
EXPERIENCES AND EXPECTATIONS OF WOMEN SUBMITTED TO HYSTERECTOMY

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ABSTRACT: The aim of this study was to understand the experiences and expectations of women submitted to the hysterectomy. The philosophical background of this study was the Alfred Schütz's social phenomenology. The data were collected through interviews with ten women who realized elective hysterectomy. The analysis of the declarations showed that the woman, facing the necessity of hysterectomy, evokes myths and social background referring to removal of the womb and transcend them, deciding by the surgery due to signals and symptoms lived in the day-by-day. When passing through the hysterectomy, the women experiences a positive process of changes, having and improvement in the sexual life and the social relations. As a project the search for quality of life, considering the biopsycosocial lived in this period of the vital cycle. The knowledge of the women's living after hysterectomy offer subsidies to the health professionals who take care of this clientele, showing the experiences and the care expectation.

DESCRIPTORS: Nursing. Women's health. Hysterectomy. Qualitative research.

EXPERIÊNCIAS E EXPECTATIVAS DE MULHERES SUBMETIDAS À HISTERECTOMIA

RESUMO: Este estudo objetivou compreender as experiências e expectativas de mulheres submetidas à histerectomia. O referencial filosófico do estudo foi a Fenomenologia Social de Alfred Schütz. Os dados foram coletados por meio de entrevistas com dez mulheres que realizaram histerectomia eletiva. A análise dos depoimentos mostrou que a mulher, diante da necessidade da histerectomia, evoca mitos e constructos sociais referentes à retirada do útero e transcende-os, decidindo pela cirurgia em decorrência dos sinais e sintomas vivenciados em seu cotidiano. Ao ser submetida à histerectomia, experimenta um processo positivo de mudanças, com melhora na vida sexual e nas relações sociais. Tem como projeto a busca por qualidade de vida, considerando as necessidades biopsicossociais vivenciadas nesse período do ciclo vital. O conhecimento das vivências da mulher após histerectomizada oferece subsídios aos profissionais de saúde que cuidam dessa clientela, sinalizando ações conforme suas experiências e expectativas de cuidado.

DESCRIPTORIOS: Enfermagem. Saúde da mulher. Histerectomia. Pesquisa qualitativa.

EXPERIENCIAS Y EXPECTATIVAS DE LAS MUJERES SOMETIDAS A HISTERECTOMÍA

RESUMEN: Este estudio tuvo como objetivo comprender las experiencias y expectativas de las mujeres sometidas a histerectomía. La referencia filosófica del estudio fue la fenomenología social de Alfred Schütz. Los datos fueron recolectados a través de entrevistas con diez mujeres que se sometieron a histerectomía electiva. El análisis de las declaraciones mostró que la mujer, ante la necesidad de histerectomía, evoca mitos y constructos sociales referentes a la extirpación del útero y los transcende, decidiendo realizar la cirugía debido a los signos y síntomas vividos diariamente. Al ser sometida a histerectomía, pasa por un proceso positivo de cambios, con mejor vida sexual y mejores relaciones sociales. Se proyecta buscar calidad de vida, considerando sus necesidades biopsicosociales sentidas en ese periodo de su ciclo vital. Conocer las vivencias de mujeres después de la histerectomía ofrece subsidios a los profesionales de salud que ofrecen cuidados para esa clientela, señalizando acciones conforme sus experiencias y expectativas de cuidado.

DESCRIPTORIOS: Enfermería. Salud de la mujer. Histerectomía. Investigación cualitativa.

INTRODUCTION

Hysterectomy is the second most frequent surgery performed by women of reproductive age, only surpassed by caesarean section.¹ In Brazil, it is estimated that about 300,000 women annually receive a recommendation for hysterectomy and need to perform it.² The performance of such surgery may involve not only the concern of the women regarding the surgery itself, but also their expectations with regard to the hysterectomy, to the postoperative experience, and to the reasons, beliefs and meanings attributed to the uterus. It is estimated that this variety is due to the fact that this organ is considered important for the performance of the social role of the women: motherhood.³⁻⁴

The hysterectomy may be experienced differently by women. It may have negative implications for their lives, often related to the social construct of attributes given to the uterus, when they find themselves deprived of this organ.⁵ Conversely, such surgery can also be considered by women as a predictor of positive implications, generally linked to the absence of typical symptoms of the underlying disease that led to the recommendation and performance of the surgery.⁴ It must be considered that the social and cultural universe in which the women are immersed can greatly influence their experiences, when hysterectomized. Research conducted with Mexican women allowed the visualization that the suffering generated by the loss of the uterus falls much more on the social body than on the biological body, substantially interfering in their life processes.⁶ These situations end up affecting not only the women, but the couple, because, although the woman who underwent the hysterectomy can maintain a normal and satisfying sexual relationship, the fear may be shared by the couple who, on many occasions, experience the resumption of relations in a distressing way.⁷

Research involving hysterectomized women has been performed by nurses.^{4-5,8} However, evaluations that refer to the subjective focus of the women themselves, who have undergone this surgical procedure, are still scarce. Attention should be directed toward women subjected to hysterectomy, because they are in a context that is permeated by important concerns related to the recommendation, decision and performance of the surgery. This context, because it is endowed with experiences and expectations, requires a syste-

matic approach from the healthcare professionals who provide care to these women. Therefore, by comprehending the subjective universe of the experience – to be hysterectomized – these professionals will be better equipped to assist the women in their singularity, in seeking care anchored in the integrality of the subject. Thus, some concerns have emerged: what is the experience of hysterectomized women? What changes take place in the daily lives of women after the hysterectomy? What do women envisage for their lives after undergoing the hysterectomy?

This study aimed to comprehend the experiences of women undergoing hysterectomy, as well as their expectations regarding the performance of this surgical procedure. It is believed that the comprehension of this experience is relevant to those who care for women who have undergone hysterectomy. The knowledge of their experiences and expectations after this surgery will promote the adoption of actions consonant to the care needs presented by these women.⁹

METHOD

This is a qualitative study, using the social phenomenology of Alfred Schütz as the framework. This framework allows the social group of women who live a certain typical situation – having been hysterectomized – to be investigated. Furthermore, the proposal is to comprehend the human phenomena guided by a concrete experience, lived in the quotidian.¹⁰ Social phenomenology seeks to comprehend the world with the others in its intersubjective meaning. It proposes to analyze social relationships and not merely the individual perspective.¹⁰ It also allows the comprehension of the action, through existential motives, that permeates the experience and the expectations of the hysterectomized women. The action is interpreted by the subjects based on their existential motives. Thus, those relating to the achievement of aims, expectations, future projects are called “in-order-to-motives”. Those that are grounded in the antecedents, in the body of knowledge, in the experience lived in the biopsychosocial context of the subject are called “because-motives”.¹⁰

The study was conducted with ten women, aged between 38 and 54 years, married, with children, who had undergone elective hysterectomy at least 60 days, and at most one year before, at a university hospital located in São Paulo, Brazil. This study included the women who participated

in group and individual activities carried out weekly at the Gynecologic Clinic of the Institution, part of a university extension project entitled "Self-care promotion in women subjected to hysterectomy and their family caregivers". This is a project developed by students of the Medicine and Nursing faculties of the University of São Paulo, under the coordination and guidance of teachers of the respective schools. The project aims to conduct self-care education during the period of diagnosis of the underlying disease that indicates a hysterectomy, which includes the treatment and recuperation process of the women who undergo such surgery.

Women who were in the up to 30 days post-operative period were excluded, considering that in this time, physical issues resulting from the surgical procedure were emerging more. Furthermore, in this period, they could not outline in depth their quotidian experiences and expectations that involve biopsychosocial aspects, essential to achieve the proposed aim of this study. The initial contact was made with the women during the group activities performed in the extension project, at which time they were invited to participate in this study. The region of investigation, therefore, taken as the situation in which the phenomenon occurs, was constituted by the quotidian of hysterectomized women.

Data collection, conducted through individual face to face interviews, was carried out at the study institution, on days and at times convenient for the interviewees. The statements were obtained between February and June 2010, based on the following guiding questions: How has your life been since the hysterectomy? Have there been changes? What are your expectations having been Hysterectomized? The women were identified as "E1, E2, E3...", according to the order in which they were interviewed. The total number of respondents was not established in advance, with the data collection stopping when the interviews became repetitive, and the content of the discourses responded to the concerns and the aim of the study.¹¹

The analysis of the results was conducted, according to the steps proposed by the researchers of social phenomenology:¹²⁻¹⁴ critical reading and rereading of each statement to capture the overall sense of the experience of the women that underwent hysterectomy; grouping of the significant aspects of the statements for the composition of the concrete categories – objective synthesis of

the different meanings of the action that emerged from the experiences; analysis of these categories, seeking to comprehend the "in-order-to-motives" and "because-motives" of the action of these women who made the decision and underwent the hysterectomy; discussion of the results in light of the Social Phenomenology of Alfred Schütz and other references related to the topic. The ethical principles were followed and the study was submitted to the Human Research Ethics Committee of the study institution, being approved under Protocol n. 1010/2009.

RESULTS AND DISCUSSION

In considering the experiences and expectations experienced by the hysterectomized women, this study outlined meanings that converged into the following concrete categories: myths related to the removal of the uterus; the decision for the hysterectomy; post-hysterectomy life; and the search for quality of life.

Context of meanings that permeate the quotidian life of women facing a hysterectomy – "because-motives"

Myths related to the removal of the uterus

As can be seen – through the excerpts of the reports extracted from the statements – the woman, when faced with the possibility of the removal of the uterus, is submerged in the values, beliefs and meanings attributed to the organ, which are permeated with cultural and socially constructed myths: *ah! I heard certain things, like: 'You will have a hole, you'll be mutilated' (E2); [...] some people say that: 'if you remove the uterus, the husband will leave the woman' (E3); Some people have said to me: 'you will operate and you will not be the same.' [...] I've heard of cases of marriages that ended because of this surgery (E8).*

The world of common sense attributes the reproductive function to the uterus, i.e. to generate a new life. Therefore, the women who undergo hysterectomy lose the ability to reproduce, and, for many, this ability is linked to decreased sexual pleasure and libido, and to the thought that they will be hollow.¹⁵ Thus, the female imagery is permeated by myths related to the hysterectomy that provoke concerns generated by the possibility of feeling frigid and hollow, resulting in a psychic

crystallization of these myths when they encounter the need to undergo surgery. Furthermore, the introjection of these myths can even affect the way in which the women experience their own surgery.²

The reports allow the elucidation of how the removal of the uterus is conceived and disseminated in the social environment. All the women reported concerns regarding the removal of the organ, in view of the reproductive meaning assigned to it, which reflects the social construct of femininity. Among these concerns, those that underlie the sexual sphere, considered significant for the social role of women, were emphasized, as shown in the following excerpts: [...] *they said I'd be like a man, that I was not going to have a good sex life (E5); many people said that the woman becomes cold and does not feel anything anymore (E9).*

Female sexuality is reflected in the different ways the woman expresses herself in her life, considering the social environment and the relationships that permeate it. In this sense, the initial concern of the women in this study focused on the fact that the surgery brings implications in their marital relationship, origination from sexual anxiety. Each person goes throughout their entire existence interpreting what is encountered in the world, conforming to the perspectives of their own interests, motives, desires, and religious and ideological commitments. The reality of common sense is given to us culturally as universal, however the way in which these forms are expressed in the individual life depends on the totality of the experiences that a person lives in the course of their concrete existence. These experiences bring together a body of knowledge that is available and accessible to interpretation, according to the biographical situation of the subject.¹⁰

The body of knowledge of the women interviewed expressed a way of signifying the function and representation of the uterus in their lives, in which the myths related to this meaning may be present. These meanings are constructed and interpreted in a social structure that permeates their quotidian life, according to the way in which their lives are inscribed in a given situation, considering the social values attributed to their role as women facing a hysterectomy. The myths concerning the removal of the uterus were minimized faced with the lack of quality of life of the women, who saw themselves limited in their personal and professional quotidian due to continued pain and bleeding caused by uterine fibroids which, in this

study, constituted the underlying condition for the hysterectomy in all the interviewees. This context led the woman to seek a resolution to their experienced disorders.

Decision for the hysterectomy

Prior to the completion of the hysterectomy, the women found themselves in a context of unexpected situations, caused mainly by profuse bleeding, impacting negatively on their quality of life, as shown by the following statements: [...] *I felt a lot of bleeding, wore diapers, my heartbeat increased, then I saw that I needed to have the operation, because it was very unpleasant (E1); I was bleeding a lot; lots of blood coming out. I was using absorbent pads one after the other. If I did not do the surgery, this would never end (E3).*

It is noteworthy that the symptoms shown prior to the hysterectomy constituted important deciding factors for submission to the surgical procedure. It may be noted that the day to day of the women before the surgery was troubled, compromised by severe pain and bleeding, this being the thing that most negatively impacted in the quotidian lives of the women interviewed, according to the following statements: [...] *I had many blood clots, I bled for eight days, I started to use one absorbent pad per hour. I was terribly unwell, in a bad mood, I had no excitement. I worked and had to go home and stay on the couch, with colic; a terrible pain (E2); before the surgery, I had a lot of colic, bleeding a lot, I had been very depressed, very down because I had a lot of pain (E9); [...] there were days that I spent all day lying in bed, because otherwise I bleed profusely (E10).*

Physiologically it is recognized that increased uterine bleeding due to myoma constitutes the most common female complaint.¹⁶ Thus, the situations and complaints relating to the period prior to the hysterectomy brought the women to accept the recommendation and to make the subsequent decision to perform the surgery, which is visualized with the potential of resolution faced with the presence of signs and symptoms experienced in the woman's quotidian.^{4-5,8} The body is endowed with values, beliefs and meanings that are transmitted to the woman by people who conduct her socialization process. Even though, for the women in this study, this body references the social role of the woman, a fact which justifies the sexual and reproductive attribute linked to womb, it is clear that, when this body is sick, the universe

of meanings assigned to it can be deconstructed, so that the woman is situated in a way that motivates her or not to perform a specific social action, such as hysterectomy.

The action is defined in social phenomenology as human behavior self-consciously and intentionally projected by the subject, endowed with purpose, being manifest or latent, positive or negative. It is never isolated, unlinked to another action, disassociated from the world. Manifest or latent, the action has its horizons of rationality in the social reality of the subject.¹⁰ Faced with the reality of physical discomfort, which extends to the emotional and social status of the woman, hysterectomy is shown by the interviewees in this study as a possible horizon for return of their quality of life.

Post-hysterectomy life

When undergoing the hysterectomy the woman experiences a process of change in different areas of her life. These changes bring new meanings concerning the personal, family and working life, configuring a new meaning to their quotidian, according to the following statements: [...] *I got rid of many problems. Now it's over, I have peace. My life is even better than it was* (E4); [...] *I think I'm even happier even going walking. I love going out on Sunday afternoon to walk. I have already been working for a month now, I am more motivated and I am very happy* (E5); *after the surgery, I am perfect. One thing that I could not do and that really impressed me after I managed to do it: to walk fast again. I'm well. I no longer need to be worried* (E6); [...] *I improved in every way because I was working and could not do the job right* (E7).

The surgery can assume a positive concept, with beneficial effects on the quality of life of the woman.³ These effects are explained by the respondents of this study in the minutiae of the quotidian, which, through the surgery, were re-signified as highly relevant to their lives. A study also conducted with hysterectomized women corroborates this finding, stating that, for the majority of these women, hysterectomy was a way to revive their social lives, as it enabled them to regain the freedom to perform day to day activities, such as going out, walking, and traveling. Allowing these women to live without the inconvenience of having the underlying disease that led to the surgery present and acting as a limiting factor.⁵

Among the changes evidenced by the hysterectomized women, the sexual sphere was again highlighted. Refuting the preconceived idea of the respondents of this study that the surgery could negatively impact this aspect of their lives, the following reports show that, in contrast, there was the maintenance and/or noticeable improvement of the sexual lives of the interviewees: [...] *it was very good, even psychologically, it did not influence anything in the sexual part* (E2); [...] *my husband is more affectionate, participates more, looks after me more, something he did not do* (E4); [...] *in my private life, at home with my husband, things are better* (E5); [...] *my life has changed a lot after the surgery. The sex life has improved. I still have my libido* (E9).

It is clear that, in this study, the post-hysterectomy sexual life does not reflect the myths that have permeated the female imaginary in the pre-operative period. The women were categorical in stating that there was no negative impact from the surgery on their lives with their companions, husbands or sexual partners. Some even reported an improvement in this aspect after the hysterectomy. Recent studies highlight this aspect of the surgery. From their experiences in the post-operative period, many women announce a process of demystification of the whole social construct that was introjected prior to surgery. Thus, they started to see themselves as beings of possibilities, allowing the return to the sexual life after the surgery, with their satisfaction in this area maintained and, in some cases, even increased.^{5,15,17} Therefore, in the statements of this study, it is perceived that the reproduction/femininity attribute conferred on the presence of the uterus was not central to the experience of sexuality, especially sexual intercourse. This reveals that, in the social world of these women, satisfaction in this area was preserved, against a structure of values, meanings and beliefs that cripple – in the world of common sense – the ability of hysterectomized women to develop themselves in this aspect of their lives.

For social phenomenology, the world of the life – the quotidian world – is the scenario where human beings live, which is structured before their births. The reading that people make of the established reality causes them to act in a natural way based on what is presented to them as the social reality. However, they have the capacity to intervene in this world, influencing and being influenced, continually transforming

themselves and changing these social structures. Natural attitude is the way human beings position themselves in the world of the life.¹⁸ Before the hysterectomy, the woman allows herself to intervene in her reality prior to the performance of the surgery, marked by socially constructed myths about the removal of the uterus. Thus, she proposes to transform the social structure pre-established by means of the surgical procedure, in view of the positive change evident in her life. In this sense, the woman, when undergoing the hysterectomy, produces a reconfiguration of her routine, modified by the absence of complications caused mainly by the pain and bleeding that were previously common in her life. Therefore, being a hysterectomized woman reflects a new way for the woman to perceive herself and take care of herself – physically and mentally – and also to take care of her relationships. From this perspective, the woman can visualize new possibilities, perceived through means of projections that she makes in her personal and professional life.

Expectations of the women subjected to hysterectomy – “in-order-to-motives”

Search for quality of life

Quality of life is a polysemic concept that involves objective and subjective, singular and plural issues. To construct this category, we rely on the quality of life concept, such as the quality of the living conditions of a person, or the satisfaction experienced in certain vital conditions. It is tied to the satisfaction that a person experiences, reflected in their personal values, aspirations and expectations.¹⁹ The woman faced with performing the hysterectomy refers to the search for the quality of life. By having it as a goal, it is perceived as a subject with biopsychosocial care needs, reflecting in physical, psychological and relational aspirations that contemplate the range of such needs. Thus, the surgery leads to an awakening to these needs as a result of a past plagued by eminently social limitations, caused by physiological disorders that overly affect the quality of life of these women, as shown by the following reports: [...] *I plan to improve even more, even as a person. With my husband, I think it will get better. I intend to work more to build my house (E5); [...] to be more healthy to work better, to do my duties at home and to be better, because without health, we do not live*

right (E7); [...] my expectation is to continue caring for myself [...] and I intend to return to being active, to work because I'm not working. I hope to improve from this point forward (E9); [...] to improve and to do things now that I did not do before the surgery [...] and not to have to be bedridden (E10).

From the statements it can be perceived that, based on the action – undergoing the hysterectomy – the women have projects that aim for a healthy life endowed with typical capabilities to perform the quotidian activities, especially those associated with the public sphere, that is, the world of work. The project is constituted in the primary and basic sense of the action, with this conceived in the future time. When an action is performed in its initial sense, as was planned in the project, it may be modified, considering the way it is carried out in practice, opening an array of infinite reflections.²⁰ Thus, it is believed that the hysterectomized woman reconstructs her living process in a perspective that will bring positive influences to her quality of life, impacting positively not only in the moment experienced, but in the expectations and projects that come from this moment.⁵

All of the women in this study experienced the hysterectomy in a positive way. Such findings can be comprehended due to the educative activities that the women had participated in prior to the performance of the hysterectomy, that had the aims of clarifying their doubts, minimizing their anxieties in relation to the surgical procedure, explaining the post-operative care and, over all, demystifying all the symbolic content that permeates the removal of the uterus. This reiterates the importance of healthcare professionals being open to the experience of these women, since it was through this openness that they gained the knowledge of their concepts regarding the surgery and the deconstruction of structured prejudices, before performing the surgical procedure. This fact, even though characterized as an apparent indicator for a positive experience of the women interviewees of this study can also represent an important limitation with regards to the generalization of the results.

FINAL CONSIDERATIONS

The experience of the hysterectomized women is permeated by beliefs, meanings and values that produce reflections on their experiences and expectations, when undergoing hysterectomy.

When reporting her actual experience, the woman refers to the motives which led to the performance of the surgery, represented by discomfort present in her quotidian that impacted significantly on her quality of life. When returning to the context that preceded the performance of the surgery, they outlined concerns with the removal of the uterus - taken by the common sense, as the defining organ of the social characteristic and feminine identity. Their experiences after the hysterectomy, however, revealed that the "loss" of the uterus took on a symbolism capable of amputating the potentiality of experiencing their relationships freely, including those of a sexual nature.

The reflections of the hysterectomy were also found in the life projects of the women. Once free of the signs and symptoms that plagued the quotidian, they became able to experience the minutiae of life in its fullness, which before was compromised by physical limitations with significant social repercussions. The search for quality of life was configured as the core of their aspirations within the biopsychosocial context. Among these aspirations, prominence is given to those pertaining to the professional field, which begins to be envisioned by some and potentialized by others, emphasizing the reflection that this surgery produced in the social, and therefore public, sphere of these women.

By revealing the experiences and expectations of women who underwent hysterectomy, having participated in educational activities prior to the surgery, this study has contributed towards indicating that healthcare professionals, among them the nurse, should include such practices in the monitoring of women who experienced and/or will experience this surgical procedure. Therefore, knowledge of the experiences of post-hysterectomized women provides support for healthcare professionals who assist these clients, indicating actions consonant to their care experiences and expectations. It is suggested that further studies are carried out, in order to corroborate, contribute and/or complement the findings of this study, in search of a broader comprehension of the experience of hysterectomized women.

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