



Original article

Marital interactions in partners of ostomized patients[☆]



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ABSTRACT

Objectives: The present study aimed to investigate the sociodemographic profile of ostomized patients, describe their daily marital interactions, and identify these individuals' health demands.

Method: The present investigation consisted of a descriptive and quantitative study of partners of ostomized patients.

Results: A total of 36 individuals were interviewed, of whom 24 (66.7%) were female. Participants were aged between 31 and 70 years, and reported an annual family income of \$20,000. The present study found that the stoma surgery did not lead to significant changes in marital relationships. The study participants appeared to be significantly invested in overcoming the barriers imposed by their partner's condition. Respondents also demonstrated dedication, sensitivity and a willingness to help their partner adapt to physiological and gastrointestinal changes.

Conclusion: The changes following stoma surgery also have an impact on patients' partners, and both individuals must work together to keep it a secret if necessary. The present results made it clear that respondents empathized with their partners, and agreed that undergoing stoma surgery is a difficult ordeal.

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O cotidiano da convivência conjugal com a pessoa estomizada

RESUMO

Objetivos: Conhecer o perfil sócio-demográfico dos participantes, descrever o modo de convivência no cotidiano na condição de parceiro do estomizado e identificar a demanda de cuidados no contexto familiar.

Métodos: Trata-se de estudo descritivo, de natureza quantitativa, realizado com parceiros de estomizados.

Palavras-chave:

Cônjuges

Estomia

Relações Familiares

Adaptação psicológica

[☆] This study was conducted in the Graduate Program of Medical Sciences, School of Medicine, University of Brasilia, Brasília, DF, Brazil.

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Resultados: Foram realizadas 36 entrevistas com parceiros de estomizados, sendo 24 (66,7%) do sexo feminino. A idade dos entrevistados variou entre 31 a 70 anos. A renda familiar mensal da maioria dos entrevistados equivale cerca de 20.000 dólares anuais. As alterações no cotidiano na vida do casal não geraram mudanças significativas nos seus hábitos em consequência da estomia. Os entrevistados procuram superar os obstáculos do enfrentamento da nova condição do seu parceiro estomizado e demonstram dedicação, apoio e acompanhamento, no tocante a adaptação das modificações fisiológicas e gastrointestinais. **Conclusão:** As mudanças impostas ao estomizado é uma situação partilhada entre o casal com o objetivo de manter a condição em sigilo. Ficou claro e explícito na pesquisa que, na interpretação do entrevistado, a condição de estomizado é muito difícil.

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Introduction

In recent decades, an increasing number of studies have been conducted on patients who underwent stoma creation. Most of these studies have investigated stoma care, skin protection and types of ostomy equipment. Although the emotional, familial and social aspects of the relationship between ostomized individuals and their partners may also have an important impact on patient health, this line of research has been neglected in the literature.

Marital relationships are distinct from other social relations in that they require both emotional and physical involvement between two individuals. The stability of marital relationships has been suggested to be one of the strongest determinants of quality of life in couples. Studies of family dynamics have suggested that marital satisfaction and stability must be more comprehensively studied, especially through investigations of the daily frequency of positive and negative interactions between couples.¹

A recent review of urinary incontinence in men highlighted the psychological suffering of the patients' partners due to the emotional, sexual and social impact of the men's condition.² Similarly, the changes experienced by patients after an ostomy surgery may also have an impact on their partner's behavior. Given their proximity to the patient, the partner is often involved in daily stoma care, and may at times take on the role of a caregiver.

Individuals with intestinal stoma often report difficulties in interacting with their partner in a natural way, as they believe that it may be difficult for the partner to be physically close to them, to participate in the same social activities, and to eat with them at family meals. Due to loss of sphincter control, the involuntary release of gas, feces and unpleasant odors is a common occurrence in these patients, and may consist of an additional barrier to social interactions.³ In light of this situation, it is important to quantitatively assess the behavior of ostomized patients and their partners, so as to better comprehend their social reality and to know how best to assist these individuals. Therefore, the present study was guided by the following research questions: How does intestinal ostomy surgery affect the patient's and their partner's life? What is the impact of such a procedure on daily family and social activities?

Based on these questions, the present study aimed to investigate the sociodemographic profile of ostomy patients and to describe their relationships with their partners.

Method

This was a descriptive, quantitative study, conducted on partners of ostomized patients. The present investigation was approved by the Human Research Ethics Committee of the University of Brasilia School of Medicine, under protocol number (CEP-FM 011/2009).

Data was collected from the treatment registry of the Stoma Care Unit of the State Department of Health (SESDF). As of October 2011, a total of 685 adult and pediatric ostomized patients were registered at the Outpatient Health Service.

In the present study, the spouses or partners of ostomized patients were interviewed, regardless of their legal marital status. The following inclusion criteria were used: agreement to participate in the study and ability to provide written informed consent; age 18 or over at the time of the study; fluency in written and spoken Portuguese; having lived with the ostomized patient for at least one year before the stoma procedure, and continuing to live with them afterwards.

Data were collected between October 2011 and May 2012, using a questionnaire designed specifically for use in the present study. The instrument was developed based on the present authors' extensive clinical experience with ostomized patients, with whom the authors have been closely involved for over 20 years.

The questionnaire was analyzed by five specialist judges with experience in questionnaire development, linguistics and health research. The following aspects were assessed by the judges: semantic equivalence; ability to assess the intended measure; relevance to the goals of the study. The questionnaire was modified according to the judges' recommendations until it was deemed adequate for use in the study.

The instrument was then administered to five partners of ostomized patients so as to assess the comprehensibility, clarity and unambiguity of items in the questionnaire. Since no problems with the questionnaire were identified and the instrument was not modified any further, these five participants were included in the final sample.

Table 1 – Gender, age, education, family income and duration of the relationship of partners of ostomized patients (n = 36), Brasília, DF – 2012.

	n	%
Gender		
Female	24	66.7%
Male	12	33.3%
Age range		
31 to 40 years	5	13.9%
41 to 50 years	11	30.6%
51 to 60 years	10	27.8%
61 to 70 years	6	16.6%
Over 70 years	4	11.1%
Education level		
Incomplete primary	4	11.1%
Complete primary	8	22.2%
Incomplete secondary	2	5.6%
Complete secondary	8	22.2%
Higher education	14	38.9%
Duration of relationship		
1 to 2 years	1	2.8%
2 to 5 years	0	0.0%
Over 5 years	35	97.2%
Family income		
Up to one minimum wage	1	2.8%
1 to 2 minimum wages	10	27.8%
2 to 5 minimum wages	6	16.6%
Over 5 minimum wages	19	52.8%
Total	36	100.0%

The questionnaire was individually administered to each participant, and no other people were present at the time of assessment. The researcher remained nearby to answer any questions or provide clarification.

Data were analyzed between July and December 2012 using the SPSS (Statistical Package for Social Sciences) software, version 16.0 for Windows. Results were obtained through descriptive analyses.

Results

The final sample was composed of 36 partners of ostomized patients, most of whom were female (n = 24; 66.7%). Participants were aged between 31 and 70 years, and a large number of individuals had a university education (n = 14; 38.9%). The monthly income of most participants (n = 19; 52.8%) was greater than three times the minimum wage. A vast majority of participants had been in a common-law relationship for over 5 years (n = 35; 97.2%), and 16 participants (44.4%) reported that their partner had undergone ostomy surgery at least 5 years before data collection. Further details on these variables are described in [Table 1](#).

Most of the participants' partners had undergone a definitive (n = 28; 78.0%) rather than a temporary stoma.

[Table 2](#) contains data regarding the daily routine of participants and their partners. A total of 28 (78.0%) participants still had meals with their partners after the stoma surgery, and only 4 (11.1%) participants reported to having changed this

Table 2 – Results regarding the daily routine of stoma patients and their partners. (n = 36), Brasília, DF – 2012.

Questions	Answers	n	%
Was there a change in the habit of sitting at the table for daily family meals?	No reply	4	11.0
	No	28	78.0
	Yes	4	11.0
	Total	36	100.0
How often do you notice unpleasant odors at mealtime?	No reply	1	2.8
	Often	2	5.6
	Never	24	66.6
	Rarely	9	25.0
	Total	36	100.0
How often do you help your partner with daily stoma care?	Often	5	13.9
	Never	9	25.0
	Rarely	6	16.6
	Always	16	44.5
Total	36	100.0	
Approximately how many of the stoma care materials used by your partner are you familiar with?	Some	12	33.3
	None	1	2.8
	All	23	63.9
Total	36	100.0	
Do you notice unpleasant odors from your partner's stoma during routine activities?	No	11	30.6
	Yes	25	69.4
	Total	36	100.0

habit. The remaining participants did not answer this question.

Twenty-four respondents (66.6%) reported to never having noticed any unpleasant odors coming from the partner's intestinal stoma during family meals, and 9 (25%) respondents claimed they only rarely noticed such smells at meals. Two respondents (5.6%) said they frequently noticed the odors coming from their partner's stoma during family meals.

The frequency with which participants helped with daily stoma care was also investigated. Sixteen (44.5%) respondents reported to always helping with these activities, while nine individuals (25.0%) never helped their partner. Another six (16.6%) individuals rarely helped their partners, while five (13.9%) reported to frequently helping with daily stoma care. A total of 23 respondents (63.9%) were familiar with all ostomy materials used by their partner, while 12 (33.3%) were familiar with some of the materials. Only a single respondent (2.8%) was completely unfamiliar with ostomy materials.

Lastly, it was found that most respondents (n = 25; 69.4%) could smell the unpleasant odors coming from the partner's stoma, while 11 (30.6%) individuals did not notice these smells.

[Table 3](#) displays participants' answers regarding their emotional and behavioral responses to their partner's stoma. Most participants (n = 29; 80.6%) frequently looked at their partner's stoma, while 4 (11.1%) respondents rarely looked at it. The remaining participants had never seen their partner's stoma (n = 3; 8.3%).

Although they could smell unpleasant odors coming from the stoma, 18 (50%) respondents were not bothered by them, 12 (33.3%) thought them slightly inconvenient and only 4 (11.1%) felt very bothered by them. The remaining participants preferred not to answer the question.

A total of 19 respondents (52.8%) did not wish to speak to anyone about their partner's stoma surgery, while 11 (30.6%) felt comfortable discussing it with others and six (16.6%) were

Table 3 – Feelings toward stoma surgery as reported by the partners of ostomized patient.

Questions	Answers	n	%
How often can you look at your partner's stoma without feeling embarrassed?	Often	29	80.6
	Never	3	8.3
	Rarely	4	11.1
	Total	36	100.0
How bothered are by the odor released by your partner's stoma?	No reply	2	5.6
	Very much	4	11.1
	Not at all	18	50.0
	A little	12	33.3
	Total	36	100.0
How often are you inclined to talk about your partner's condition with other people?	Often	6	16.6
	No	19	52.8
	Rarely	11	30.6
	Total	36	100.0
Does your partner specifically ask you not to comment on his condition with other people?	Sometimes	6	16.6
	No	20	55.6
	Yes	10	27.8
	Total	36	100.0
In your view, what would it be like to undergo stoma surgery?	No reply	1	2.8
	Difficult	23	63.9
	Don't know	1	2.8
	Normal	8	22.2
	Bad	3	8.3
	Total	36	100.0

frequently inclined to talk about their partner's situation with other people.

Most interviewees ($n=20$; 55.6%) claimed that their partners had not requested them to keep their stoma surgery a secret. Ten respondents (27.8%) said their partners specifically asked them not to speak of their condition to others, and 6 (16.6%) individuals said their partners sometimes asked them not to comment on their situation.

Twenty-three participants (63.9%) said they would think it difficult to undergo stoma surgery, while 8 (22.2%) considered it a normal procedure and 3 (8.3%) thought it would be bad.

Discussion

The present study investigated a number of aspects of the relationship between ostomized patients and their partners, such as changes in the habit of sitting at the table for family meals, the perception of unpleasant smells coming from the patient's stoma, the partner's role in helping the patient with daily stoma care activities, the partner's familiarity with ostomy materials, their ability to look at the stoma without being embarrassed, and their perceptions of their partner's ostomy surgery.

Most participants were between 31 and 60 years old, and therefore, it can be assumed that the ostomized patients were in the same age range. These findings differ from a number of studies⁴⁻⁷ whose samples of ostomized patients were largely composed of individuals who were at least 60 years old. Most of the study participants were also female, had completed university education and had been with their partner for over five years.

This observation, combined with the fact that all individuals included in the study had been in a relationship with their

partner for at least one year prior to their stoma surgery, suggests that individuals tend to remain in stable relationships and to be supported by their partners following the procedure. Individuals who had not been in a relationship prior to the stoma surgery are generally more likely to remain single after the procedure.³

Mean family income was over five minimum wages for most study participants, which suggested these individuals earned approximately USD20,000 a year.

Participants reported that their partners had had a definitive intestinal stoma for over five years, which speaks to the increase in the life expectancy of ostomized patients. The high rates of definitive stoma found in the present study were similar to those reported in other studies in the literature.^{5,7} Most ostomized patients investigated in the present study were young, and were likely to live for a long time after their surgery.

When asked about changes in the habit of sitting down for family meals with their partner, most respondents reported that this did not change following their partner's stoma procedure. However, this is a somewhat controversial finding, since a number of previous studies have shown that limits on the intake of certain foods as well as the involuntary release of gas following the ostomy surgery lead patients to avoid social contact, and decrease the pleasure derived from eating food. To avoid embarrassment during meals, these patients often avoid socialization at meal times and rarely eat in public.³ These individuals may also make extreme changes to their diet, due to a fear of being discriminated by individuals who are part of their social circle, such as family and friends.⁸

Most survey respondents reported to never having noticed unpleasant smells during meals with their partner. However, a significant number of study participants did notice such smells in these situations.

The inability to control the odor released from the stoma is a major source of worry for most patients. To solve this problem and maintain regular social activities, patients often exercise strict control over their diet in an attempt to regulate intestinal function.⁸

A number of studies in the literature have offered dietary recommendations for ostomized patients based on the likelihood that different foods will lead to the involuntary release of gas and unpleasant odors, or cause gastrointestinal impairment and other complications. However, few studies have looked into the environment in which ostomized patients have their meals.

Most of the study participants reported to always helping their partners with daily stoma care activities. These individuals appeared to be dedicated and willing to care for their partner. However, a significant number of individuals reported to never or only rarely helping their partners to care for their stoma.

The fact that some individuals did not usually help their partner could be explained by the fact that the patient himself may not be comfortable with such actions due to shame and fear of not being accepted by their partner once they saw him in that condition. Self-rejection is a common phenomenon in ostomized patients.⁹

Studies have shown that the stoma should be cleaned and the ostomy bag emptied in private locations such as the

patient's own home, so that at times, their partner is left with no choice but to help with these tasks.¹⁰ Studies have found that, when placed these situations, patients' partners may feel embarrassed or even disgusted.¹⁰ Therefore, although it may be a challenging task for the patient's partner, he must provide help and support so that the patient can overcome the effects of his new condition.

When the partners' familiarity with stoma care materials was investigated, it was found that most partners were familiar with all ostomy equipment used by their partner, while a third were familiar with at least some of these instruments. Only a single participant reported to not knowing any ostomy materials.

The wide variety of ostomy bags and similar materials available on the market may allow patients to select their equipment in the way that best suits their needs.⁷ Both the patient and their partner must be familiar with these materials so as to facilitate their selection and use of ostomy appliances. The continuous use of these materials requires rigorous medical follow-up, since ostomy devices may need to be changed or replaced over the course of treatment.

If the stoma patient's partner expresses rejection or disgust while helping him with self-care activities, the patient may, in turn, experience conflicting feelings of repulsion and compassion. In these cases, it is best that the partner does not assist the patient.¹⁰ In the present study, participants reported that they noticed unpleasant odors coming from their partner's stoma on a daily basis. When asked whether this bothered them, half the participants answered negatively, and only two participants declined to answer. The remaining participants answered affirmatively.

Participants in the present study reported that they often looked at their partners' stoma. These data are not in agreement with previous research,³ which showed that individuals did not tend to look at their partner's stoma. This may be interpreted as an expression of rejection.

Data from another study, which, like the present investigation, was also conducted on partners of ostomized patients, did not find that participants expressed rejection toward their partners. Based on these results, the authors concluded that both parties in the couple had been able to find adaptive ways to deal with their situation.¹⁰

The present study also found that approximately half of the respondents did not discuss their partner's situation with members of their social circle. However, this was not an external imposition, as the same percentage of individuals reported that their partners had not asked them to avoid discussing their condition with others. These results contrast with those of a previous study which found that ostomized patients often isolate themselves due to shame, and hide their condition from others.³

The present data suggested that a number of ostomized patients may not worry about being identified as such, and have no problems with their partner discussing their condition with others. Although ostomized patients may not explicitly forbid their partners from commenting on their condition with others, the partners themselves may notice some embarrassment about the ostomy on the patient's part, and based on this perception, decide against discussing the situation with

their peers. Therefore, while keeping the patient's condition a secret may not always be an easy task, a high number of participants in the present study reported to helping their partner in this regard.

Lastly, a majority of study participants responded that they would consider it "difficult" to undergo stoma surgery.

The present study had some limitations. Firstly, the scarcity of similar investigations in the literature limited comparisons between the present findings and those of other studies. Secondly, the intimate nature of the issues discussed may have influenced results, as the accuracy and reliability of self-reports of personal issues such as marital relationships can be influenced by a number of methodological and assessment issues.

However, in spite of these limitations, the present study was able to report that a number of aspects of marital functioning may remain unchanged after one of the parties undergoes stoma surgery. The respondents appeared to make an effort toward overcoming the barriers imposed by their partner's condition, and demonstrated dedication, sensitivity and a willingness to help their partner adapt to physiological and gastrointestinal changes.

The changes suffered by the ostomized patients are actually shared by the couple, and both parties must work toward adapting to the condition and keeping it a secret if necessary.

The present results also made it clear that respondents empathized with their partners, and agreed that undergoing stoma surgery is a difficult ordeal.

Conflicts of interest

The authors declare no conflicts of interest.

REFERENCES

1. Mosmann C, Falcke D. Conflitos conjugais: motivos e frequência. *Revista da SPAGESP*. 2011;12:5-16.
2. Bicalho MB, Lopes MHBdM. Impacto da incontinência urinária na vida de esposas de homens com incontinência: revisão integrativa. *Rev Esc Enferm USP*. 2012;46:1009-14.
3. Silva AL, Shimizu HE. O significado da mudança no modo de vida da pessoa com estomia intestinal definitiva. *Rev Latino-Am Enfermagem*. 2006;14:483-90.
4. Pereira APdS, Cesarino CB, Martins MRI, Pinto MH, Netinho JG. Associação dos fatores sociodemográficos e clínicos à qualidade de vida dos estomizados. *Rev Latino-Am Enfermagem*. 2012;20:93-100.
5. Violin MR, Mathias TAdF, Uchimura TT. Perfil de clientes colostomizados inscritos em programa de atenção aos estomizados. *Rev Eletr Enf*. 2008;10:924-32.
6. Ramos RdS, Barros MD, dos Santos MM, Gawryszewski ARB, Gomes AMT. O perfil dos pacientes estomizados com diagnóstico primário de câncer de reto em acompanhamento em programa de reabilitação. *Cad Saúde Colet*. 2012;20:208-86.
7. Fernandes RM, Miguir ELB, Donoso TV. Perfil da clientela estomizada residente no município de Ponte Nova, Minas Gerais. *Rev Bras Colo-Proctol*. 2010;30:385-92.

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8. Silva DG, Bezerra ALQ, Siqueira KM, Pranaguá TTB, Barbosa MA. Influência dos hábitos alimentares na reinserção social de um grupo de estomizados. *Rev Eletr Enf.* 2010;12:56-62.
 9. Santana JCB, Dutra BS, Tameirão MA, Silva PF, Moura IC, Campos ACV. O significado de ser colostomizado e participar de um programa de atendimento ao ostomizado. *Cogitare Enferm.* 2010;15:631-88.
 10. Andrade V, Müller FS, Barco AMFdS, Goes FCG, Loureiro SCC, Santos VLCdGd. A sexualidade do ostomizado na visão do parceiro. *Rev bras coloproctol.* 1997;17:269-76.