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Original Article

Oncology ostomized patients' perception regarding sexual relationship as an important dimension in quality of life

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ABSTRACT

Introduction: For ostomized oncological patients, the physical body alterations affects the quality of life, as the changes in the self-concept are factors that directly affect the sexual life.

Objective: To analyze the perceptions of ostomized men due to intestinal cancer regarding sexual relations as an important dimension of quality of life, treated at the Ambulatory Care Program for Ostomized Patients of the Health Secretariat of the Federal District, Brazil.

Methods: Epidemiological-based study, of the analytical type, with a cross-sectional descriptive design, with quantitative and qualitative approach considering the content analysis. The convenience sample included 56 participants. Sociodemographic, clinical, and the WHOQOL-BREF questionnaires were used, as well as an individual interview. Data were analyzed by Microsoft Office Excel 2010 and SPSS 20.0 software. Statistical significance was set at 5%.

Results: The Physical, Social Relations and Environment Domains are correlated with the mean score, statistical significance ($p < 0.0001$), and the content analysis resulted in five categories: Ostomy, Self-Care, Acceptance, Self-concept, and Companionship.

Conclusion: Sexuality should be considered as a process of daily living of ostomized individuals due to intestinal cancer.

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Um olhar dos homens estomizados intestinais oncológicos sobre a relação sexual como dimensão importante na qualidade de vida

Palavras-chave:
Qualidade de vida
Ostomia
Sexualidade
Neoplasias colorretais

RESUMO

Introdução: Para a pessoa estomizada intestinal oncológica o significado da alteração no corpo físico afeta a qualidade de vida, pois encontra-se com as alterações no autoconceito são fatores que dificultam diretamente o relacionamento sexual.

Objetivo: Analisar as percepções dos homens estomizados intestinais oncológicos quanto ao relacionamento sexual como dimensão importante na qualidade de vida, atendidos pelo Programa de Assistência Ambulatorial ao Estomizado da Secretaria de Saúde do Distrito Federal, Brasil.

Métodos: Estudo de base epidemiológica, de caráter analítico, com delineamento transversal e descritivo, com abordagem quantitativa e qualitativa à luz da análise de conteúdo. A amostra foi constituída por conveniência, incluídos 56 participantes. Utilizou-se os questionários sóciodemográfico, clínico, e o *WHOQOL-bref* e uma entrevista individual. Os dados foram analisados pelos programas Microsoft® Office Excel 2010 e SPSS 20.0. A significância estatística aceita foi de 5%.

Resultados: Os Domínios Físico, Relações Sociais e Meio Ambiente estão correlacionadas com o escore médio, significância estatística ($p < 0{,}0001$), a análise de conteúdo resultou em cinco categorias: Estomia, Autocuidado, Aceitação, Autoconceito e Companheirismo.

Conclusão: A sexualidade deve ser considerada como processo do viver cotidiano do estomizado intestinal oncológico.

Introduction

The World Health Organization defines quality of life as "the individuals perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns".[1] Based on this aspect, quality of life is a broad and comprehensive concept, affected in a complex way by the health of the physical person, that is, it is multidimensional, dynamic, subjective, individual, complex and seeks to interconnect the physical, social, spiritual and environmental aspects.[2,3] Furthermore, from a subjective perspective, the assessment of quality of life depends directly on the evaluation of the individuals. In the multidimensional domain, it is important to evaluate their physical well-being, their functional capacity, their psychological and social health.[2,3] Therefore, and considering the quality of life as one of the dimensions of human life, its evaluation becomes very important, particularly regarding the sexuality of the oncological ostomized male patients.

However, sexuality can be understood as a fundamental aspect of life and is present since until death, having specific characteristics in each period of the life cycle. Sexuality is, therefore, the set of emotions, feelings, fantasies, desires, and interpretations that the human being experiences throughout life.[4]

Simultaneously, sexuality constitutes an integral part of the human personality, associating personal and emotional experiences, sociocultural knowledge, beliefs, and values built throughout history and, thus, the sexual life cannot be separated from the social, historical, anthropological and psychological themes.[4]

In this sense, for the oncological ostomized individual, the meaning of the alterations in the physical body and the suffering caused by the new lifestyle affects the quality of life, due to the changes in body image, the low self-esteem, with feelings of rejection and changes in daily activities, which are factors that directly affect the sexual life.[3,5]

Based on this conception, the objective of this study was to analyze the perceptions of oncological ostomized male individuals regarding sexual relations as an important dimension of quality of life, treated at the Ambulatory Care Program for Ostomized Patients of the Health Secretariat of the Federal District, Brazil.

Material and methods

Study methodology

This is epidemiological-based study, of the analytical type, with a cross-sectional descriptive design, with quantitative and qualitative approach considering the content analysis. Participants included in the study belonged to a group of ostomized individuals due to colorectal cancer. The observation and measurement of the variables of interest were performed simultaneously, constituting a statistical image of what occurs at a given moment.

The data collection of the interview was analyzed considering the Bardin Content Analysis, which is based on the phase of description or material preparation, inference or deduction and interpretation.[6]

The study protocol was approved by the Research Ethics Committee of Fundação de Ensino e Pesquisa em Ciências da

Saúde of the State Health Secretariat of the Federal District, Brazil, under protocol number 418/200. The individuals who agreed to participate in the study signed the Free and Informed Consent form, after receiving detailed explanations on proposed goals and procedures. The confidentiality about the origin of data and the volunteers' anonymity was guaranteed, as stated in the Brazilian regulations for research involving human beings.[7] In this sense, to respect the anonymity of the volunteers each interview was identified with the letter "I" (individual) and a number indicating the order of its performance.

Sample

The present was a convenience sample, considering the spontaneous demand for the study participation. We included 56 ostomized individuals due to colorectal cancer and enrolled in the Ambulatory Care Program for Ostomized Patients of the Health Secretariat of the Federal District, Brasília, Brazil.

The inclusion criteria comprised male patients with a diagnosis of colorectal cancer, submitted to a surgical intervention for the preparation of an intestinal stoma, and stable marital status of twenty years or more. Children, adolescents, pregnant and nursing women, bedridden individuals, female gender, individuals with other physical disabilities, and individuals who refused to participate were excluded from the study.

Data collection

Data were collected from March 2010 to August 2012. Two tools were used: a sociodemographic and clinical questionnaire and the validated version of the WHOQOL-bref questionnaire for the Portuguese language. It comprised 26 items: two general questions, related to the perception about quality of life and satisfaction with health. The four domains (Physical, Psychological, Social Relations and Environment) were observed.[8]

Data collection from the interview was analyzed based on Bardin's Content Analysis,[6] starting with the study's guiding question: "Tell me about your sexual relationships". The interviews were transcribed in full, right after each report. The speeches were read in their totality, several times, and at different moments, so that it was possible to understand the discourses, identify the central ideas and key words, observing the repetitions and similarities between the interviews. The next step was to condense the interviews, to begin the categorization. A flow chart was created to analyze the categorization data (Fig. 1).

Statistical analysis

The descriptive statistical analysis of the sociodemographic and clinical questionnaire data was performed, in addition to the interview. Data from the WHOQOL-bref questionnaire were analyzed through means, standard deviation and proportions and inferential analysis using the following statistical procedures: 95% confidence interval, Student's *t* test, and Pearson's linear correlation coefficient.

The statistical analysis was performed using the SPSS software (Statistical Package of the Social Sciences, SPSS Inc., Chicago, USA) for Windows version 20.0, according to the World Health Organization guidelines. The accepted statistical significance was set at 5%

Results

Table 1 shows the sociodemographic and clinical characterization of the study participants. The mean age of the 56

Table 1 – Sample of oncological ostomized individuals according to sociodemographic and clinical characteristics. Brasília, Federal District, Brazil, 2016.

Variables	Oncological ostomized individuals	
	n	%
Age range		
20–30	02	3.57
30–40	04	7.14
40–50	32	57.15
50–60	11	19.64
60–70	07	12.05
Total	56	100
Religious practice		
Yes	37	66.07
No	19	33.93
Religion		
Catholic	28	50.00
Evangelical	19	33.93
Spiritualist	06	10.71
Others	03	5.36
Total	56	100
Marital status		
Married	27	48.21
Common-law marriage	13	23.21
Divorced	09	16.07
Widowed	04	7.15
Single	03	5.36
Total	56	100
Schooling		
None to elementary school	20	35.72
High school	27	48.21
College/University	09	16.07
Total	56	100
Income		
<1–3 MW	29	51.79
4–5 MW	20	35.71
>6 MW	07	12.50
Total	56	100
Diabetes mellitus		
Yes	21	37.5
No	35	62.5
Total	56	100
Arterial hypertension		
Yes	32	57.15
No	24	42.85
Total	56	100
Smoking		
Yes	24	42.85
No	32	57.15
Total	56	100

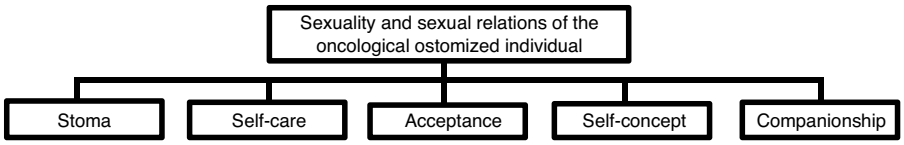

Fig. 1 – Organogram of content analysis of oncological ostomized individuals. Brasília, Federal District, Brazil, 2016.

oncological ostomized individuals was 56.42 ± 12.16 years, and most of them, 57.15%, was aged between 50 and 59 years ($n = 32$).

Considering the other sociodemographic variables, a predominance of the Catholic religion was found in 50% ($n = 28$) and 66.07% ($n = 37$) performed religious practices. Regarding formal education, 48.21% ($n = 27$) had finished high school. Regarding the monthly income, the most common range reported by the participants, 51.79% ($n = 29$), was between 1 and 3 minimum wages.

About the clinical aspect related to comorbidities, 57.15% ($n = 32$) had arterial hypertension and 37.5% ($n = 21$) Diabetes Mellitus. Additionally, 57.14% ($n = 32$) of the participants were smokers.

Regarding the results of Table 2, they showed statistically significant differences in the mean scores for the physical, psychological, social relations, and environmental domains, as well as overall quality of life, leading to statistical significance ($p < 0.0001$).

Table 3 describes the categorization of interviews, resulting in five categories, namely: Ostomy, Self-Care, Acceptance, Self-concept and Companionship.

Discussion

The analysis of sociodemographic and clinical data revealed that the mean age was 56.42 ± 12.16 years. Studies indicate a prevalence of colorectal cancer in the age group older than 50 years, and it is verified that more than 90% of these cancers occur in individuals older than 50 years.[2,3,9,10]

Colorectal cancer is among the main causes for the stoma creation. Among the risk factors for this type of cancer, there is a direct association with the food pattern, characterized by addictions and inadequate eating habits favoring bacterial proliferation and the consequent degradation of bile acids producing carcinogenic agents.[2,3,9,11]

It was observed that the predominant religions were Catholic 50% ($n = 28$), followed by Evangelical religions, 33.93% ($n = 19$), and 66.07% ($n = 37$) of participants performed religious

Table 3 – Categorization of the interviews of the oncological ostomized individuals. Brasília, Federal District, Brazil, 2016.

Ostomy

"It is very sad to live with this stoma. [...]." (I1).
"This stoma makes me feel depressed, how can I think about having intercourse with my wife [...]." (I2).
"This pouch impairs my life, I do not feel like leaving home." (I3).
"I am much quieter during sex. This pouch really interferes [...]." (I4). "
I get very worried about the pouch and thus, I cannot do it [...]." (I5).

Self-Care

"I always depend on my wife to change my pouch. I feel safer" (I6).
"My God, it is so difficult to change this pouch [...]" (I7).
"My wife and even my daughter help me sometimes to change the pouch [...]" (I8).
"I did not have much difficulty. My family helped me. [...]" (I9).

Acceptance

"I thought to myself, there is no other way. So, I need to adapt to this pouch." (I10).
"What made me accept and live with this pouch was the support of my family". (I11).
"At first it was very difficult to accept this pouch [...]" (I12).
"My family gave me the courage to live with this pouch." (I13).

Self-concept

"For me, it is not normal to have a hole in my belly, the most depressing thing is to evacuate in a pouch. I have no stimulus for anything." (I14).
"It is very difficult to see myself in the mirror with this body. [...]". (I15).
"I feel like I'm carrying a cross on my waist" (I16).
"Today, when I look at myself, I feel mutilated... I always took care of my body". (I17).
"After the surgery, I never let my wife see me naked again. I feel I am no good as a man anymore [...]". (I18).

Companionship

"Without my wife, I could never live with this pouch [...]". (I19).
"My wife from the beginning always did everything so that I would not feel bad about the pouch." (I20).
"I have a blessed wife, who is my companion. [...]." (I21).
"My wife made me feel like a better man. [...]." (I22).

Table 2 – Mean scores of the domains and quality of life of the WHOQOL-bref questionnaire in oncological ostomized individuals. Brasília, Federal District, Brazil, 2016.

	Group of oncological ostomized individuals				
Domains	*n*	Mean	SD	95%CI	*p*
Physical	56	12.02	2.38	11.41–12.31	<0.0001
Psychological	56	12.20	2.74	11.47–12.53	<0.0001
Social relations	56	12.44	2.87	12.05–13.02	<0.0001
Environment	56	12.02	2.23	11.58–12.32	<0.0001
Overall QoL	56	12.06	2.08	11.65–12.47	<0.0001

practices. Studies have shown that religious practices in the presence of the disease can lead to spiritual development, since it reminds the individual of his fragility and closeness with human finitude.[2,3,5,9,12]

Regarding the family income and educational level, both were relatively low, with an average family income of 2.68 minimum wages. These data emphasize the relevance of government assistance to these individuals. Low schooling may be a factor for the non-prevention of colorectal cancer, due to the precarious explanation about the factors that cause this neoplasm, including dietary ones.[5,12]

Regarding comorbidities, most participants had arterial hypertension (57.15%) ($n = 32$), and a significant number had type 2 diabetes (35.50%) ($n = 21$). The combination of these two conditions contributes to the high risk of developing colorectal cancer.[2,3,10] Additionally, 57.14% ($n = 32$) of the participants were smokers. Although the colon is not directly affected by the tobacco composition, the carcinogenic substances carried by the blood stream have a negative impact on the risk of developing colorectal cancer.[2,3,13]

The mean scores for the domains and quality of life of the WHOQOL – bref questionnaire, in Table 3, show statistically significant differences in the mean scores for the physical, psychological, social, and environmental domains, and in the mean score of the quality of life. Studies on the quality of life of oncological ostomized patients indicate that the creation of the intestinal stoma involves not only the use of the collection equipment, but also a new body image that needs to be reconstructed. This is a process that is at the same time subjective, collective, and social, and deeply reflective about the coexistence with an intestinal stoma, which can affect the physical and psychological domains, as well as social relations and the environment, impairing their quality of life.[2,3] In the "stoma" category, the participants' statements about the creation of the intestinal stoma disclose several disorders for the individuals, and among them are sexual function, marital adjustment and change in behavior related to the sexuality. It is believed that these changes may be closely related to changes in body image and consequent decrease in self-esteem.[5,12,14]

In addition to the emotional difficulties, the intestinal stoma generates a series of physical alterations that impairs social life. As a consequence, the person feels different from others and even excluded. This occurs because all human beings build, throughout their lives, an image of their own body, which adapts to their customs, the environment where they live, etc., which meet their needs to feel situated in their own world.[4,15,16]

In the "Self-care" category, it can be observed that in the reports of the ostomized patients, the collecting equipment starts to represent the lost body part, establishing new habits through learning, mainly regarding self-care. The intestinal stoma alters the role of the ostomized individual in the family and in society. After the surgery, many ostomized individuals start to depend on family care, even temporarily, in addition to experiencing the socially imposed disabilities and leaving behind the attributes of independence, efficiency, and productivity, which interfere with sexual relations.[5,16–18]

Regarding the "Acceptance" category, the reports show that the ostomized individual undergoes a process structured into four phases, with the final one being the evolution of acceptance, a process that must be a constructive one; according to their perception of the presence of the intestinal stoma, so their acceptance is reflected, which ends up contradicting the obtained results. In this sense, this reality depends on the support and encouragement that the patients receive from those around them, including the health professionals who are part of the support system presented to them. The oncological ostomized individual requires care that must be maintained, promoting their independence, their quality of life for themselves, their families, and their caregivers.[4,17]

In the "Self-concept" category, participants, when asked about the interference of the intestinal stoma in their intimacy, reported that sexual activity is affected. Thus, the sexual relations are closely related to the idea of self-concept and the consequent alteration in the body image and decrease in the self-esteem and the perception of sexual attraction, especially regarding the loss of control in the elimination of stool and gases as a condition predisposing to psychological and social isolation, based on negative feelings that permeate interpersonal relations.[5,18–21] The use of the collection pouch makes social interaction difficult as they raise several concerns in the patient, inducing the ostomized individual to a situation of detachment and social isolation, impairing the self-concept.[2,3]

Regarding the "Companionship" category, the reports of the participants about companionship related to sexual activity was considered essential for the sexual relations and, therefore, sexuality is a broad function that covers biological, psychological, and social aspects.[5] Respect, companionship, admiration, and reciprocal love are necessary between the individuals. Therefore, the modifications that occur in the sexuality of ostomized individuals are so profound and mutilating that the sexual act becomes secondary and is usually replaced by feelings of love, affection, respect, and companionship.[4,22,23]

On the other hand, the sexuality of the human being is not restricted to the purely procreative approach. A sexual relation between two individuals involves not only biological duties, but, on the other hand, all corporeality, an emotional bond, an infinity of feelings, as well as social and cultural values of the couple.[4,17]

In view of the above, the sexual relation is significantly impaired, as the ostomized individual has negative feelings for having an externalized part and for experiencing the stigma of being an ostomized individual, especially in the male gender, as they suffer greater pressure regarding their sexual performance.[4,5]

However, sometimes such changes may be related to the complications resulting from the surgical procedure, especially nerve damage. Most patients with intestinal stomas do not return to their sexual activity or do so only partially, due to physical problems, problems with the collection pouch, a decreased sense of hygiene during sexual activity, i.e., a feeling of being dirty and shame or fear of non-acceptance by the partner.[5,15]

In several studies, the literature indicates that the sexuality domain is little considered among health professionals, regarding the patient with intestinal stoma. It can be observed that health professionals need more training to answer the doubts of ostomized individuals, also highlighting issues pertaining to sexuality, such as sexual dysfunction, altered body

image and strategies to deal with these issues with patients in a sensitive manner that fully meets their needs.[5,23]

Conclusions

Thus, oncological ostomized individuals reported changes in body image, low self-esteem, and changes in daily activities, which are factors that impair the process of adaptation in the sexual relations within a reality that was, to date, unknown. In this sense, sexuality should be considered as a process of daily living for the patient, stressing the importance of their correlation with professional practice so these professionals can assist the patients and their partners in the process of adaptation to the new conditions and in the search for new coping strategies for an active and pleasurable sexual life, resulting in improved quality of life.

Conflicts of interest

The authors declare no conflicts of interest.

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