

WORKING LIFE AND STOMIZED PEOPLE: PERCEPTIONS AND FEELINGS¹

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ABSTRACT

The aim of this study was to analyze the perception of people with stoma elimination of their inclusion in the working world. Qualitative, descriptive, exploratory search, held in Rio de Janeiro hospital. Participants were seven ostomy that were attending a support group of the institution. The collection took place in August and September 2013 through semi-structured interviews. We used content analysis technique for processing the data. It was found that the participants had dialectical feelings about the stoma, configured as an element that saves lives, but results in psychological distress by causing a strong break in lifestyle. Also contacted mixed feelings about work, because while it gives the feeling of usefulness and social inclusion, also results in feelings of fear of social rejection. It is concluded that the difficulties of labor insertion roam the biopsychosocial dimensions of this population, lacking a comprehensive and multidisciplinary care.

Keywords: Surgical stomas. Rehabilitation. Return to work. Occupational health.

INTRODUCTION

The presence of a stoma determines physical, psychological and social changes in the lives of individuals. These changes that occur in people with Stoma focus on disposal loss of toilet control, resulting in the constant disposal of feces and bolting the dependence on use of equipment collectors. The individual tends to isolate themselves, away from the socializing with family, friends and labour activities, for fear of rejection in relation to his new condition⁽¹⁻²⁾.

When the customer hears about the Ostomy reactions appear to transcend the barriers of race, color, age, culture, religion and sex, forcing him to start deep changes in your life. Organic disorders caused by basic pathology, the diagnosis, the surgical procedure, the presence

of the stoma, the use of wastewater collector and the stigma generated by both the disease that predisposes the stoma, and the presence of the same, are changes that require considerable management in personal and social life⁽³⁾.

In epidemiological issues and profile of ostomized in our country, there is an elevation in your related quantitative increase of diseases predisposing to generating a stoma surgery such as colorectal cancer and inflammatory bowel diseases, without counting the high incidence of stomata due to trauma, represented by auto accidents and with firearms and/or white increasingly frequent in our society⁽³⁻⁴⁾.

Highlights that these pathologies and the stomata caused by trauma reach younger individuals, included in the considered productive age, and probably have the desire to give continuation to their life and social inclusion plans⁽⁴⁾.

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The assistance provided to the people ostomized it gives the participation of the multidisciplinary team in monitoring the process of physical rehabilitation, psychological and social. The nurse attends directly to customers, having the commitment of quality guidance and inclusion of individuals in various activities of daily life, according to their functional capacity⁽⁵⁾. Nursing guidelines, in particular, assist the process of adaptation of the individual ostomy and contribute to the pursuit of independence and accomplishment of self-care⁽⁶⁾.

One of the goals of the process of rehabilitation of people with Stoma is social inclusion, including the return to labor activities, because the work has a role of centrality in contemporary society and helps to rescue the self-esteem and the feeling of usefulness of the subject⁽⁶⁾.

However, the return or the search for new productive activities can become a challenge both for the ostomy person, as for the health team, due to social barriers preventing to social inclusion, permeated by prejudice and by the emotional insecurity of ostomy's. In addition, the society for ignorance, just judging these individuals unfit for work, denying them opportunities⁽⁶⁻⁷⁾.

It should be noted that as of 2004, the person with Stoma has become considered disabled, and can make use of the following laws: the national integration Policy) Person with disabilities, ensuring social inclusion and rights to work of these individuals; and b) of Law 8.213/91 that defines, through Social Security, enabling services and vocational rehabilitation, but also is intended for employment quotas in private companies for people with disabilities⁽⁸⁾.

In addition, the Ordinance 400/09, represents major advances for people ostomized because it establishes national guidelines for health care of people with Stoma within the unified health system (SUS), ensuring full service specialized to this clientele, as well as providing free equipment and adequate collectors and adjuvants⁽⁹⁾.

In this sense, reinforces that the ostomy to return to participate in labour activities need to win some barriers, such as lack of appropriate toilets and the scarcity of jobs tailored to their condition. Besides the impediments inherent to

their ostomy condition, centered on loss of toilet control^(1,10).

Integral assistance to individual's ostomy's is extremely important, because it helps social inclusion, preparing them for entering or returning to the world of work. Thus, the present study drew the following objective: to analyze the perception of people with Stoma of elimination on their inclusion in the work world.

METHODOLOGY

Qualitative, descriptive and exploratory research, held in a general surgery outpatient clinic of a university hospital in Rio de Janeiro, which has a multidisciplinary ostomy support group named "the flower of skin and with great affection". This group has as members three nurses stomatherapists of general surgery at this hospital, a social worker, medical lap-and professional team of proctologists nutrition. Meetings occur every two months during 3 hours, at amphitheatres or classroom practices.

In this group are developed subjects such as: emotional aspects that involve the Ostomy; the impact of the disease; coping strategies; the understanding of body image; specific care with the stoma; equipment collectors and adjuvants, and the legal rights of this population.

The criteria for inclusion of ostomy's in the survey were: I) between the ages of 18 and 64 years, because it is considered that the population in this age group is able to exert a labour activity; II) be of both sexes; III) are with the stoma for at least a year, because it was believed that this period of time the person would be more familiar with the stoma and can express more appropriately the perception about the same; IV) have the stoma in finality; V) have been worker at some point in your life, regardless of exercise any labour activity at the time of collection; and VI) don't have complications that would prevent them from performing activities labor.

Study participants were seven ostomy's clients who frequented the group in the period of data collection, which happened in the months of August and September 2013 after project approval by the Ethics Committee under the Protocol 262.671, in consonance with the 466/2012, Resolution of the National Council of Health/Ministry of health⁽¹¹⁾.

Telephone contacts were made with the participants of the Group and elucidated the objectives of this study, requesting so, participation in research, marking a time and day to conduct the interview. This number of participants gave for the fact that in the period of data collection occurred the refusal of some components in participating in the research, the aggravation of health conditions of some members of the group, as well as the impossibility of attendance to the support group for the fact that reside in other municipalities outside of Rio de Janeiro.

The data collection instrument was a screenplay for semi-structured interview, containing two parts: the first part was the data on the characterization of the subject in terms of socioeconomic and health profile. The second part linked to the object of study, namely, questions about the world of work.

Each participant received and signed an informed consent form while preserving the identity of respondents through the use of a code of letters and numbers. The collected data were analyzed by means of Thematic Content Analysis⁽¹²⁾.

RESULTS AND DISCUSSION

The analysis of sociodemographic and health information showed that this set, four were female and three males. The prevalent age group was 38 to 47 years. Ostomy time ranged from 1 to 7 years. As for education, had incomplete elementary 01; 01 claimed to have complete primary school; 02 had incomplete secondary education; and 03 had full secondary education. In relation to the family income of the participants reported having income 06 1 to 2 MW and 3 receive the stated 01 4 minimum wages.

As the current labour situation, there has been a great representative of people who didn't work: 04 were receiving sickness, disability, retired 01 01 was labor activity in the informal market, without contracts and rights 01 didn't get any kind of aid and was not working.

Regarding the perception of people with Stoma of elimination on their inclusion in the work world, emerged two categories that guided the discussion of the results of this research: the meaning of work for people with Stoma of

elimination and the dialectic of work issue to be ostomy.

The category "**meaning of work for people with stoma elimination**" presented the perception and the sense of the participants about the work, its benefits and also the difficulties to fall in industrial environments.

It was noted that the work is critical for them to meet their subsistence needs and buy the drugs and supplies needed, especially when there are changes to the health-disease process. Often, only the benefit received by the National Social Security Institute (INSS) is not sufficient to provide all demands, causing them to take on other productive activities. This can be evidenced by the following lines:

I have the sickness, but every once in a while I do food out, do to my church. Also I've done cleaning out (E5).

The work is good because people are always money. Because people need to buy things, especially medicines, which sometimes lack (E4).

The presence of a disability does not mean inability to work, and with experts of the SOCIAL SECURITY and health services of the worker adequate evaluation of these people, and routing of same to the vocational rehabilitation programs, so that they can return to the previous occupation, or new jobs, while they don't harm the health of the person with disabilities⁽¹⁰⁾.

Therefore, in our society there are numerous demands materials that are necessary for maintenance of life and of its quality. There is a need for clothing, education, transport, food, leisure, health, and when you're sick you need to buy medicines and other supplies to minimize or treat the health-disease process changes.

In addition to the financial issues, the subjects reported the importance of the work to forget their health problems, as if they were at home, might remain in his thoughts on disease and, especially, in the stoma and everything that brings. That is, isolation, feelings of worthlessness, an inability to control the eliminations, among other thoughts that can lead to depression among other mental illness⁽¹³⁻¹⁴⁾. So, when asked about the willingness to return to work, all subjects expressed this wish:

I can't wait to return to my activity. I have a great desire to return to work because I'm going to be

busy doing anything which occupies the time and also makes me feel useful (E2).

The essentiality of work in the life of subject is focused on the importance of it as relevant social integration and recovery factor; as a form of distraction and forgetfulness of its pathology, as well as the feeling of life and usefulness, as can be verified in the following statements:

Because I was busy time, I leave for work, I took a bus, lived with other people (E6).

Without work we're nothing, is not recognized, is not valued. (E4)

Most stay committed two months in the hospital as I was, for I have to work. When I work I forget that I am with Stoma retracted, I forget that my debt is very liquid. The importance of the work for me is to unlink the disease, because I am a normal person. The work gives me this: a normal person. (E7)

Work for me is everything, before I ever liked. Now I like more because the bus passes to give more value to life, after illness. (E5)

Reinforces that the work in the lives of individuals with disabilities is of great importance. He promotes feelings of happiness and well-being, both in social and psychological aspect, because it ensures the participation in the production process results in social valuation, and contributes to reducing social stigma. Besides the insertion in the world of work encourages people to seek increasingly ostomized independence and economic and social autonomy⁽¹³⁾.

The work also goes back the negative feelings in the life of ostomized people, and these feelings were evidenced in the interviews of the participants of the study. It was found that such feelings are linked mainly to the prejudice that may occur in the workplace, due to social ignorance of what it means to be a ostomized person and their potential. In addition, the inclusion in work means an exhibition of this clientele and his "disability". The loss of toilet control and the discomfort caused by the Elimination of gases, the need for emptying the collector equipment can cause embarrassment to ostomy's working environments, which leads to the removal of the world of work.

There's only difficulty because drains enough. I worked sitting, driving, and there is no way out all

the time to empty the bag [...] no company would take me under those conditions. (E3)

The people speak: "fits". Fits between quotation marks, a person who lost an arm, I'm not saying it's easier than my situation. Only the person who loses an arm or a leg, she doesn't have special needs as I. The mine, in addition to becoming a cripple, I have special needs even as I'm talking to you here, and the waters break and I have to go out and have that change in time. (E1)

It is obvious the feeling of prejudice experienced by the patient ostomy, expressed by the participants, as well as the isolation of same, identified in a few lines:

I get really indoors, leave when it is to go to the doctor, other than that I stay in the House. (E6)

The owner of the company itself when you called me back, right after the second surgery, wanted me to come back to work with her, then she asked how I would work for ignorance of what was the stoma. It makes me a little upset. (E7)

The fear of going back to work and to be discriminated against is great among the ostomy's. Will analyze the work is a form of social inclusion, of belonging to a group, building and strengthening the identity, well-being. However, depending on the conditions of work, the characteristics of the professional collective and did not support Labour Organization for inclusion of "different" social standards established culturally, so the work is illness and worsening factor of the biopsychosocial state⁽¹⁴⁾.

The category "**The dialectic of work issue to be ostomy**" talked about the physical, social and mental repercussions involved in problematic to be ostomy, and your joints with insertion or reinsertion into the world of work. Include also the positive aspects of the stoma, which configure in the improvement of the quality of life and the preservation of life. However, negative aspects, that make the sociality and insertion in the world of work.

The presence of the stoma means something contradictory to the participants of this study, as shown in the following statements:

For me that I have the disease that couldn't do anything, you better be wearing a bag than live sick and unable to do anything. Means life! This is lifetime warranty! To improve the quality of my life (E7)

There's no facility to have the Ostomy, you have to try to adapt because the concerns and fears are many. (E4)

There is a dialectical aspect that permeates the problem of people ostomized. Yes, it is known that the stoma may be a positive factor in the lives of these people, to ensure and prolong its survival. In this perspective, the stoma is cure for pathology, providing subsidies for individuals rebuild their lives and continue their existence with more quality⁽¹³⁾.

At the same time, the stoma dates back to negative feelings related to loss of control, dependence on toilet sink equipment, change in body image, and fear of public exposure of their disability. It turns out that fear permeates the lives of these people, because there is the fear of the effluent leak out and wet the clothes; There is also the fear of the uncontrollable and unpleasant odor flatus, situations that society, culturally, built as unacceptable and shameful.

Therefore, it is configured the dialectic of feelings in relation to the stoma: he saves his life, but also results in a paradigmatic break and suffered of style and habit of life^(1,3,15).

These situations are linked to biological changes cause several constraints in ostomy's and may lead to psychological and social changes, reinforcing social segregation and feelings of worthlessness. Include the following statements:

If I had driving, let's put it like this: because I work more or less executively, for entrepreneurs. Imagine..., I'm driving to an Executive and my purse overflows. (E3)

The ostomy feels constrained in various ways, he has no control, he has no control of anything. The only embarrassment I feel, with the removal of gasses that I let go, it's too much! Even with the bag that bursts make me ill. If I'm at a party, I have to keep repairing on bag is full of gas. There I mean, let's put it this way: I go to a party, the bag is full of gas, I'm going to have to go to the bathroom, the bathroom is public, have three or four people there, then climbs that odor during the Exchange. And at work? It would be even worse! (E6)

The loss of toilet control and fear to be discriminated against in employment living spaces are considered obstacles to the return to

work, due to dependency on the use of a collection bag, which can at any time to fill and take off, generating the extravasation of feces; not to mention the noise originated by the output of gases and the unpleasant odor exhaled. The following statements demonstrate this result:

I had to reject, I don't care of it, then how to work? (E5)

People think we are anti-hygienic, that offends. Most people in ignorance, think we're dirty (E7).

In the case as I work on the street, I'm going to have to use a public restroom, no condition, is totally out of the default [...] Bathroom for disabled is only for wheelchair. (E1)

For people with special needs re-entered the world of work, it is necessary that the working environment is tailored to its limitations, in this regard, emphasizes the urgency of themselves proper bathrooms, which should exist in firms and also in public places, which would avoid constraints for these people. In addition, it is necessary to articulate the Government's campaign media, in order to sensitize and guide the population to welcome people with such needs, trying to deconstruct stigmas and prejudices about this condition^(1, 3, 6).

However, the existence of bowel control methods that contribute in the rehabilitation process of this clientele, making a pseudo continence of up to 48 hours, bringing greater confidence, independence and social inclusion at work. The irrigation system and Cap Occluder must be prescribed by a doctor, and a nurse-driven stoma.

In this regard, stresses the importance of nurses in presentation and orientation of the strategies and information that may be suitable for people ostomized, with the aim of minimizing the impact of the situation and enhance their social inclusion⁽¹⁶⁾.

The return of the person ostomy the working world is also hampered by the inability of these people develop the same work activities prior to the stoma. The lack of training and educational opportunities, as well as disability presented by vocational rehabilitation programs, and the lack of orientation of health professionals with regard to labour inclusion, end up moving away from

these individual's work, as can be evidenced in the following lines:

For me to get back to work you have to be a job that there is virtually no physical effort, that will allow me to go to the bathroom several times a day and have people accept this condition, because gases come out without us wanting. (E2)

Back to my previous work has no conditions because I couldn't stand the physical effort. Maybe if it were in a different job, lighter, adapted to my situation, I could be back. But, it would be a good thing to return, making one more thing I would like to occupy my mind. (E3)

Ease today to be going back to work with what I worked before the stoma, which was home to family, today wouldn't have any facility. (E5)

You can see the lines of respondents that they are aware of their limitations in relation to physical exertion and that need to avoid weight overload. This limitation entails difficulties in returning to work, due to the low level of education and professional qualification. So, considering such problems, it is important beyond the creation of new job opportunities, the development of training programs and training that are tailored to the limitations of people with disabilities⁽¹⁰⁾.

It should be noted that the supply of employment quotas for people with disabilities do not guarantee the inclusion of these individuals at work; What must exist are effective social inclusion policies, to ensure efficient and effective training programs. In the case of ostomized, it is suggested the elaboration of a programme of Social inclusion at work specific to this clientele.

FINAL CONSIDERATIONS

The characterization of the participants of the study points to the favoring of the return to work, with age less than 60 years, most without complications and the need to supplement the family income, due to low values of government aid, and the extra costs that might occur with equipment collectors and adjuvants.

The work represents in the lives of people with Stoma positive and negative senses,

because while gives you feelings of usefulness, productivity and social insertion, causes them fear, due to prejudice that may arise from co-workers and employers, who are unaware of what a stoma and their possible limitations.

The difficulties of labour inclusion travel the physical sphere, with the loss of control over the Elimination of feces and gases, passing through psychological, focused on the isolation of the individual due to fear of prejudice and non-acceptance, and socially, because the subject affects deviate from social conviviality and of work, feeling useless and unable to return to normal activities of daily life.

It is believed in the need for disclosure of the condition of the ostomy, for which the company decrease the prejudice I dismiss these subject, collaborating like this, to greater social inclusion. The Government agencies, in conjunction with the Ostomy's associations and Brazilian Society of Stoma therapy, should intensify the campaigns of clarification for the population, creating inclusive programs for inclusion in the work, focusing on providing training and professional qualification.

Nurses, as essential members of the team of the rehabilitators has key role in caring for people with Stoma, and should address not only relevant aspects to his physical recovery, but also to psychosocial, highlighting your return to work. When the guidelines take place focusing all these dimensions, in fact, meet the comprehensive needs of the human being.

This study was intended to contribute to the ostomy customer service on your procedure for inclusion in the work world, influencing positively about the rehabilitation process. It is hoped a change of position between employers, the State and the media, that is, they can perceive these people as able to work by offering them opportunities, seeking ways of labour replacement, as long as you respect their physical limitations.

This study has as limiting the fact of having reduced quantitative participants. It is suggested the development of further research, aiming to deepen this topic, focusing on nursing care labor inclusion of people-oriented ostomized.

RESUMO

O objetivo deste estudo foi analisar a percepção das pessoas com estoma de eliminação sobre sua inclusão no mundo do trabalho. Pesquisa qualitativa, descritiva, exploratória, realizada num hospital fluminense. Participaram do estudo sete estomizados, que frequentavam um grupo de apoio da instituição. A coleta ocorreu em agosto e setembro de 2013 por meio da entrevista semiestruturada. Utilizou-se a técnica de análise de conteúdo para tratamento dos dados. Verificou-se que os participantes tinham sentimentos dialéticos em relação ao estoma, configurando-se como um elemento que salva vida, mas resulta em sofrimento psíquico por ocasionar uma forte ruptura no estilo de vida. Também se contatou sentimentos contraditórios em relação ao trabalho, pois ao mesmo tempo em que ele origina sentimento de utilidade e de inclusão social, também resulta em sentimento de medo da rejeição social. Conclui-se que as dificuldades de inclusão laboral percorrem as dimensões biopsicossociais desta população, carecendo de uma assistência integral e multiprofissional.

Palavras-chave: Estomas cirúrgicos. Reabilitação. Retorno ao trabalho. Saúde do trabalhador.

EL MUNDO LABORAL Y LAS PERSONAS OSTOMIZADAS: PERCEPCIONES Y SENTIMIENTOS**RESUMEN**

El objetivo de este estudio fue analizar la percepción de las personas con estoma de eliminación sobre su inclusión en el mundo laboral. Investigación cualitativa, descriptiva, exploratoria, realizada en un hospital de Rio de Janeiro. Participaron del estudio siete ostomizados, que frecuentaban un grupo de apoyo de la institución. La recolección de los datos ocurrió en agosto y septiembre de 2013 por medio de entrevista semiestructurada. Se utilizó la técnica de análisis de contenido para el tratamiento de los datos. Se verificó que los participantes tenían sentimientos dialécticos en relación al estoma, configurándose como un elemento que salva vida, pero que resulta en sufrimiento psíquico por ocasionar una fuerte ruptura en el estilo de vida. También se ha constatado sentimientos contradictorios con relación al trabajo, pues al mismo tiempo en que él origina sentimiento de utilidad y de inclusión social, también resulta en sentimiento de miedo del rechazo social. Se concluye que las dificultades de inclusión laboral recorren las dimensiones biopsicosociales de esta población, siendo necesaria una atención integral y multiprofesional.

Palabras clave: Estomas quirúrgicos. Rehabilitación. Reinserción al trabajo. Salud laboral.

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