

THE NURSE AND HER PARTICIPATION IN THE PROCESS OF REHABILITATION OF THE PERSON WITH A STOMA

O enfermeiro e sua participação no processo de reabilitação da pessoa com estoma

El enfermero y su participación en la rehabilitación de personas con estoma

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ABSTRACT

The object of this study is the role of the nurse in the process of rehabilitation of persons with stomas, with emphasis on their inclusion in work. The objective was to discuss, from the perspective of the person with a stoma, the guidance provided by the nurses in relation to inclusion in work activities. It is descriptive-exploratory qualitative research, carried out using a semi-structured interview with twenty persons with permanent stomas, in a rehabilitation institute in Rio de Janeiro. The results showed that few of the people with stomas received guidance from the nursing professionals in relation to returning to work activities, and the health professionals were not referred to as essential for the study's subjects' rehabilitative process. It is concluded that there are gaps and misconceptions in this process of rehabilitation, principally in relation to the advice on social inclusion through work, which may be caused by the nurses' lack of knowledge regarding the issue; and the non-application of Systematization of Nursing Care.

Keywords: Worker's health; Surgical stomas; Rehabilitation.

RESUMO

O estudo teve como objeto o papel do enfermeiro no processo de reabilitação dos estomizados, destacando-se sua inclusão laboral. O objetivo foi discutir, a partir do ponto de vista do estomizado, as orientações fornecidas pelos enfermeiros em relação à inclusão laboral. Trata-se de uma pesquisa descritivo-exploratória, qualitativa, realizada com vinte estomizados definitivos, em um instituto de reabilitação localizado no Rio de Janeiro, por meio de entrevista semiestruturada. Os resultados revelaram que poucos estomizados foram orientados pelos profissionais de enfermagem a respeito do retorno às atividades trabalhistas, e que os referidos profissionais não foram citados como essenciais para o processo de reabilitação dos sujeitos do estudo. Conclui-se que há lacunas e equívocos neste processo de reabilitação, principalmente em relação às orientações sobre a inclusão social pelo trabalho, que podem ser ocasionados pela falta de conhecimento dos enfermeiros em relação à temática, e pela não aplicação da Sistematização da Assistência em Enfermagem.

Palavras-chave: Saúde do trabalhador; Estomas cirúrgicos; Reabilitação.

RESUMEN

The object of this study is the role of the nurse in the process of rehabilitation of persons with stomas, with emphasis on their inclusion in work. The objective was to discuss, from the perspective of the person with a stoma, the guidance provided by the nurses in relation to inclusion in work activities. It is descriptive-exploratory qualitative research, carried out using a semi-structured interview with twenty persons with permanent stomas, in a rehabilitation institute in Rio de Janeiro. The results showed that few of the people with stomas received guidance from the nursing professionals in relation to returning to work activities, and the health professionals were not referred to as essential for the study's subjects' rehabilitative process. It is concluded that there are gaps and misconceptions in this process of rehabilitation, principally in relation to the advice on social inclusion through work, which may be caused by the nurses' lack of knowledge regarding the issue; and the non-application of Systematization of Nursing Care.

Palavras-clave: Worker's health; Surgical stomas; Rehabilitation.

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INTRODUCTION

The author's interest in addressing the rehabilitation process of the person with a stoma was kindled during a nursing residency in Clinical Surgery, in Rio de Janeiro State University, when they experienced innumerable questions, on the part of those with stomas, about their return to activities of daily living. It should be emphasized that, of all the clients' doubts, those referent to returning to work stood out, as this is considered essential for maintaining self-esteem and supporting oneself financially.

An in-depth investigation of this issue resulted in the development of a Master's dissertation entitled '*The person with stoma and the process of inclusion in work: contribution to nursing*'¹, to be presented in this article through an excerpt, the role of the nurse in the process of the rehabilitation of people with stomas, with an emphasis on inclusion in work. The objective is to discuss, from the viewpoint of the person with a stoma, the guidance offered to her by the nurse in relation to the process of social inclusion, with stress on work.

Seeking to bring together bibliographic data which might help in understanding the study object, in March 2009 a search was made in the Virtual Health Library (VHL), the aim being to locate scientific productions on the topic. To this end, the following data bases were accessed: Medical Literature Analysis and Retrieval System Online (MEDLINE); Latin American and Caribbean Health Sciences Literature (LILACS); Scientific Electronic Library On Line (SCIELO); and the Nursing Database (BDENF). This bibliographic search was made using the following descriptors: stomas/work and stomatherapy/work.

Using this search procedure, no scientific production was found on the topic of the person with stoma in the world of work. During the search with the VHL, however, some productions were found which had a certain similarity with the issue proposed in the present study. To this end, studies were checked which addressed the rehabilitation of people with stomas in social life as a whole: these works, however, neither focussed on the world of work nor were produced by nursing professionals.

In the light of the results learned from the research in the VHS, it was observed that there is an unambiguous evidence of scientific production on the person with stoma and their inclusion in the world of work. This circumstance intensified the authors' interest in the study object indicated above.

The presence of an intestinal or urinary stoma brings significant changes to the life of the individuals, due principally to the loss of sphincter control and to the use of the accessories for collecting feces and/or urine. In addition to the physical transformations, there are the psychological and social ones, associated with changes in body image,

which cause many individuals to feel unable to return to activities of daily living, leading to social isolation²⁻⁵.

The social inclusion of people with stomas is therefore a great challenge for all the professionals involved in this process as, in seeking a cure through a surgical procedure, traumas are triggered resulting from the changes in organic functions, fears, fantasies, and frustrations, without mentioning the ignorance and prejudice of society, relatives and the people with stomas themselves, who judge themselves incapable of carrying out activities of daily living such as returning to work⁶.

The process of the rehabilitation of people with stomas is largely geared towards offering these subjects participative inclusion in society, through the development of their capacities of adaptation⁷. As previously stated, these individuals' professional condition stands out among all these rehabilitative factors, it being considered extremely relevant for them to return to work, this obviously being adapted to the degree to which their productive and participative capacities are limited^{6,8}.

Returning to work causes the people with stomas to feel active and important in social terms as, in addition to contributing to the production of goods and consumption, they return to coexisting with individuals other than relatives and friends; furthermore, they can contribute actively to the financial support of their families, which improves their self-esteem and security.

Nurses are considered essential in the process of rehabilitating people with stomas, as they are present from the moment of diagnosis, when people choose to have the stoma, in the outpatient or hospital environment, throughout the period of hospitalization and preparation for discharge, and in the late post-operative period, encompassing the Specialized Rehabilitation units, the health clinics, and the Family Health teams. Thus, it may be observed that nurses are also responsible, being members of the multidisciplinary team, for guiding the people with stomas regarding stoma care, food and hygiene, preparing them for self-care and the return to activities of daily living.

The Systematization of Nursing Care (SNC), as an organizational process, is capable of providing support for the development of humanized and interdisciplinary methods of care in Stomatherapy, allowing a holistic assessment of the person with a stoma and care planning geared towards her real needs. The importance stands out of applying SNC from the pre-operative period, in which the client presents innumerable questions regarding her new condition of life, even when she has previously been advised; through to the late post-operative period, when the individual, now living with the stoma, needs advice relating to her difficulties in activities of daily living and social inclusion^{9,10}.

It is relevant to highlight that studies encompassing people with stomas are extremely important, as the number of people with stomas is continuously increasing. The two major causes of stoma construction, which are colorectal cancer and trauma, cover ever-larger and ever-younger proportions of society, even without adding that stomas are constructed as a palliative measure for the prolongation of the individuals' lives^{1,10-12}.

Due to the epidemiological changes in the profile of people with stomas, with increasingly young individuals being affected by this health problem, the need is highlighted for their social inclusion, preparing them to enter or return to the world of work, as in our society, working is essential for financial maintenance and relevant for self-esteem.

To the extent that this study serves as a resource to be consulted by students and professionals in nursing and/or health, it may awake interests, as well as increasing knowledge regarding this type of clientele's problems. As a result, these professionals will be more alert to the needs for inclusion and social rehabilitation in clients with stomas and, therefore, will place greater emphasis on guidance for self-care and for acceptance of the new condition of life, by the client herself and by her family.

LITERATURE REVIEW

Worker's Health is a field of theoretical-practical knowledge which aims to understand the relationships between work and the processes of health/illness, developing alternatives for intervention which lead to transformations geared towards the appropriation by the workers of the human dimension of the work, in a teleological perspective¹³.

In December 2004, the National Policy of Worker's Health and Safety (PNSST) was developed in Brazil, with guidelines and aims of extending safety actions at work, providing Brazilian workers with actions of health promotion, health protection, and carrying out treatment, as well as backing up the importance of the structuring of the National Health Information Network and of encouraging continuous education among the same¹⁴.

In this perspective, among the most complex aspects of this Policy of Attention to the Worker's Health restrictions on working and the return to work both gain emphasis, these being the focus of the present study's interest. The client with a stoma, as a worker and a person with a disability, seeks at many times to return to work, re-adapting or seeking a new occupation which does not worsen her health¹.

The success of professional rehabilitation depends directly on the ideal therapeutic care, on the support of the family, and on the support of society, as well as on the earliness of the intervention, with a view to physical and psychosocial rehabilitation, these actions being necessarily

interdisciplinary in nature. In this situation, the possibilities both of temporarily having to stop working and the process of returning to work are highly relevant. This last aspect acquires specific characteristics according to the nature of the worker's restriction and the company's receptiveness^{15,16}. All this makes professional rehabilitation a dynamic process of attending the worker globally, in which companies must be included for there to be success throughout the process of prevention, treatment, rehabilitation, re-adaptation and inclusion in work.

When it is impossible for the worker to return to the same work activity, her re-allocation depends on the company's conditions to provide work positions which are suited to the individual's disability, on her appropriate fitting-in, on the changes which will have to occur in the work environment and, above all, on a policy with defined programs such that the worker may have wide opportunities for inclusion in the work¹⁶.

It is evident that the person with a stoma, according to the Worker's Health Policy - the question of professional rehabilitation being included in this perspective - has the right to return to her work activities, in a condition appropriate to her physical capacity and limitations. This person is also supported legally by the National Policy for the Integration of Persons with Disabilities, being able to take advantage of the employment quotas.

It should be stressed that there are still many flaws in the process of professional rehabilitation, as there is no appropriate monitoring of workers in their work environment, without mentioning that many companies do not have the appropriate conditions to receive these workers, whether in the ambit of the physical structure or in the issues to do with receptiveness¹. It follows that many changes must occur in professional rehabilitation, it being essential for appropriate public policies to be created, which should be inspected by the authorized bodies.

In addition to this, it is important to highlight that it is fundamental for the nurse to participate in this process of social inclusion of the person with a stoma, whether it is in the environments of the health services or their homes and/or work environments. This is no easy task, due to the problem being multifaceted, to the existence of stigma and prejudices in relation to these people, and also due to the fact that content on this issue is low in undergraduate nursing courses¹. However, it is important to seek professional competences and skills that take account of the complexity of the problem, and an important way of caring with excellence and meeting the social needs of people with stomas is to develop and carry out professional nursing activities based on a methodology of work, which gives a scientific character to the conducts and attitudes, indicating weak points and areas with potential in the rehabilitation process. To this end, it is recommended that action should be based in the precepts of Systematization of Nursing Care, which

makes it possible to develop and carry out activities in an organized, safe, critical and reflexive way, also taking into account the various intervening factors which can change the success of the rehabilitative process^{9,10}.

METHODOLOGY

The study was of the descriptive-exploratory type, with a qualitative approach. The research setting was a Municipal Physical Rehabilitation Institute located in the city of Rio de Janeiro, which has a Program for Care of People with Stomas, which functions in the rehabilitation of people with stomas and in dispensing collective equipment and adjuvant items.

The subjects were twenty people with permanent stomas in place for over a year, aged between 35 and 62 years old, who were part of the program mentioned above. In order to be part of the research, the patients: I) had to have been workers at some point in their lives; II) could not have presented complications which stopped them from carrying out work activities; and III) had to participate in the study through their own free will, due to its voluntary character, coupled with ethical principles.

Data collection took place between January and March 2010, during the mornings, through semi-structured interviews, recorded using an MP4. The project was sent to the Research Ethics Committee of the Municipal Health Department of the City of Rio de Janeiro, from which a favourable decision was obtained under protocol n.º 274^a/2009. In accordance with Resolution 196/96 of the Ministry of Health, the client was approached with explanations about the study, anonymity was guaranteed, and the optional character of participation was upheld. After these clarifications and a positive response to participate in the study, the Terms of Free and Informed Consent were signed in two copies by the researcher and subjects.

The decision was made to use Thematic Content Analysis for treating the data, with the following category emerging: The nurse and her participation in the rehabilitation of the client with a stoma.

RESULTS AND DISCUSSION

The characterization of the study's subjects highlighted that 55% were female and 45% male; 70% were aged below 60 years old; the predominant level of schooling was unfinished basic education (50%); 70% were married; 55% had a family income of up to two minimum salaries; 95% lived in their homes with more than one other person; and 85% of the people who lived with the people with stomas carried out some sort of work thus contributing to the financial support of the family, as well as providing social support and support to the people with stomas.

In relation to the work situation prior to the stoma, there was a predominance of professionals from the service sector (10%), in professions which require few qualifications, which is consistent with the level of schooling presented in the study. This research's data indicated that 75% of the people with stomas still worked, even receiving governmental assistance; of the three individuals who worked and did not receive any assistance at all, only one worked in the formal job market, having the benefits of worker's rights. It should be noted that those with stomas are aware that, on receiving sickness benefits or retirement on grounds of invalidity, they cannot return to work without losing the benefits, but they do so for the additional income and for the well-being that working causes.

The time the subjects had spent with stomas in place varied between one and twenty-four years. The main reason for the stomas (55%) was colorectal cancer, followed by inflammatory intestinal diseases (40%) and accidents with fire-arms (5%). In relation to the local complications with the stoma, 35% of the clients asserted that they had had them at some point, principally dermatitis, but did not have them at the time of the research, which further viabilized their return to work.

After the presentation of the characterization of the subjects, the decision was taken to present the analysis referred to the category which emerged based on the application of the method of thematic content analysis.

The nurse and her participation in the rehabilitation of the client with a stoma

The discussion of the present category originated based in two themes which emerged from the accounts of the people with stomas: a) the nursing professional as an advisor and carer for the client with a stoma; and b) the nursing professional's shortcomings in the process of providing guidance in relation to work.

Positive guidance from the health professionals on the return to work of the client with a stoma was found in five interviews, representing 14 Unit Records (URs), examples being shown below:

The doctor said: you can get a job (S1).

Some nurses, yes, some, said that I could go back to work (S4).

Yes, yes. I had one nurse who I'm still friends with who talked with me, about work, about how to go about it, I should take care of myself (S13).

It can be seen that some health professionals, including nurses and doctors, advised the clients in relation to returning to work. However, it is important to analyze that only five of the twenty subjects mentioned having had this type of guidance. As stated, work is held as essential in the life of human beings and is a constant concern in the process of rehabilitation of those with stomas. The lack of this type of advice shows an immense gap to exist in Brazilian centers of excellence in stoma care. The scarcity of advice for clients with stomas in relation to work, which is considered one of the pillars of rehabilitation, is considered an error which must be corrected in the current support programs existing for clients with stomas⁶.

It is essential to highlight the importance of the nurse's participation in the rehabilitation, as the nurse acts providing direct and qualified assistance to the clients, having an important role in the multiprofessional team of rehabilitators, preparing the individuals for undertaking the tasks of daily life, including work. The nurse, as an essential professional in the process of guiding people with stomas, should include systematized actions which are related to returning to the world of work in the Nursing Process, introducing this approach gradually in meetings with the clients. It should be noted that good social inclusion, encompassing the world of work, depends on the ability of people with stoma to carry out self-care; therefore, this must be one of the first steps in the nurse's approach with the client with a stoma^{8,17}.

Moreover, this approach and the care given must be based in a scientific method, with Systematized Nursing Care (SNC) being highlighted as an example: it makes possible a holistic understanding of the human being and contributes to the nurse developing good decision-making, foreseeing and acting in the face of possible complications, and also makes continuous training possible, as it helps the nurse to re-assess the entire process of caring/being cared for⁹.

In advising in relation to the process of inclusion in work, the nurse must assess, with the multiprofessional team, the individuals' ability to return to work, guiding them in relation to the work activities which they will be able to undertake without damaging their health. Thus, these individuals should avoid occupations I) which require of them excessive force, II) which expose them to constant heat and to chemical products in the region of the stoma, III) which require them to wear tight uniforms, IV) which do not permit flexibility in schedules such that they can attend consultations with the multiprofessional team, V) which do not permit them to go to the toilet when necessary and VI) which do not provide appropriate conditions for attending to hygiene¹.

Six subjects mentioned guidance from the nursing professionals regarding their condition of having a stoma (twenty URs):

The nurses advised me about the pain, how to change the pouch, what to eat and drink (S 6).

The nurse told me: you've got to take care with everything, with what you eat, avoid gaining weight, about activities in general (S 7).

These reports indicate that the nurses, even when not advising the clients with stomas in relation to the world of work, guide them in other aspects of extreme importance, such as hygiene measures and skin care, care with food, activities of daily living, and avoidance of activities requiring excessive strength. This guidance is considered of extreme importance, as it alludes to self-care, which is essential to the process of rehabilitation.

The health professional seen as essential in the rehabilitation process of the person with a stoma was mentioned by three subjects (six URs):

The nurse who cares for us? I think she can help, the nurse from the consultation can help (S 1).

Look here, the people here in the sector were marvellous, in professional terms the people here, from nursing, were indispensable, let's put it like this, the nurse who I had here, was the best possible (S 11).

These accounts evidence how important the presence of the nurse is to the people with stomas, as the nurse represents support and safety to the clients. Nevertheless, it stands out that only three accounts in a study with twenty subjects indicates a low number of perceptions of the nurses' action, although qualitative research does not concern itself with numerical expression. This situation can be a strong point for reflection, or even for further research, regarding the role of the nurse in the rehabilitation process for people with stomas.

The lack of professional guidance in relation to work was mentioned by 15 of the study's subjects (twenty URs), as stated in a number of interviews:

No nurse ever gave me advice in relation to returning to work (S 1).

They told me, you can't work any more, because you might push your guts out and then you'll have to rush back to hospital, to put them back in (S 7).

No, he doesn't give advice! On the contrary, there was one nurse who told me I would be like a little bird, that I'd be crapping myself all the time! (S3).

The accounts indicated previously (interviews from S3 to S7) provide evidence of extreme misconceptions in how the nurses advise the clients with stomas regarding their health problem and returning to work. From this, it is clear that there are many shortcomings in the process of rehabilitating people with stomas, not only in the Center of Excellence where the study was undertaken, as these clients passed, and continue to pass, through the hands of other health teams. It is relevant to stress that all the persons with stomas were in conditions to carry out work activities, so long as these are carefully analyzed and selected, that is, that they are appropriate to their physical limitations^{1,18}.

One can deduce that the main causes of the qualitative and quantitative scarcity of guidance in an area crucial for the rehabilitative process are: I) the lack of Systematized Nursing Care (SNC), in both the clients' periodical consultations and in the perioperative period⁹; and II) nursing professionals' ignorance of labor legislation, including the citizens' rights to exercise the process of professional training and rehabilitation, and the condition of the person with a stoma as physically disabled, and therefore included in the system of quotas in public jobs and in private companies^{17,18}.

Systematized Nursing Care helps nurses in the process of rehabilitation, as through identifying the needs and main difficulties presented by people with stomas in the nursing consultation, the nursing diagnoses and prescriptions are elaborated, with the definition of goals and objectives proposed for the minimization of the problems⁹. In this way, the nurse monitors her client's progression and prognosis, continuously re-assessing the possible appearance of new difficulties. Hence, all the aspects which are reported by the individuals and observed by the person doing the examining during the nursing history are addressed during the consultation, which facilitates the creation of links between the client with the stoma and the health professional, and contributes to success in addressing matters which are essential for the rehabilitation, such as social and work life. These issues are little addressed in many nursing consultations, which focus their advice predominantly on caring for the skin and the use of the collecting pouches for feces and/or urine¹.

It is believed that the nurses must be trained and taught to use Systematized Nursing Care in the care for persons with stomas, as in this way they will be able to assess them holistically and seek complementary actions with other health professionals, such that the rehabilitation process may be successful.

CONCLUSIONS

The results showed that the majority of the subjects had characteristics encouraging them back to work, whether through economic necessity due to low family income, and the need for an increase in income for buying the collecting pouches and other items used in stomas care, or through the feelings of usefulness and life created through the social inclusion caused by work. To be aged below 60 years old, which includes these individuals in the "productive age", the presence of relatives who support them at home, and the absence of physical complications, which would hinder them from working, all stand out as factors which facilitate inclusion in work.

When developed in a holistic and systematized way, through the application of the Nursing Process, the process of rehabilitation for people with stomas is an encouraging tool for returning to activities of daily living, including work, as it is at this time that guidance in relation to self-care with the stoma and peristomal skin is initiated, showing the client that she can live without great tensions because of her stoma. It stands out that it is only after the person with a stoma has adapted to her new condition that she acquires the confidence and security to return to social activities and work.

The nurse, as a member of the multiprofessional team, has an important role in the process of giving advice to the person with a stoma, as she has competence and assistential tools, such as Systematized Nursing Care, for detecting all the difficulties in adaptation that these clients may face in their condition of having stomas, as well as outlining together actions aimed at minimizing and overcoming such difficulties.

Some people with stomas mentioned the nurse's importance as an advisor in relation to self-care practices, which is without doubt essential for the process of the social inclusion for the person with a stoma. However, the nursing consultations must not focus only on the physical difficulties presented by the individuals. The nurse carrying out the nursing consultation must be attent to the individual as an indissociable whole, in which, for example, the psychological, social and spiritual/religious dimensions are included, rather than the physical dimension alone. When the Nursing consultation is carried out systematically, favoring all these dimensions, attendance to all the human being's integral needs genuinely occurs.

Nevertheless, for this to take place, the health professionals must be made aware of the problems of people with stomas; from the moment that this awareness is achieved, continuous training and qualification become necessary to assist this clientele, which requires professional competence. It is also noteworthy that the lack of guidance in relation to the world of work can also occur due to the nurse's ignorance of labor laws involving clients with stomas.

The results showed that of the 20 people with stomas interviewed, only 5 had been advised by the nurses in relation to the importance of returning to work. This data evidences an immense gap in the rehabilitation process for people with stomas, as it represents the health professionals' ignorance of the importance of work in these clients' lives. Thus, some questions remain: How is the process of reception of these persons with stomas? Is guidance given systematically and continuously? Is the guidance documented? Is there a way of ascertaining if the clients understood the information they were given? Although they were not the present research's object of study, these reflections may encourage the scientific curiosity of other health professionals interested in the issue.

Further, it may be deduced that it is extremely necessary to set up training courses for the nurses who work directly with people with stomas, as one of the causes of the scarcity of guidance was the nurses' ignorance of the issue. It is therefore essential for health centers who attend this clientele to offer specialization courses and continuous education to the health professionals involved in the attendance, such that there may be continuous improvement in the quality of the care given.

In addition to this, it is emphasized that knowledge involving Worker's Health applied to the field of Stomatherapy Nursing can lead to quality of life and to a better understanding of people with stomas in the context of which they are part, helping in maintaining and/or recovering their health and their self-realization related to work.

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