

PERCEPTION OF SPOUSES OF PEOPLE WITH INTESTINAL OSTOMY ON THE SEXUALITY OF THE COUPLE

PERCEPÇÃO DOS CÔNJUGES DE PESSOAS COM ESTOMIA INTESTINAL SOBRE A SEXUALIDADE DO CASAL

PERCEPCIÓN DE LOS CÔNJUGES DE PERSONAS CON OSTOMÍA INTESTINAL SOBRE LA SEXUALIDAD DE LA PAREJA

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Funding: No funding.

Submitted on: 2017/10/28

Approved on: 2019/08/02

ABSTRACT

Objective: to identify the perception of spouses of people with intestinal ostomy on the sexuality of the couple. **Method:** this is a descriptive research with a qualitative approach, based on the focal life story, using the in-depth interview. Thirteen spouses of ostomized people were interviewed from August to November 2014. The interviews were submitted to the content analysis technique in the thematic modality. **Results:** four thematic categories emerged from the analysis process: a) conceptualizing sexuality based on the participants' opinion on sexuality; b) sexual intimacy, with the exposure of various nuances in the exercise of sexuality, specifically during sex; c) feelings generated by the ostomy in the spouses, which addressed the sensations experienced after the stoma surgery; d) and strategies used to favor the exercise of sexuality, whose tactics used by the couple in this area were listed. **Final considerations:** it was found that, from the perspective of the spouses of people with intestinal stoma, sexuality is closely linked to sex, and the changes in the exercise of the couple's sexuality ranged from unchanging to radical changes, including references of abdication of this dimension of human living, prioritizing various activities.

Keywords: Surgical Stomas; Sexuality; Spouses; Nursing.

RESUMO

Objetivo: identificar a percepção de cônjuges de pessoas com estomia intestinal sobre a sexualidade do casal. **Método:** trata-se de pesquisa descritiva, com abordagem qualitativa, fundamentada na história de vida focal, utilizando a entrevista em profundidade. Foram entrevistados 13 cônjuges de pessoas estomizadas, no período de agosto a novembro de 2014. As entrevistas foram submetidas à técnica de análise de conteúdo na modalidade temática. **Resultados:** do processo de análise emergiram quatro categorias temáticas: a) conceituando sexualidade com base na opinião dos participantes sobre sexualidade; b) intimidade sexual, com a exposição de diversas nuances no exercício da sexualidade, em específico durante o sexo; c) sentimentos gerados pela estomia nos cônjuges, que abordou as sensações vivenciadas após a cirurgia de confecção do estoma; d) e estratégias utilizadas para favorecer o exercício da sexualidade, cujas táticas utilizadas pelo casal nessa área foram elencadas. **Considerações finais:** identificou-se que, na perspectiva dos cônjuges de pessoas com estoma intestinal, a sexualidade está intimamente atrelada ao sexo, sendo que as alterações no exercício da sexualidade do casal variaram desde a inalteração até mudanças radicais, incluindo referências de abdicação dessa dimensão do viver humano, priorizando atividades diversas.

Palavras-chave: Estomas Cirúrgicos; Sexualidade; Cônjuges; Enfermagem.

RESUMEN

Objetivo: identificar la percepción de los cónyuges de personas con ostomía intestinal sobre la sexualidad de la pareja. **Método:** investigación descriptiva con enfoque cualitativo, basada en la historia de vida focal, utilizando la entrevista en profundidad. Fueron entrevistados trece cónyuges de personas ostomizadas

How to cite this article:

Santos FS, Vicente NG, Bracarense CF, Dal-Poggeto MT, Goulart BF, Rodrigues LR. Perception of spouses of people with intestinal ostomy on the sexuality of the couple. REME – Rev Min Enferm. 2019[cited ____];23:e-1217. Available from: ____ DOI: 10.5935/1415-2762.20190065

de agosto a noviembre de 2014. Las entrevistas fueron sometidas a la técnica de análisis de contenido en la modalidad temática. **Resultados:** del proceso de análisis surgieron cuatro categorías temáticas: a) conceptualizar la sexualidad basada en la opinión de los participantes sobre la sexualidad; b) intimidad sexual, con la exposición de varios matices en el ejercicio de la sexualidad, específicamente durante el sexo; c) sentimientos generados por la ostomía en los cónyuges, que trató de las sensaciones después de la cirugía de estoma; d) y estrategias utilizadas para favorecer el ejercicio de la sexualidad y se habló de las tácticas de la pareja en esta área. **Consideraciones finales:** se descubrió que, desde la perspectiva de los cónyuges de las personas con estoma intestinal, la sexualidad está estrechamente vinculada al sexo, y los cambios en el ejercicio de la sexualidad de la pareja iban desde cero cambio hasta cambios radicales, incluyendo referencias a la abdicación de esta dimensión de la vida humana, dándoles prioridad a otras actividades. **Palabras clave:** Estomas Quirúrgicos; Sexualidad; Esposos; Enfermería.

INTRODUCTION

The construction of an intestinal stoma alters body image and functioning, generating major changes in how people see and relate to each other socially.¹ There are unique ways of coping with this situation, through one's own particularities and understandings, in the various aspects of life, including those concerning sexuality.²

The expression of sexuality is often altered in these people, triggering feelings of shame, isolation and disinterest in the sexual experience. The change in body aesthetics is an important constraint on quality of life, especially sexual health.³ The intestinal ostomy generates intense changes to the ostomized person, also affecting the spouses, which may influence the couple's relationship and coexistence.⁴

The satisfactory relationship with the spouse is an important aspect for the emotional well-being. In addition to physical problems related to stoma and change in body image, these people suffer from psychological stress. Anxiety related to resuming sex life can cause changes in a couple's life.³ For these reasons, people exclude themselves from society and from their own families, with the partner being the person most commonly affected by these changes.¹

The affective relationship of the spouse is important for the ostomy to better deal with the difficult moments inherent to the disease and the ostomy, constituting its main support network.⁵ It often represents the closest relative of the person with ostomy, and their emotional response plays a relevant role in adapting the partner to the condition of being ostomized.⁴

During adjustment to the ostomy, subject and spouse should be oriented about sexuality. Therefore, health professionals need to consider this theme as an indivisible part of being and include the couple in this approach. However, there

are few studies regarding the partner's reaction to the stoma, its adaptations and how it deals with the various aspects of life that may change after the stoma.⁶ Thus, it is necessary to know the ways in which spouses deal with sexuality and the coping mechanisms, so that the care provided occurs holistically. The affective relationship of the spouse is important for the ostomy to better deal with the difficult moments inherent to the disease and the ostomy, constituting its main support network.⁵ It often represents the closest relative of the person with ostomy, and their emotional response plays a relevant role in adapting the partner to the condition of being ostomized.⁴

Thus, this study aimed to identify the perception of spouses on people with intestinal ostomy on the couple.

METHOD

This is a descriptive research with a qualitative approach, based on the focal life story (FLS), using the in-depth interview. The FLS method is composed of pre-interview, with the preparation of the meeting for recording after the interviewee's acceptance; the interview itself; and post-interview, for acknowledgments and/or necessary adjustments, in which the researcher presents to the participants the statement for the consent.⁷

The selection of the participants/collaborators occurred after telephone contact with patients with intestinal ostomy enrolled in a collection equipment dispensing program in the inland of *Minas Gerais*, in which they had spouses with relationships started before surgery. Subsequently, a list of these companions was constructed by contacting the first name on the list and the subsequent two-partner interval (the first, the fourth, the seventh, the tenth, and so on). Theoretical saturation was the criterion used to define the sample, with the interruption of data collection after finding that no new elements emerged to support the desired theorization, so that the interaction between the research field and the researcher did not provide data. to mark or deepen theorizing.⁸

Thus, the sample consisted of 13 spouses of people with intestinal ostomy and the used inclusion criteria were: individuals aged 18 years old and over, who had an affective relationship with the ostomized person (registered in the aforementioned program), since the pre-operation phase and who lived in Uberaba. The following are considered spouses in this study: boyfriend, spouse, concubine, and people in stable union with the ostomized person. Those who did not meet these criteria and who declined to participate in the survey were excluded.

For data collection, individual interviews were conducted by the researcher herself, recorded on digital media, at home or at the equipment dispensing center. In order to ensure confidentiality and privacy, the collaborators in the survey were identified by the letter "C", followed by an Arabic number,

according to the order in which the interviews took place. Data were collected between August and November 2014.

The interviews were open type, semi-structured, with the guiding questions: "how was sexuality exercised by the couple before the ostomy? And later on?" A script for orientation and a field diary were also used, where the researcher's observations and feelings during the meeting were noted.

Audio written record took place in three phases: transcription, with change of oral content recorded in a written text; textualization, which fuses questions to the narrative and brings together themes referred to at different times; transcreation, which elaborates a text recreated in its fullness, incorporating extra-text elements, with consultation in the notes of the field notebook. Finally, the interviewee's approval to know which order to give to the narrative.⁷

For data analysis, we used content analysis, thematic modality, following the methodological criteria of categorization, description, inference and interpretation. The analyzed material was analyzed in parts; part distribution into categories; description of the categorization result, exposing the findings found in the analysis; inferences of the results; and interpretation of the results obtained with the aid of the adopted theoretical foundation.⁹

This study was approved by the Ethics Committee on Research (ECR) with human beings of the *Universidade Federal do Triângulo Mineiro* (UFTM), under protocol No. 736,570/2014. The participants in the research signed the Free and Informed Consent Term.

RESULTS

Thirteen people took part in this study, 10 women and three men aged between 18 and 79 years old, who earned one to five (or more) minimum wages. Regarding schooling, six had incomplete elementary school; one, complete elementary education; one, incomplete high-school education; four, complete high-school; and one master's degree. Regarding the marital status, 10 were married, one with a stable union, one in concubinage and one in a dating situation. The relationship time ranged from three to 63 years (with a mean of 18.2 years) and the partner's ostomy time ranged from four months to 11 years (with a mean time of 2.5 years). The sexual orientation declared by all was heterosexual.

From the analysis of the collected material, four thematic categories emerged, named: a) conceptualizing sexuality; b) sexual intimacy; c) feelings generated by the ostomy in the spouse; d) strategies used to favor the exercise of sexuality.

The "conceptualizing sexuality" thematic category contemplates the participants' definitions on sexuality. It was considered relevant to the study because the way it is

designed impacts on its exercise. Some deponents have no definite conceptualization on the subject; this finding may have been due to the fact that the subject matter was very intimate, which made them feel embarrassed or shy; or even because this concept is not clear to the interviewees. This can be evidenced in the following reports:

When I think about sexuality, nothing comes to mind [...] (C8).

I don't know what sexuality is, my mind went blank. I don't know what it is (C9).

On the other hand, it also emerged that most collaborators perceive sexuality as restricted to sex, and also reported an even greater restriction: to the youth. This may be justified by the fact that this correlation is usual, not encompassing other aspects known to correspond to the theme, as illustrated in the following statements:

I understand sexuality as the sexual time of life; talking about sex (C2).

Sexuality is good when you're young. It's been a long time since I've been caring, or messing with this (C11).

The following account refers to sexuality in a more complex way than before, relating it not only to sex, but to other aspects such as friendship, respect and dialog.

It is very difficult to specify what sexuality is; it is a set: Affection, touch [...] and I think it comes from friendship, dialog, consideration, respect [...] (C1).

In the thematic category "sexual intimacy", the spouses exposed the alterations in the sexual intimacy of the couple after the ostomy, being observed several nuances in the form of exercising the sexuality in the partner's view. Among the difficulties, the physiological ones were mentioned, such as impotence and urinary incontinence, according to the following statements:

Sometimes he looks for me in bed but can no longer have an erection (C11).

He became impotent after the surgery, and sometimes gets angry (C7).

Even before the surgery we no longer had a sex life. Then we never had sex, nor did we even try; because with the incontinence it is complicated (C8).

As reported above, it can be inferred that besides the physical problem, there were other emotional issues that influenced the exercise of sexuality. The participant states that since before the husband's surgery, the couple had no sexual relations. This fact was also expressed at other times and by other deponents, revealing that the relationship before surgery was no longer satisfactory for the partner, which may interfere with how it will occur after the ostomy. This can be seen through the following speeches:

He was never affectionate with me, to tell the truth. Since before getting sic. (C8).

When he had the surgery, we had no sex in one year. Before, he focused only on sex. Maybe that's why I lost interest and enthusiasm in having sex (C11).

In the following speech, the collaborator has the conception that they are psychological problems that prevent his partner from exercising his sexuality, corroborating what has already been described that they are not physical impediments that alter the sexual sphere in most cases:

We had close contact until admission before the colostomy. He completely lost his sexuality all of a sudden. He didn't look for me anymore, this affected his mind too much (C1).

In the following grouping, statements describing other negative changes that occurred in the exercise of the couple's sexuality after the ostomy, at various levels, were related. This confirms what has already been mentioned, that sexuality is lived in a unique way, both for each person and for each couple, and the caregiver must have sufficient sensitivity and aptitude to deal with and address the issue effectively.

Moreover, it changes the skill to act, is not the same thing that it was before (C6).

I don't think the bag has upset our relationship, but our intimate life has changed a lot. We still have sex, but rarely. He says it is uncomfortable (C9).

It changed our sex life, changed the routine, changed everything (C3).

It is noteworthy that a certain load of anger and anguish was observed, expressed on the countenance and excessive articulation of the hands of the collaborator of the last mentioned speech.

Feelings such as fear of injury due to the exertion required by the sexual act also arise, since surgery and ostomy are generally unknown to most people, as well as the physical activities that can be done after the ostomy. This fear could be minimized by better guidance provided by the health team that assisted this couple. Such fear of injury is expressed by the following statement:

It changed not only because of the little bag, but because I was worried about him because of his illness and his treatment. I was afraid of forcing him because he was weak (C6).

It is noted in the following statements that ostomized patients may feel embarrassment and shame during sex, while for the partners the changes do not have much influence on the couple's relationship. There may also be emphasized the care of the spouses so that the wives were as comfortable as possible during the act and the sensitivity to respect the times when they did not feel well. The partner is an undisputed part of the rehabilitation process of the ostomized patient, especially when thinking about the sexual issue. When support from the partner occurs, acceptance of the new condition becomes easier.

The scholarship did not affect the relationship for me. She was more embarrassed than me, feeling ashamed. It's not pain, but it has changed for her. If she's not in the mood, I respect (C12).

There are times when you feel uncomfortable, so I choose not to do. I find it more uncomfortable for him than for me, not because of the pain, but not accepting the body that it is now (C10).

Some participants also mentioned the long wait for sexual activity to resume, although they still said it was possible to maintain the pre-surgery routine. The return to the sexual routine was delayed after the surgery, and the sexual act was performed only after months from the ostomy, as observed in the statement:

Our sexual interaction has declined from 2012 until today. In 2012 it was a cut like this [...] of about eight months. Then we started every 15 days (C3).

Another point observed was that some collaborators abdicated a marital relationship to dedicate themselves to other aspects of their life, such as family, home care or ostomy, according to the following statements:

When he got sick, he suddenly stopped everything. But I never felt bad about it, I'm fine. I've been busy living with other things that absorb me (C1).

I'm not with him because of sex. We started a family, I have my three children, so I don't need it (C7).

On the other hand, discourses on the maintenance of the sexual routine of the ostomized/partner binomial arise, as shown below:

We have our relationship as we always have had. The little bag does not disturb (C3).

Nothing has changed in our sex life, we have not made changes, everything is the same (C5).

There were also speeches that emphasized that sexuality is exercised with tenderness and cuddling, which explicitly includes aspects beyond the genitals, reinforcing other forms of affection that can remain present in the couple's life, even when there is no more sex. The following account illustrates this aspect:

And, even without sex, we kept other forms of caresses and affection between us (C7).

The thematic category of "feelings generated by the ostomy in the spouse" includes reports that address the main feelings occasioned in the spouse after the surgery. The sensations generated by inconvenient situations arising from the ostomy and the collecting equipment were expressed, as well as the inadequacy to the circumstance of being ostomized by the partner.

From the way that deponent C2 describes the discomforts arising from the ostomy and the collecting equipment, such as odors, diarrhea and difficulties at night, it is noticeable that she has not yet adapted to the condition of her partner of being ostomized.

It's not quiet cool, because I feel so much trouble with the smell. Regarding the ostomy, I have already adapted a little more to it. If it were not for the discomfort that the bag generates, diarrhea, bad smell, the escape of the poop out of the vase... If it was not for that, there would be no difference (C2).

The description of the ostomy as "this" and the repulsion observed in speech are also emphasized. The way how the partner alludes to the ostomy or when, involuntarily, by facial or body expressions expresses displeasure to this condition

can generate pejorative feelings in the ostomized patients. Consequently, a trend to diminish self-esteem, social isolation and even repudiation of the sexual act due to fear of rejection or shame because of the ostomy.

One collaborator claimed to have difficulty accepting that her partner's physiological functions have changed, showing feelings such as anguish and disgust, both expressed through verbal and body language during her statement:

I still can't swallow the bag, understand that it is leaking feces 24 hours a day (C3).

On the other hand, there were reports that the stoma did not generate any change in the couple's life. Participant C13 refers to the collection equipment in the third person plural, denoting assuming the partner's ostomy as an inseparable part of the partner and, consequently, of the relationship between them. One can infer a strong feeling of affection and complicity in the couple.

I think my life has not changed since we used the little bag [...] My relationship is the same as before, normal (C13).

One of the main foundations for a successful relationship is respect. In difficult situations, such as the making of an ostomy, appreciation undoubtedly facilitates the couple's acceptance of the new life condition, as observed in the following statements:

I have already told her that when you are with a person, you are for everything, whatever comes and goes. I don't care, I have to respect her time (C12).

We have a lot of affection for each other. It's not because I have pity. I'm with him for the rest of my life, for the rest of my days (C7).

In the thematic category of "strategies used to promote the exercise of sexuality" there are testimonials that showed the couple's tactics to facilitate the exercise of sexuality. The mentioned methods are cleaning the collection equipment before the sexual act, minimizing the risk of accidents, and covering it so that the spouse does not see it and to reduce the noise of the friction of the body with plastic, as observed in the following statements:

Before we go to bed, he usually empties the little bag, but doesn't attach it [...] (C5).

When we meet, he cleans it, because he is afraid and hides it. He uses a washcloth, which holds with crepe tape (C6).

We use the diaper over the bag as a strategy, but then a friction noise comes (C3).

He washes it before, the bag is too uncomfortable. Plastic friction bothers you a lot (C9).

Another strategy concerns the changes in sexual positions, since those that generated more comfort to the couple were chosen, mentioned by the following interviewees:

There are certain positions that we can't do. And even taking care, I kept thinking that I had to take it easy for her to be well (C10).

At the time of the relationship, I look for a little way, otherwise it is more complicated. A position that doesn't harm her, make her comfortable. Sometimes I put my hand on the bed and get over so that I don't lean so much on her belly, on her abdomen (C12).

On the other hand, there is a report that, even without sex, the couple maintains complicity, sleeping together, as a form of physical contact between them, to adjust the intimate moment. Sex can be replaced by gestures of affection and love, as follows:

Sleeping with him is normal in everyday life. We lie down, he leans me down, sleeps, doesn't bother me at all. He likes to sleep without clothes, I'm not afraid to get dirty (C7).

DISCUSSION

The results allowed us to analyze various aspects related to sexuality, such as the concept and expression, feelings about the ostomy and its influence on the couple's sexual life, strategies for adaptation to the stoma and the possibility of exercising sexuality.

The few conceptualizations obtained are strongly anchored in the idea that sexuality and sex are synonymous, ignoring other aspects relevant to the expression of sexuality. Such a concept is convergent with the literature. It is clear that the concept of sexuality is little explored in today's society and, despite the evolution of the media, this theme is still a taboo for social relations. It is evident that the exercise of sexuality still permeates fears and constraints. However, it is important to note that it goes beyond the genital organ, it is polymorphous and polyvalent, it goes beyond physiological need and involves more than physical acts of sexual expression, but also the whole of the human being.^{10,11}

In this research, there were statements that established sexual rules and values that guide the behavior and orient the differentiation of right and wrong. Thus, culture influences

acceptable desire and conduct, and sexual practices vary among societies according to constructed references. The particular conception of sexuality implies the social use of bodily and sexual norms.¹¹

The reports address the couple's sexual intimacy and the changes experienced after the partner's ostomy. Several dysfunctions may come to occur after the preparation of an intestinal stoma, among which the physiological ones stand out. In men, sexual impotence, partial erectile dysfunction and loss of ejaculation are frequent complaints,¹² while women report discomfort and vaginal dryness. The main causes for impotence and libido loss are psychological factors such as fear and anxiety during sex. Many ostomized patients report fear of accidents with collecting equipment, such as stool leaks. Others believe its performance may be directly affected by the stoma. Associated with this, feelings of guilt over personal and partner dissatisfaction, may be noted.³

The alteration of the ostomized patient's sexuality interferes with that of the spouse, because the feelings of filth and disgust can generate anxiety, depression and shame. Study evaluated the marital relationship and the care with the stoma. Many partners participated in daily stoma care, including hygiene. However, some did not, because the ostomy himself would not allow it and for fear of causing revulsion to his partner.¹³ The ostomy can generate feelings of inferiority due to changes in body image, a feeling of non-attraction and the body being unable to function as before.³

Sexuality has an important role in the lives of the individuals, with family support being essential; both, ostomized patients and partners, experience changes in their lives after the stoma.⁶ Moments of insecurity, distortion of appearance, and diminishing self-love lead to changes in psychic well-being and sexuality, as the person with a stoma tends to feel inferior to his partner and to believe that he is no longer attractive.¹⁴

Another aspect evidenced in the interviews was concerning the influence that the quality of marital union exerts on the subsequent adjustment of the relationship. Some reports show that the couple's relationship was no longer satisfactory before the surgery and that after the intimate relationships were abolished. At times personal convictions, such as religion and lifestyle, can impact the couple's sex life and acceptance of the new image of the ostomized patient. Partner revulsion to the stoma can be a cause of these couples' sexual inactivity and dysfunctional and unsatisfactory relationships.¹²

Talking about the ostomy can be embarrassing not only in new relationships, but also in stable relationships. Partners feel uncomfortable talking about the stoma with people from the same social circle, as well as with the ostomy itself. In their view this can be disconcerting and so they prefer not to discuss their partner's situation.¹³ On the other hand, it is observed

that the search for information by relatives acts as a positive reinforcement to cope with the new condition of the ostomy. Forming a support network is crucial for re-adaptation and the establishment of a normal life.²

Dissatisfaction with sexuality may come to occur due to a negative attitude of the partner, which influences sexual performance. There may be important associations between quality of marital life and physical health, as well as possible conflicts between the couple, which may trigger functional limitations and reduce the desire for mutual support.⁶

It is noteworthy that a small portion of the study collaborators stressed the non-occurrence of sexual interaction due to physical problems. A similar result was also found in a study similar to this one, with a predominance of psychological problems associated with changes in body image, which negatively affects the conception of sexuality of both the individual and the couple in changing roles or sexual functioning.³

The reports that contemplate feelings arising after the stoma are convergent with a study that sought to identify the repercussions of stoma surgery on the life of people with stoma. In such research, it was found that, due to previous lack of coexistence with ostomized patients, feelings of revulsion and non-acceptance arose. In addition insecurity in the event of leakage of collecting equipment and release of odors and noises arouses fear, anguish and shame. In this context, the person with a stoma tends to isolate himself from society and, under certain circumstances, from himself, even refraining from contemplating his own body.¹⁵ This aversion to body self-image may reflect on the love and sexual realm, so it is paramount to be concerned about the emotional changes felt in this new life condition.¹

Among the reasons for the removal of ostomized patients from their partners are the discomfort of collecting equipment, the fear of leaking feces, the noises that occur due to friction, the escape of gases,¹⁶ beyond the physical and psychic factors already mentioned. The contact and pressure exerted on the equipment can make the sexual act difficult and lead to loss of interest of the spouse.

In a study that aimed to know how the stoma affects the living and sexuality of ostomized women, the interference of the stoma in the experience of sexuality was identified. Most of the interviewees did not resume sexual activity or avoid such contact, alleging physical and collector equipment problems, shame, and non-acceptance of their spouse.¹⁷ In another research, the partners have different opinions about the collection equipment and, for one third of the interviewees, it was not an impediment for the relations to occur. However, it is noteworthy that the other two thirds reported that either the equipment disturbed or they no longer had sex. But even in the face of difficulties, the couple can take a proactive stance

and seek mechanisms of adaptation to the new reality in order to promote marital understanding.⁴

Another factor recurrently cited as hindering sexual intercourse is the fear of hurting the ostomized partner. Such fear and caution may cost the decrease or even cessation of sexual practices.⁴

In the results that contemplate the strategies used by the couple to provide improvements in the exercise of sexuality, the zeal that the spouses had for the ostomized to have comfort in the sexual act, is highlighted. The partner is an undisputed part of the rehabilitation process of the person with ostomy, especially in the sexual matter. If there are, however, alterations in the ostomized patient's self-esteem, however accepted by the partner, it can still be difficult to exercise sexuality. Many ostomized patients begin to feel that they are no longer attractive after surgery. As a result, there is considerable loss of libido and predisposition for sex.³

In women this process is accentuated, as they tend to express great concern with the sexually objectified body and valued for its aesthetics. Thus, after surgery, they undergo body transformations, such as the stoma, the collecting equipment, the surgical scars and, in some cases, hernias, prolapses and fistulas. Such transformations disfigure her body and deconstruct her image, which needs to be re-signified in order to be able to express herself sexually in a healthy and pleasurable way.¹⁶

There were discourses on abdication of the exercise of sexuality, with prioritization of other aspects. A similar result was also found in another study, in which some women interviewed reported that they chose to dedicate their lives to their children and religious activities, neglecting their woman side, which needs sexual pleasure.¹⁸

The results reveal the long wait until the resumption of sexual activities. Initially, the physical problems are more emerging and worrying, rather than the psychological ones. Over time, physical adaptation occurs, and psychological conditions become effective, which may indicate more difficulty or acceptance.³ For many couples, it takes some time before sexual practices are rescued. However, it should be noted that many spouses adapt to the new condition of the ostomy, which does not affect the exercise of sexuality.⁴

In a study that compared the perception on sexual activity by partners of people with and without ostomy, it was found that the sexual performance of an ostomized patient was often poor in their spouse's view of the control group. It was also reported that one third of the interviewed ostomized patients no longer had sex after surgery.⁶

In another research, aiming to evaluate the impact of ostomy on the sexuality of the ostomized individual, 83 people with stoma were interviewed. All considered that sexuality plays an important role in their lives, but 45 claimed not to

engage in sexual activity. In contrast, of the 38 respondents who reported having an active sex life, 34 were satisfied.¹⁹

On the other hand, in a study aimed at identifying how the ostomy affects the life of the ostomized patient and their partner, the majority of respondents cited having no problems looking at the stoma and the collecting equipment. They also reported that they smelled unpleasant odors from their partner's stoma; the number of people who reported bothering with the odor did not differ significantly from those where the smell did not cause discomfort.¹³

With the ostomy, people can focus on values related to bowel elimination, which now goes against known normalcy, as if they were dealing with the contaminated. Conflicting feelings, concerns, and difficulties in coping with this situation are generated, resulting in confusing attitudes toward the closest and most affectionately important people,²⁰ of the ostomized patient and their partner. The adaptive process can be painful for both, and the quality of the established relationships is paramount to minimizing stress.

The changes identified in sexuality after the stoma are related to emotional and physical issues, and men may present erectile dysfunction, while women may develop psychological distortions associated with self-esteem and self-perception of the body. Faced with these obstacles, it is up to the couple to adopt devices to adapt sexual positions and affection in order to maintain the sexual experience in the relationship.²⁰

The interviewees revealed strategies to reduce the discomfort related to the ostomy and ensure the maintenance of sexual activities, converging with the literature. Reports show that spouses choose more comfortable positions for their partners, while partners are looking for ways to keep the device safe and free from harms to the partner.¹⁶

It is emphasized that a number of aspects of marital functioning may remain unchanged after one of the parts has a stoma. The partners demonstrated to strive for the barriers imposed by the condition of having a stoma and expressed dedication, sensitivity and willingness to help the ostomy adjust to physiological and gastrointestinal changes. The changes that took place were shared by the couple, and both worked to adapt, empathizing with their partners.¹³

Health institutions and their professionals should offer the ostomized person and their family a care based on comprehensiveness, in which self-care and the discussion about sexuality are stimulated, because body and self-esteem changes resulting from the ostomy trigger insecurities regarding the partner and to the couple's sexuality. The educational process in this area is relevant, since sexual activity is closely linked to the perception of quality of life.¹⁴ The couple also need to be oriented to respect each other's wishes, because in order to be satisfactory to both, the sexual act must be pleasurable and spontaneous.

FINAL CONSIDERATIONS

It was found that, from the perspective of the spouses of people with intestinal ostomy, sexuality is intimately linked to sex. The reports on the exercise of the couple's sexuality ranged from their unchanging to radical changes, including references to abdication of this dimension of human living, prioritizing various activities.

The ostomized patient and their partner, in order to maintain a satisfactory relationship for both, need to seek internal and/or external tools to reconstruct the couple's identity. The encouragement and partnership between them favor the experience of sexuality more intensely, which is enhanced when health professionals provide information and support. The more oriented they are about the many nuances of sexuality, including the sexual act, the more likely it will be to find complicity, mutual respect for desires, and the attainment of pleasure.

It is suggested that the approach to sexuality be included with more emphasis on the curricula of undergraduate health courses. Proximity to the subject may minimize the cultural clashes surrounding the free and spontaneous approach to the subject.

Among the limitations of the study are some refusals to participate, either from ostomized patients who did not want to expose their peers to the interview, or from partners who did not understand why their participation would benefit the community. An inferred reason for not participating in the research was that it was an intimate, delicate and taboo subject, and the assumption that couples who are in conflicting moments of their relationships do not want to talk about it.

It is hoped that this research will provide reflections on the importance and comprehensiveness of the theme, thus prioritizing the integrality of health care, with the aim of encouraging the ostomized and their partners to fully enjoy sexuality, in all its magnitude.

REFERENCES

1. Sena RMC, Nascimento EGC, Sousa WPS, Oliveira MAM, Maia EMC. Emotional aspects of the subject on confronting the ostomized condition. *Rev Estima*. 2017[cited 2017 Aug 10];15(1):43-9. Available from: <https://www.revistaestima.com.br/index.php/estima/article/view/450/pdf>
2. Bonill-de-las-Nieves C, Celdrán-Mañas M, Hueso-Montoro C, Morales-Asencio JM, Rivas-Marín C, Fernández-Gallego MC. Living with digestive stomas: strategies to cope with the new bodily reality. *Rev Latino-Am Enferm*. 2014[cited 2017 Aug 10];22(3):394-400. Available from: <https://www.revistas.usp.br/rlae/article/view/86591/89486>
3. Vural F, Harputlu D, Karayurt O, Suler G, Edeer AD, Ucer C, et al. The impact of an ostomy on the sexual lives of persons with stomas: a phenomenological study. *J Wound Ostomy Continence Nurs*. 2016[cited 2017 Aug 10];43(4):381-4. Available from: 10.1097/WON.0000000000000236
4. Silva AL, Kamada I, Sousa JB, Vianna AL, Oliveira PG. Singularities of the Coexistence of Spouse and its Partner Ostomized. *Estima*. 2016[cited 2017 Aug 10];14(2):68-75. Available from: <https://www.revistaestima.com.br/index.php/estima/article/view/379>

5. Reis FF, Carvalho AAS, Santos CSB, Rodrigues VMCP. Perceptions of the social support for colostomized men in northern Portugal. *Esc Anna Nery Rev Enferm*. 2014[cited 2017 Dec 21];18(4):570-7. Available from: http://www.scielo.br/pdf/ean/v18n4/en_1414-8145-ean-18-04-0570.pdf
6. Silva AL, Monteiro PS, Sousa JB, Vianna AL, Oliveira PG. Partners of patients having a permanent colostomy should also receive attention from the healthcare team. *Colorectal Dis*. 2014[cited 2013 Dec 15];16(12):431-4. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/25104405>
7. Meihy JCSB, Ribeiro SLS. Guia prática de história oral: para empresas, universidades, comunidades, famílias. São Paulo: Contexto; 2011.
8. Fontanella BJB, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DG. Sampling in qualitative research: a proposal for procedures to detect theoretical saturation. *Cad Saúde Pública*. 2011[cited 2013 May 13];27(2):389-94. Available from: <http://www.scielo.br/pdf/csp/v27n2/20.pdf>
9. Gomes R. Análise e interpretação de dados de pesquisa qualitativa. In: Deslandes SF, Gomes R, Minayo MCS, organizadora. *Pesquisa social: teoria, método e criatividade*. 27th ed. Petrópolis: Vozes; 2008. p. 79-106.
10. Ferreira SMA, Panobianco MS, Gozzo TO, Almeida AM. Sexualidad de la mujer con cáncer de mama: análisis de la producción científica de enfermeira. *Texto Contexto Enferm*. 2013[cited 2017 Aug 10];22(3):835-42. Available from: http://www.scielo.br/pdf/tce/v22n3/en_v22n3a33.pdf
11. Sehnem GD, Pedro EMR, Budó MLD, Silva FM, Ressel LB. The construction of sexuality of nursing students and their perceptions on the theme. *Ciênc Enferm*. 2014[cited 2017 Aug 10];20(1):111-21. Available from: http://www.scielo.cl/pdf/cienf/v20n1/art_10.pdf
12. Iqbal F, Kujan O, Bowley DM, Keighley MRB, Vaizey CJ. Quality of life after ostomy surgery in Muslim Patients: a systematic review of the literature and suggestions for clinical practice. *J Wound Ostomy Continence Nurs*. 2016[cited 2017 Aug 10];43(4):385-91. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/27196687>
13. Silva AL, Faustino AM, Sousa JB, Vianna AL, Oliveira PG. Marital interactions in partners of ostomized patients. *J Coloproctol*. 2014[cited 2018 Jan 21];34(4):210-5. Available from: <http://www.scielo.br/pdf/jcol/v34n4/2237-9363-jcol-34-04-0210.pdf>
14. Kimura CA, Kamada I, Guilhem DB, Abreu BS, Fortes RC, Santos WL. The sexuality of a colostomized person as a major component of quality of life and nursing care. *J Nurs Educ Pract*. 2017[cited 2017 Aug 10];7(8):104-12. Available from: <http://www.sciencedirect.com/journal/index.php/jnep/article/view/10742/6914>
15. Mota MS, Gomes GC, Petucco VM. Repercussions in the living process of people with stomas. *Texto Contexto Enferm*. 2016[cited 2017 Aug 10];25(1):e1260014. Available from: <http://www.scielo.br/pdf/tce/v25n1/0104-0707-tce-25-01-1260014.pdf>
16. Hueso-Montoro C, Bonill-de-las-Nieves C, Celdrán-Mañas M, Hernández-Zambrano SM, Amezcua-Martínez M, Morales-Asencio JM. Experiences and coping with the altered body image in digestive stoma patients. *Rev Latino-Am Enferm*. 2016[cited 2016 Dec 13];24:1-9. Available from: <http://www.scielo.br/pdf/rlae/v24/0104-1169-rlae-24-02840.pdf>
17. Mota MS, Silva CD, Gomes GC. Life and sexuality of women with an ostomy: support nursing. *R Enferm Cent O Min*. 2016[cited 2016 Dec 13];6(2):2169-79. Available from: <http://seer.ufsj.edu.br/index.php/recom/article/view/1004>
18. Barreto APCP, Valença MP. The ostomy patient's sexuality: integrative review. *Rev Enferm UFPE Online*. 2013[cited 2016 Dec 13];7(spe):4935-43. Available from: <http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/.../6757>
19. Vera SO, Sousa GN, Araújo SNM, Moreira WC, Damasceno CKCS, Andrade EMLR. Sexuality of patients with bowel elimination ostomy. *J Res Fundam Care Online*. 2017[cited 2016 Dec 13];9(2):495-502. Available from: <http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/5451/pdf>
20. Cardoso DBR, Almeida CE, Santana ME, Carvalho DS, Sonobe HM, Sawada NO. Sexuality of people with intestinal ostomy. *Rev Rene*. 2015[cited 2016 May 13];16(4):576-85. Available from: <http://periodicos.ufc.br/index.php/rene/article/view/2732>