24). Furthermore, they reflect the impact of their diagnosis with cancer, the presence of post-operative discomfort, and changes in body image after treatments (8).

In physical discomfort, patients from 1 to 12 months of surgical intervention have a greater burden, that is, a greater number of symptoms, a finding that coincides with that described in the literature (6, 25). After total or subtotal gastrectomy, there is initial worsening of physical symptoms (loss of appetite and weight [which are not easily recovered], diarrhea and distress [6-9]), but tend to recover slowly between 3 and 6 months. Said symptoms, which are new, are associated with symptoms derived from complementary treatments and are aggravated.

Bearing in mind that patients in follow-up after cancer surgery experience different symptoms according to the type of neoplasia and treatment, intervention strategies must adapt to specific management approaches. Education on the risk of developing late symptoms must start prior to treatment because it can help patients to predict and control their symptoms (21).

Likewise, it is necessary to classify side effects or complications expected to provide information during the follow-up, which permits patients to treat symptoms with greater efficacy and, thus, improve their quality of life (26).

In a long-term follow-up study, after total gastrectomy due to carcinoma (9), alteration of sleep pattern was identified, linked to multiple factors, like physical discomfort, uncertainty regarding the future, and anguish, findings that coincide with our study.

Weakness, distress, and fatigue are reported as a group of symptoms that must be cared for in follow-up programs. Fatigue is a common discomfort and of high prevalence, with great impact

on the quality of life of people that endure it and on their social functioning (27). Junn *et al.* (28) state that fatigue may be related with anemia, due to lack of iron. Lim *et al.* (29), in an observational study of patients gastrectomized due to early gastric cancer, reported that the risk of anemia increased over time and affected 37.1 % of patients 48 months after surgery.

In the sociocultural and family component, economic problems and difficulty to return to the work role prevail in the three groups of patients, findings that coincide with Han *et al.* (30). Cancer survivors experience difficulties due to the economic impact they face because of the reduction of their socioeconomic activity or because of problems returning to work, besides the burden of health costs during treatment.

Multidisciplinary rehabilitation during follow-up of gastrectomized patients is an intervention that can have a positive impact on the capacity of patients to return to work and, hence, reduce the economic burden on their families and society in general (31).

Nursing plays an active role in caring for patients with cancer, who have complex care needs at home (32). Due to this, nursing must consider the physical symptoms, emotional alterations, and limitation of the functional state in survivors with cancer. Thus, it is essential to strengthen the education of these patients in aspects concerning eating habits, report of discomfort symptoms during monitoring and follow-up of outpatient programs.

In addition, it is decisive to involve other health professionals to obtain articulated care, based on management consensus, with active participation by patients with gastric cancer.

This type of study has several limitations, which is why the findings must be carefully interpreted. Disease burden perceived by patients with gastric cancer was addressed in only one cancer institution in the city of Bogota; this, although a referent, is not the only institution managing these types of users. Additionally, access to patients turned out wasteful and affected involving a higher number of participants.

Bearing in mind the aforementioned, future research must include a higher number of patients and be of longitudinal nature in gastrectomized survivors to determine the contribution by clinical, social, and cultural factors in perceived burden. However, this is a first referent that approached patients as source of direct information. It compared three groups with the variable *time of surgical intervention* to provide information related to morbidity expressed in the symptoms to define the disease burden. All this will permit proposing strategies aimed at improving the quality of life of survivors with cancer.

Conclusions

Most patients gastrectomized due to gastric cancer in the group of up to 36 months of follow-up have a low global disease burden in the dimensions of symptoms of emotional and spiritual distress, physical discomfort and sociocultural and family alteration. However, in the follow-up group from 1 to 12 months, physical discomfort is higher. In relation with the functional scale, most patients are above 90 in their score.

Conflict of interests: None declared.

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