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ORIGINAL ARTICLE

GUIDELINES FOR NURSING AND IMPLICATIONS FOR THE QUALITY OF LIFE OF STOMIZED PEOPLE

ORIENTAÇÕES DE ENFERMAGEM E IMPLICAÇÕES PARA A QUALIDADE DE VIDA DE PESSOAS ESTOMIZADAS

DIRECTRICES PARA LA ENFERMERÍA Y LAS IMPLICACIONES PARA LA CALIDAD DE VIDA DE LAS PERSONAS ESTOMIZADAS

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ABSTRACT

Objective: analyzing the impact of guidance provided to stomized customers, regulars of a support group called 'On edge and with love', with a view to achieving a better quality of life. **Method:** a qualitative and descriptive study against the backdrop of a university hospital with nine stomized patients. The technique of data collection was the semi-structured interview, and data were analyzed by the technique of thematic analysis of content. **Results:** it was found that the nursing instructions are important for these people to achieve quality of life, for the teaching-learning process developed by nurses go beyond technical aspects, addressing, among others, issues, such as leisure, interpersonal relationships, legal aspects. **Conclusion:** nursing guidance provided to stomized customers positively influences the adaptation to new health situation and provides a better quality of life for these people. **Descriptors:** Nursing; Intestinal Stoma; Quality Of Life.

RESUMO

Objetivo: analisar as repercussões de orientações fornecidas aos clientes estomizados, frequentadores de um Grupo de Apoio denominado *À flor da pele e com muito carinho*, na perspectiva do alcance de uma melhor qualidade de vida. **Método:** estudo qualitativo e descritivo tendo como cenário um hospital universitário com nove estomizados. A técnica de coleta de dados foi a entrevista semiestruturada, e os dados foram analisados pela Técnica de análise temática de conteúdo. **Resultados:** constatou-se que as orientações de enfermagem são importantes para que essas pessoas alcancem qualidade de vida, pois o processo ensino-aprendizagem desenvolvido pelos enfermeiros vão além de aspectos técnicos, abordando, dentre outras, questões como lazer, relacionamento interpessoal, aspectos legais. **Conclusão:** as orientações de enfermagem fornecidas aos clientes estomizados influenciam positivamente na adaptação a nova situação de saúde e propiciam uma melhoria na qualidade de vida dessas pessoas. **Descritores:** Enfermagem; Estomia Intestinal; Qualidade De Vida.

RESUMEN

Objetivo: analizar el impacto de la orientación proporcionada a los clientes estomizados, asiduos a un grupo de apoyo llamado 'Nervioso y con amor', con vistas a conseguir una mejor calidad de vida. **Método:** un estudio cualitativo y descriptivo, en el contexto de un hospital universitario con nueve estomizados. La técnica de recolección de datos fue la entrevista semi-estructurada, y los datos fueron analizados por la técnica de análisis temático de contenido. **Resultados:** se encontró que las instrucciones de enfermería son importantes para estas personas para lograr la calidad de vida, para el proceso de enseñanza-aprendizaje desarrollado por enfermeras, pues van más allá de los aspectos técnicos, abordando, entre otros, temas como el ocio, las relaciones interpersonales, aspectos legales. **Conclusión:** la orientación de enfermería prestada a los clientes de ostomía influye positivamente en la adaptación a la nueva situación de la salud y proporcionan una mejor calidad de vida de estas personas. **Descriptores:** Enfermería; Estoma Intestinal; Calidad de Vida.

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INTRODUCTION

People stomized, focus of this study, are inserted in a Group of Multidisciplinary Support, called 'On edge and with love', which is also characterized as an Additional Internal Stage Design of a Public University of Rio de Janeiro. This Group is in the hospital belonging to the mentioned University, specifically in the Proctology Service of the Department of General Surgery, and aims to promoting the rehabilitation of ostomy patient clients through educational and charitable actions.

The Support Group is coordinated by two stomatherapists nurses, who proposed the said Complementary Internal Training Project to the University that the hospital is linked, including receiving, two nursing students - scholarship holders - to contribute to the project and to enrich their learning. Over time, other professionals were adding to the Group's activities, such as a social worker, nutritionist and doctor, forming thus a multidisciplinary team.

One of the authors of this paper went through the experience of being the first scholarship holder of that stage of the project; from their involvement in it, the desire to perform a search came up with themes to bond to the activities developed in the Group - Guidelines for stomized people - and that could also be characterized as its Work Course Conclusion (TCC) degree in Nursing.

We present in this space the clipping of TCC, which aims to analyze the impact of nursing guidance provided to ostomy clients attending the Support Group, in view of achieving a better quality of life.

After conducting a search in the Virtual Library databases in Health (BVS), in various times and days of the months of April and May 2012, using the keywords "ostomy", "health education", "quality of life", "nursing" and "ostomy", were found three publications. Of these, only two were related to the object of this research, which justifies the performance and the relevance of the study, since it may help expand research on the subject, as well as socialize a subject still little discussed in academic and care nursing.

This research can highlight the practice of health education and nursing guidelines as an important care for stomized people, because through this care contributes to these people both achieving more autonomy over their health issues as to better understand the experienced disease process and also medical

and nursing procedures with the need to cure/treat the disease. It is also expected that the study will contribute to increased knowledge of the students and nursing professionals who work with these clients, encouraging them to a holistic and systematic care delivery to the real needs of these individuals.

LITERATURE REVIEW

The stomized person can be defined as an adult, elderly or child, who has a stoma. Etymologically, the term stoma or ostomy means mouth or opening, according to its Greek origin. Currently, the scientific terminology in the medical field refers to surgically created openings involving the gastrointestinal tract or urinary tract.² In this study, the focus is given on customers with colostomy and/or ileostomy, ie the procedure in which manifesting the large intestines and slender, respectively. These stomata, derived from a surgery, have the purpose of providing the elimination of organic waste products - feces.³

The stoma, according to its surgical indication and the etiology of the disease, can be temporary or permanent. However, the care they require the ostomy customers must be met and differentiated according to each reality of their lives, because they are temporary or permanent, are dramatic and profound biopsychosocial changes which they experience.⁴

Due to the presence of the new body dynamics after making the intestinal bypass, the stoma person needs, and face the consequences of disease or trauma causing the stoma, dealing with losses, real and symbolic, caused the extinction of a body of important organic performance; between those losses, cite the lack toilet, with constant elimination of feces and gases; and mutilation of body image and self-esteem, resulting in a feeling of disgust and disrespect to society, which in turn may result in psychological and social isolation.^{2,5,6}

Due to the changes that are exposed through which they pass, the ostomy experience different feelings, triggering conflicts, concerns and daily difficulties. These include disturbances related to the use of the collector equipment, as in the gas elimination episodes in accidental leaks and consequent emission of odor.⁷

Socially, many ostomy prefer to keep secret their health condition and end up moving away from friends and even family members, due to fear of prejudice and stigma

caused by the stoma. So many fail to engage in leisure and recreation activities, opting for insulation.⁵

The presence of a nurse becomes essential in the lives of people with stoma and their families, because this professional acts assisting them in understanding that there are numerous social activities that they can engage in without prejudice to their health. Therefore, it is for health professionals, especially members of the nursing team, the responsibility to provide guidelines to facilitate the adaptation to the new condition of life, entering the client and its family in the context of care and caregiver, enabling approach to the problem and providing opportunities for the construction of new meanings to the pathological-CABG. This generates a tendency to improved body image and customer self-esteem, as well as providing the continuity of professional contact and social.⁷

The process of teaching and learning in health should be made through socialization of knowledge and life experiences, by professionals and customers, making the construction of the mutual and dynamic knowledge. This learning should be ongoing, whether at home or while participating in support groups, it is through it that the individual and its family build their foundations to live in a way adapted to their new health condition.⁸

The care of ostomy developed by a support group fosters the emergence of coping strategies that these people often will not get through life, as well as the exchange of knowledge and experiences that provide greater resistance to stress of the situation. In this sense, participation in the group allows the construction of means to restart the contact with both the inner world, psychological, and with the external society. And understanding of some authors, such groups are characterized as a kind of social support network, in which there is establishment of mutual aid links.^{9,10}

Also, through this perspective, a social support network is important for recovery ostomized people, not only proved to be a means of establishing contact with others going through similar feelings, frustrations, doubts and fears, but also characterized as a tool which enables to measure the professional support triggered by the people involved, so you can include them in a therapeutic plan of individual or collective action.⁶

Support groups become important strategy in the rehabilitation process of stomized

people. This process, although complex, seeks to improve the quality of life of these clients, enhancing their well-being and social inclusion, enabling or facilitating the return of those subject to the earlier activities to ostomy as work, leisure and recreation activities, sexual activities, travel etc.^{9,10}

The nurses in their practice and in the development of health education must individualize nursing care to this population, and not focus only on its guidelines related skin care and use of the collector device because, as mentioned earlier, needs of ostomy outweigh the physical changes and include the psychological and social levels.

The nurse develops a fundamental role building an individualized and comprehensive care, because in addition to being responsible for the care, also fulfills the goal of providing knowledge to the client and its family, playing the educator role. And it is through health education that fosters the professional training of individuals aware and free to make choices about their care, which provides self-care and, consequently, better quality of life.¹¹

From the knowledge acquired by the ostomy client, with the help of nurses and support groups, it becomes autonomous to decide about their health and their care process, becoming a facilitator in the process of social inclusion. The exchange of experiences with other ostomy and health professionals becomes an important way of acquisition and multiplication of knowledge, encouraging increased confidence, self-esteem and consequent improvement in quality of life.¹¹

METHOD

Article compiled from the Work Course Conclusion << The nursing guidelines and their impact on quality of life of ostomy customers >> submitted to the Faculty of Nursing, State University of Rio de Janeiro/UERJ, Rio de Janeiro-RJ, Brazil, 2013.

This research, qualitative and descriptive character, took place at the surgery clinic of a university hospital located in the city of Rio de Janeiro; is this clinic occurring meetings of the Multidisciplinary Support Group customer with ostomy.

The Group began in July 2010 with the main objective to discuss theoretical concepts that provide self-care and promote rehabilitation of ostomy patient clients. Its operating dynamics is through multidisciplinary meetings for support and guidance for this type of clientele.

The Group meetings take place every two months, on Fridays, lasting about three hours. However, the time of the activity depends on the demand of the ostomy group. In these meetings, initially the team members present and then the word to each guest is offered, so that people come forward and share their experiences as ostomy, and address their insecurities, fears and anxieties regarding your new health condition. It also provided specific guidelines for each team member, through multimedia, educational brochures, and workshops on the care of the stoma, as collecting equipment and adjuvants.

The study subjects were members of the Group 'On edge and with love', men and women with temporary ostomy and/or permanent, by history of malignancy or inflammatory bowel disease. Participants in this group were, on average, fifteen customers. However, only nine showed up available for the study: four men and five women. The other could not attend for various reasons, namely: family nature of impairments (2) and labor (1), schedule incompatibility (1) death (2), which characterized the difficulty faced during the data collection period.

The data collection tool was the individual semi-structured interviews, containing three open questions. Responses were recorded using multimedia player and, soon after each completed interview, they were transcribed. The collection period occurred in October and November 2012. The data were analyzed and interpreted according to the Thematic Analysis Technique Content.¹²⁻³

To ensure the ethical principles, the participants signed an informed consent and informed, which guaranteed anonymity, freedom and secrecy of information, and the research reviewed by the Ethics Committee of the State University of Rio de Janeiro. After evaluation, obtained positive opinion filed under number 071.3.2012, as recommended in Resolution 196/96 of the National Health Council/MoH.¹⁴ In this procedure, there was a concern not to disclose the names of the subjects (anonymity guaranteed principle), using color names to refer to each of them.

RESULTS AND DISCUSSION

The nursing instructions provided in the Support Group have a positive impact on people's lives stomized for several reasons; one of them is the fact that the orientation process make up in order to meet the specific needs of each client. That is, educational approaches focused on the doubts and afflictions of specific person are developed,

considering even the socio-cultural and economic context of the same.

The following lines show that individualized character of the guidance provided by nurses:

For me, in particular, helped me a lot in the care, explained to me what I had certainly not the doubts of others. So before putting gloves, clothing, was a preparation out of the ordinary, now I do with more tranquility and simplicity. I enter the bathroom to unload normally sit to clean, just the fear.
(Red)

They [nurses] showed me several times the tricks to clear my own bag, take all the rest of things here inside and the air too. How it is done and how to close that runs through this small plastic here. Until kept the mold they did up here, so I guide me later.
(Green)

Another reason that contributes to a positive impact of nursing instructions in the quality of life of ostomy customers is the way you drive the dynamics of the Group, also considering the doubts and anxieties family, welcoming and supporting the family to help them ostomy to resume their lives.

After the guidelines started doing me, cleaning, measuring; my skin is already good [dermatitis]. I always have to do that, I suppose; I am now; do not take coffee in the morning, I get up, take a shower, do all I have to do, I take that will change the bag, al also shave the leg, wash the head, now started doing some things, but who did everything before was my daughter, my family was very important in this and the group gave guidance to her [daughter].
(Yellow)

It is worth highlighting the importance of family around ostomy rehabilitation process, as the stoma presence very commonly causes individuals in periods marked by difficult adjustment, which can be minimized by emotional support and understanding of loved ones and friends.^{15,16}

As seen in the reports, the family is the person who was present at all stages of the disease, supporting and giving meaning to the struggle for life, becoming a concrete support to the individual adaptation process, providing care, protection, comfort and affection even if subsequently the stoma person acquires security and autonomy for self-care. In this way, the family is also a key element in the acceptance of this new condition of life, so necessary in the educational process of ostomy patients.

Another important aspect on the guidelines provided by nurses is the concern for the legal rights of ostomy. The subjects value the amplitude of the Guidelines, going beyond the technical aspects and addressing their rights

as citizens. This professional conduct positive impact on quality of life in them since enables financial savings, greater access to social assistance and health services. The following selected lines characterize this discussion:

In the group, I learned about legislation, which is very important for us. (Rosa)

Much is spoken in group discussions: talk about unemployment benefits, which rights and benefits that each has. (Rose)

They speak of our rights, that before I did not know my rights, now I know. Each time I come here [in Group] I learn a little bit more. Today I got my special pass card, special valley, jobless; I am entitled to it all and did not know. I was given time treating me and did not know I had that right. After, I joined the group, which I learned. If today I enter the mall and it is full and has no vacancies, I can stop in the poor; I can go in there, because I'm right. And I do exercise my right. (Rose)

To the extent that the individual knows their rights and duties, it can best become part of the society in which it lives. In the particular case of stomized people, their rights have changed as the Ministry of Health, through Ordinance No. 400 of November 16th, 2009; establishing national guidelines for the Health Care of Ostomized, which confer certain benefits and rights to such persons.¹⁷ This Ordinance is intended to meet all patients with ostomy indicated for granting collectors equipment. For those rights, the ostomy must register in a reference center of a program and to undergo clinical evaluation of nurses and doctors. However, all ostomy were considered physically disabled people from 2004.¹⁷

From the mentioned legal provisions, the ostomy now acquire rights, such as receiving increased amount of equipment and collectors adjuvants by the Unified Health System and guidelines for skilled health professionals in appropriate locations for such physically, called Care Services to health Ostomized. There are also the rights to accessibility to employment quotas and to compete in public office as people with disabilities.¹⁸

With regard to leisure activities, studies show that most of the ostomy, after hospital discharge, does not resume the activities they performed previously, preferring to stay at home to go out and get distracted¹⁹. This position is due to possible limitations imposed the stoma, which forces them to spend most of the time at home, segregated and isolated, which in turn promotes the loss of enjoyment of life, the occurrence of anxiety, loneliness, depression, and other negative feelings and destructive to biopsychosocial integrity.¹⁶

It appears that there is, as of nursing instructions provided in the Group, an incentive to leisure activities, to contact with other people and practice the activities that developed before the existence of stoma:

The group instructs the person, this here is not a disease, is a natural consequence that the person can go to the beach, traveling, eating. (Red)

In the group, they pass that is for us not give up, never lose self-esteem, and there improved our self-esteem. That was very important, if he had not a good accompaniment, the person would fall into depression and die slowly, so ... They encourage us much to practice leisure activities. I started to ride a bike, go to dances, to samba, I was very motivated. (White)

The resumption of leisure activities and pleasurable activities generates in the person stomized an improvement on self-esteem, thereby encouraging attend other environments, whether leisure or laborative, seeing new people. From these experiences, the ostomy realizes it can and should resume its former life to the stoma, allowing it to rediscover the fun and feelings different from those present in its life from the stoma, which improves its quality of life.

Nursing guidelines are also in choosing collectors and adjuvants equipment that usually originate feelings of doubt, insecurity, anguish and anxiety. In this sense, it is essential to support and / or guidance of nurses in an attempt to find, together with the client and family, the collector system best suited to the patient without causing complications, discomfort and/or seizures.^{20,21}

This choice should be based on individual characteristics of ostomized people: the stoma, the effluent, the area to mount the equipment and the customer lifestyle. Socioeconomic characteristics, mainly, is also relevant to sex, age and economic profile.²² Thus, it appears that subjects such value orientations of nurses, which positively affects the quality of life of ostomy, as evidenced below:

Using the pouch, how long to change, ointments that we should go and how to pass. I shot for me, at first I bought a tube of ointment and spent, did not use the ointment, alas after they [nurses] taught me to use, today I spent a tube for almost a year, because everything there is guidance they give to us. (Rosa)

They talked, for example, the use of that folder leveling the skin around the stoma, which has to pass as a mass race. There are several little details, you know? That helps a lot, (Lilac)

People who their your body altered by surgery - in which they lost part of a body and, as a result of this change, you must relearn how to deal with your body - experience negative feelings that influence their way of living. Thus, ostomy, to view physical changes in your body dynamics, can be deprived of their integrity, undermining its dynamism and autonomy, which generates internal conflicts, triggering changes with the outside world.²³

The ostomy, to experience body changes, it is seen initially as a person who had his mutilated body and therefore should not be exposed to social life because individuals may question the reasons for the organic modification. Thus, because of fear of possible unpleasant situations, prefers to exclude socially, which increasingly diminishes their self-esteem.¹⁸

By reports, it appears that the nursing guidelines contribute to raising the self-esteem of individuals, through the exchange of experience between the parties, promoting the improvement of quality of life, as follows checked:

What changed after the group was my self-esteem, improved somewhat. Because the group we discuss, exchange experiences. Before I was very crestfallen, was kind of depressed. After the group I realized that I improved, I changed. (Grey)

As can be seen from that speech, ostomy patients sometimes have the feeling of low self-esteem and social exclusion triggered by factors such as dissatisfaction with their bodies and the difficulty in controlling their feces, which required the use of a bag collector to condition their waste. But these feelings, when identified and worked by properly trained professionals and support groups can be modified, since the firm is specialized biopsychosocial support to the client, acting on behalf of adaptation and quality of life. This work should be done in conjunction with the family, seeking coping strategies that will assist in the rehabilitation process.¹⁸

Regarding the adaptation of ostomy, each individual uses its specific mechanism. For example, many people stomized, after reaching their rehabilitation and, hence, quality of life, assume the posture of being able to see how they help other conditions are the same. Thus, build websites and blogs and participate in support groups in order to exchange experiences with the newly ostomy or who still have trouble accepting such a condition.¹⁸

Such strategies are also ways to help others to accept the existence of a stoma. In this perspective, there are various ways to promote the rehabilitation of individuals, which are explained in the Group. The best way is the one that best suits the particular person that demands an action and/or directed care.

What is evident, the speech was the importance of nursing instructions discussed in the Group, which could be shared with other people, favoring the improvement of the quality of life of other ostomy. The participants of the Group's customers have become multipliers of knowledge acquired, according to the reports:

I take the knowledge from here [Group] to others. I gained knowledge. And when I see a small bag of person who has a colostomy, do this exchange! That's pretty cool. Today I can to help others. (Lilac)

With the group I see that I can help others, not only look and feel sorry, but if I can help, I will and help. (Grey)

The stance that subjects take characterizes called social support network, as mentioned above, in which individuals or groups interact, establishing aid of links that can be emotional or material. These networks are characterized for being an activity that allows the exchange of experiences, personal experiences, among others. The participation of ostomy as multipliers of knowledge triggers a positive character reaction, generating well-being, enabling the improvement of the health status of those who receive support and, above all, leading to an improvement of the biopsychosocial aspects of the individuals involved in the rehabilitation process.⁹

It is important, therefore, that the nurse acts performing its role of providing quality care, not only aimed at the physical recovery of the patient after surgery, but also providing guidance on the new dynamics of the organism, so that individual can adapt and have a quality of life.

The nurse then has an important role as an educator and should have as basic premise in this context facilitate orientation strategies for health and self-care, from the knowledge of the socioeconomic reality of the assisted clientele, their psycho-emotional characteristics and physical conditions.

The nursing guidelines in this context should be systematic and holistic, permeating all biopsychosocial aspects involved in the recovery of people with stoma. Teaching self-care, understood as the first step in the rehabilitation process, should also guide the guidelines aimed at recovering the self-

esteem of customers, reinforcing the importance of social inclusion in their lives. Thus, with the help of the nursing team and the family, the ostomy may seek a better quality of life, even in the presence of stoma, and realize that they can return to the many activities of daily living and pursuing their life plans.

FINAL REMARKS

The nursing guidance provided to customers ostomy positively influenced the adaptation to the new health situation, as well as providing an improved quality of life of these people, as they have come to understand the ostomy and face more conditions organic and psychosocial changes arising from the stoma.

The results show that the guidelines were comprehensive and targeted to the needs of ostomy, respecting the principles of nursing care: individuality and integrity. In this sense, the guidelines permeate issues of biological and act also in social, psychological, Legal, economic and cultural. Family members should also be included in the teaching-learning because their presence is essential in the care/care of ostomy patients.

How developed the nursing guidelines is also considered positive, as the coexistence in the Support Group, with others stomized enables the sharing of experiences and reveals that these people with stomata are not alone. That is, other people share their fears and doubts, and they can even share solutions to common problems. In addition, the dynamics of the Group favors the feeling of welcome and belonging to a support network - stomized patients, families, health care professionals - enabling the reconstruction of a new identity and subjectivity.

By attending the Group's meetings, the stomized people realize that what bothered them before; now, through the knowledge acquired, no longer worried so much, and the fact of being inserted in a warm environment that offers comfort, support and care - Support Group - enables to have the perception that you are not alone and that there are way out of their problems. In this perspective, it is concluded that obtaining knowledge about their new life conditions, the client has their fears, anxieties and discomforts minimized, which favors self-care, rehabilitation and a better quality of life.

It was found that the nurse is seen as a professional who drives self-care process of stomized people acting to return to customers the role of its own care agent, making it more participatory, which

contributes to the development of more independent individuals and holders of knowledge about their bodies, and thus of their lives.

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