

## COPING STRATEGIES OF OSTOMIZED INDIVIDUALS

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*This study aimed at understanding the experience of individuals with intestinal diversions as regards coping with their new life conditions. The qualitative approach was used, involving 11 ostomized subjects. The data were collected by means of semi-structured interviews which were taped and later fully transcribed and analyzed according to Content Analysis as proposed by Bardin and the Coping theoretical framework. The findings in the study were evidenced by three core categories denominated: i did not choose it; i had to accept it and i have to live with the ostomy. The form to manage the condition of being ostomized was revealed by coping strategies which were based on both emotions and the problem itself. The study contributed for reflection and application of knowledge in assistance practice and teaching for care the ostomized.*

**DESCRIPTORS:** ostomy; adaptation, psychological; nursing

## ESTRATEGIAS DE ENFRENTAMIENTO (COPING) EN PERSONAS OSTOMIZADAS

*El objetivo del estudio fue comprender la experiencia que personas con derivaciones intestinales presenta al enfrentar esta nueva condición de vida. Se utilizó un enfoque de naturaleza cualitativa, con 11 sujetos estomizados. Los datos fueron recolectados a través de entrevistas semiestructuradas, grabadas y posteriormente transcritas en su totalidad, siendo analizadas según el Análisis de Contenido de Bardin y el fundamento teórico de Coping. Los hallazgos del estudio fueron en tres categorías centrales, denominadas: no lo elegí; tuve que aceptarlo y con(vivo) con la estomía. La estrategia para controlar la condición, ser estomizado, se realizó a través de estrategias para enfrentar tanto aspectos emocionales como el problema en sí. El estudio contribuyó para reflexionar y utilizar el conocimiento en la práctica asistencial y para la educación en cuanto al cuidado del entomizado.*

**DESCRIPTORES:** ostomía; adaptación psicológica; enfermería

## ESTRATÉGIAS DE ENFRENTAMENTO (COPING) DE PESSOAS OSTOMIZADAS

*Este trabalho objetivou compreender a experiência de pessoas com derivações intestinais, quanto ao enfrentamento à nova condição de vida. Realizou-se estudo qualitativo, sendo entrevistados 11 sujeitos ostomizados. Os dados foram coletados por meio de entrevistas semi-estruturadas, gravadas e posteriormente transcritas na íntegra e foram analisadas segundo a proposta de análise de conteúdo de Bardin e do referencial teórico de Coping. Os achados do estudo evidenciaram-se por três categorias centrais: eu não escolhi; tive que aceitar e con(vivo) com a ostomia. A forma para manejar a condição de estar ostomizado revelou-se por estratégias de enfrentamento tanto baseadas na emoção, como no problema. O estudo contribuiu para a reflexão e a utilização do conhecimento na prática assistencial e de ensino para cuidar do ostomizado.*

**DESCRITORES:** ostomia; adaptação psicológica; enfermagem

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## INTRODUCTION

Giving care to ostomized patients requires understanding them, since the compromising of various dimensions in their new life condition is evidenced by significations and symbolic expressions of a singular experience in the health-disease process, which brings ways to adapt.

The main idea in this study aims at showing coping strategies, which are defined as a process with the purpose to control the requirements of the individual-environment relationship that will be designed by individuals with intestinal stomas in their daily lives.

By performing as a nurse/professor conjointly with a group of undergraduate nursing students in a specialized public service, the Ostomized Patient Care Center (*Núcleo de Assistência ao Ostomizado (NAO)*), which has assisted ostomized patients in the region consisting in the Regional Health Division (DIR XI) since the Center was established in 1994, the importance of diagnosing and understanding our clients' requirements was acknowledged so as to propose an individualized interlocution-based form of care giving<sup>(1)</sup>.

An ostomized person is one who has been submitted to an ostomy surgery, which is the opening of the abdominal wall and of an intestinal or urinary segment with the purpose to divert fecal or urinary transit to the external environment. This surgery is attributed to various causes, among which the most frequent are traumas, congenital diseases, inflammatory diseases, tumors, and bowel and bladder cancer<sup>(2)</sup>.

In this study, intestinal rather than urological diversions will be approached due to the inference that different effluents may result in people's distinct behaviors.

When facing the postoperative stoma, the ostomized patient begins to deal with this new reality, showing various feelings, different and individual behaviors and reactions. The impact of the presence of ostomy determines an alteration in body image and different reactions occur, depending on individual characteristics, social support found by the patient and on the perception of loss experienced<sup>(3)</sup>.

The literature and the experience in giving care to ostomates show that such individuals experience various losses in their lifetime, which may be real or symbolic. They face the loss of self-esteem, and that may lead to a feeling of disrespect in face of

society. The loss perceived by the individual immediately following ostomy is that of the physiological and anatomical function of defecating. In this condition the ostomate is a person who will not sit on a toilet, but will have to discreetly pour his feces and face an artificial anus that can no longer be controlled<sup>(4)</sup>.

After surgery, the ostomate thinks about how to resume his life, that is, how to incorporate his concerns related to the more practical aspects of his life, such as the possibility of performing self-care and maintaining his previous social, interpersonal and leisure activities. Additionally, issues concerning the purchase of devices, frequency of medical appointments and how to deal with the difficulties that may arise over the adaptation period are part of an ostomate's life. Other challenges are also added, such as caring for the stoma, concern about others' opinions and his sexuality as well as concerns about his diet<sup>(3-4)</sup>.

An ostomate's experience gradually changes over time, and depending on the development of his disease and the possibilities of adaptation found, the ostomate develops coping strategies with which he begins to deal with the daily problems or changes occurring as a result of the ostomy. To that end, the person needs a personal period of time to think about and adapt to his new ostomate's condition. Such period of time may take days, weeks or months, and encouragement and reinforcement from other people, relatives or professionals participating in the social support provided to him are essential<sup>(3)</sup>.

The existence of Care Programs for Ostomized Patients maintained by the public service largely contributes to adaptation, since there is an opportunity for the exchange of experiences among ostomates, the provision of pouches and support from a group of professionals who favor learning as regards caring for the stoma and resuming self-esteem<sup>(3)</sup>.

In face of the complexity of the treatment and rehabilitation of ostomates, this study aimed at understanding the experience of individuals with intestinal diversions as regards coping with the new life condition.

## THEORETICAL AND METHODOLOGICAL DESIGN

When beginning the composition of these theoretical presuppositions, the coping concept is presented "the set of processes that an individual

interposes between him and the event perceived as threatening in order to master, tolerate or reduce its impact upon his physical and psychological well-being". According to authors coping is defined as "the set of cognitive and behavioral efforts intended to master, reduce or tolerate internal or external demands which threaten or surpass an individual's resources"; this response is called "coping strategy"<sup>(5-6)</sup>.

With respect to the coping functions classified them into two divisions: problem-solving coping strategies and emotion-focused coping strategies. Problem-solving coping refers to the efforts to manage or change problems or also to improve the relationship between people and the environment. These are strategies that are referred to as adaptive, which are more closely related to reality and to the possibility of removing or minimizing the stressful source. Emotion-focused coping strategies involve the attempt to replace or regulate the emotional impact of stress on the individual. They mainly stem from defensive processes which cause individuals to avoid conscious confrontation with the threatening reality<sup>(6)</sup>.

This was a qualitative study performed at the Ostomized Patient Care Center (*Núcleo de Assistência ao Ostomizado (NAO)*) in connection with the Coloproctology Outpatient Unit of the University Hospital Gastroscopy Department of the Botucatu School of Medicine - UNESP.

Eleven subjects with intestinal diversion who had previously agreed to participate in investigation were evaluated in the study. The sample was composed until data were saturated, according to systems developed in qualitative research.

The project was submitted to and approved of by the Ethics and Research Committee of the Botucatu School of Medicine – UNESP (OF.119/2006-CEP), and the individuals agreed to participate in the study by signing an Informed Consent Form.

The data were collected by semi-structured interviews, tape-recorded and later fully transcribed by the researcher.

Initially, the individual and social contexts of the subjects involved in the study were identified according to the following data: age, sex, education, profession/occupation, reason for ostomy, time of ostomy, temporary or definitive ostomy. Next, the guiding questions below were applied:

- When were you told about the ostomy, and how did you feel about it?

- Tell me about what it was like in you home, about you and the stoma.

- What were the difficulties at the beginning, and what are the difficulties today stemming from the fact that you are an ostomate?

- What social roles do you play today? What is your everyday life like?

- How do face the problem today?

The data were obtained by means of semi-structured interviews, and analyzed according to content analysis, which is defined as "A set of communication analysis techniques aiming at obtaining, by means of systematic and objective procedures for description of message content, indicators (quantitative or not) which will allow the inference of knowledge related to the conditions of production/reproduction of such messages". Content analysis works on words and their meanings, seeking to learn what is behind the analyzed words, "... it is a search for other realities *through* (italicized by the author) of the messages"<sup>(7)</sup>.

The coping theoretical framework as well as studies by ostomy experts were used to analyze and discuss the data<sup>(6)</sup>.

## RESULTS AND DISCUSSION

Among the 11 patients from the Ostomized Patient Center (NAO) who were interviewed, 7 (63.63%) were females, and 4 (36.36%) were males. There were 4 (36.36%) patients in the age range of 50 to 59 years old, and the others were distributed in the following age ranges: 2 (18.18%) were 30 to 39 years old, 2 (18.18%) were 40 to 49, and 3 (27.27%) were 60 to 69.

As regards education, 8 (72.72%) patients had not graduated from elementary school, 1 (9.09%) was illiterate, 1 (9.09%) had not completed high school, and 1 (9.09%) was a high-school graduate. Concerning occupation, 3 (27.27%) patients were housewives, 3 (27.27%) reported to no longer work, 2 (18.18%) were retired, and the others had different occupations.

In 7 (63.63%) of the subjects, the reason for ostomy was bowel cancer, and 4 (36.36%) reported other causes: Crohn's Disease, Ulcerative Rectocolitis + Intestinal Tuberculosis, Intestinal Ulcer and Sacral Ulcer due to occupational accidents. The ostomy time varied from 1 to 3 years and a half in 7 (36.63%)

subjects and from 7 to 10 years in 4 (36.36%). As regards the type of stoma, 7 (63.63%) presented a definitive stoma and 4 (36.36%) had a temporary stoma.

The composition of this analytical unit is represented by three categories which emerged in the study and are presented in Figure 1, described as: *I did not choose it* – consisting of two sub-categories named The date when information about the ostomy was given was remarkable and

Inadequacy in the way to give the information concerning the need for ostomy; *I had to accept it* – consisting of two sub-categories: It is accepted because there is no other option and Acknowledgment of the severity of the problem helps with acceptance, and from category *I have to live with the stoma* there emerged the following sub-categories: Being helped to handle the pouch, and Everyday activities take place whenever possible.

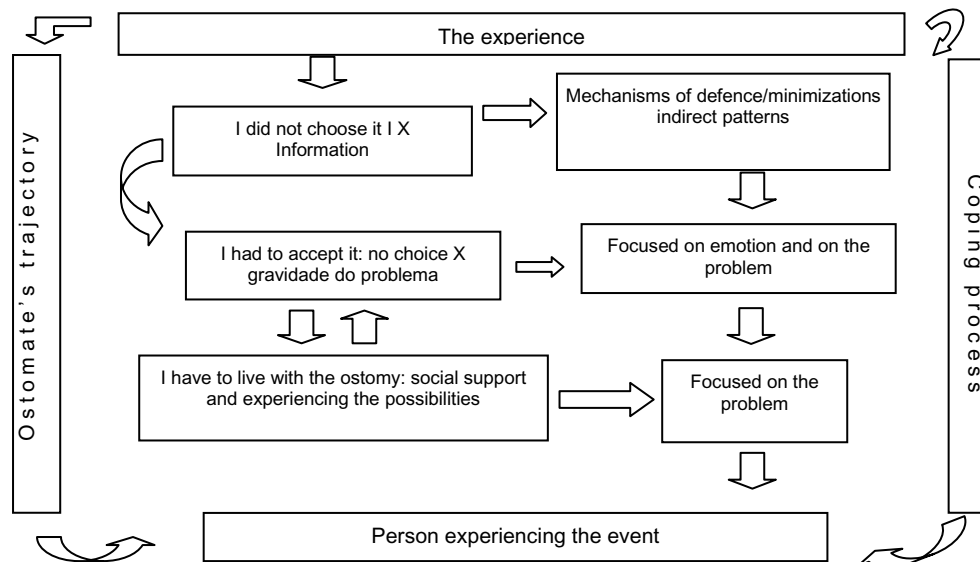


Figure 1 - Movement of meaning apprehended, according to the ostomates' experience

### 1<sup>st</sup> Category – I did not choose it

When talking to the patients, it was observed that they did not have a choice as regards having the ostomy. And even when they were informed about it prior to the surgery, they did not have a moment to stop and think about their own wishes either, since the situation was put to them in the condition that "no more waiting was recommended". Also, a physician-patient interaction that would allow for another choice was not clear.

Sub-category - The date when information about the ostomy was given was remarkable

A very noticeable aspect in the ostomates' statements was the memory evoked which allowed for accuracy concerning the date when they were informed about the performance of the ostomy, thus showing that it was a remarkable moment in their lives... *Ah, it was on May 13, 2005... I was there in the gastroenterology department, and then they told me that I had to be operated...and had the thing put on on May 18. E2*

... *Ah, it was one month before having the surgery, on March 7. He told me that I was going to be operated and that I may have to use the pouch. E3*

From the first moment when the patient hears about ostomy, there are reactions that break all race, color, age, culture, religion and sex barriers, forcing him to begin a deep personal change. When an individual becomes ostomized, he does not only lose a part of his body, but he also changes his esthetic conformity and loses his capacity or competence to control his fecal and/or urinary waste elimination. Therefore, although the stoma is something that is added to the subject, it represents a violation and a loss of continence, body frontiers, a part of one's self, confidence, dignity, independence, forms of life and previous roles<sup>(8-9)</sup>.

Sub-category – Inadequacy in informing about the ostomy

Another noteworthy aspect is how the healthcare professional informs the patient about the need for an ostomy. It is perceived as a simplified

attitude that lacks support and increases the impact and responses from these people: *...When I was to be operated, the doctor told me that it was necessary to operate, and that I might not go back to normal, he told me! Then, I was operated, and he said: look, there's something, the thing is you will have to use the pouch forever, there's no way to go back to normal E4.*

The way to talk about the diagnosis, the rituals used to inform the patient, the professional-patient context in which the diagnosis information is given are aspects that influence the responses to the disease and treatment<sup>(10-11)</sup>

In this category, *I did not choose it*, the defense mechanisms that were compatible with the beginning of the experience were made explicit in convergence with the sub-categories.

Although the discourses revealed, through the recording units, a serious and risky borderline situation which imposed a surgery as an extraordinary measure for the moment, these individuals were still conscious, aware and in control of themselves prior to the surgical procedure. And this did not guarantee them the right to a decision, not even the right to deciding whether or not to be an ostomate. It seemed to us that the principle of alterity was not guaranteed to these people.

The contact with this situation shows the management of stress mainly by indirect patterns, for although there was "consent", a coping method denominated as direct pattern could have been considered by relating it to the use of abilities in order to solve the problem; concretely the process had only been initiated, since the condition of being ostomized was going to begin. Indirect patterns which are compatible with the necessary time to adjust to the unsolvable situation were, therefore, applicable. Such palliative coping strategy aims at gaining time for the individual to be able to access direct coping<sup>(6)</sup>

Hence, in face of this period in one's life and according to the contribution, each individual has a characteristic repertoire of defense mechanisms when facing anxiety-generating conflictive situations. These are to protect the individual *"against situations that he perceives as dangerous"* and threatening. The following are cited as examples of such defense mechanisms: denial, withdrawal, reaction formation, introjection, repression, rationalization, isolation, regression, conversion, projection, etc. Other unconsciously used defense mechanisms are apathy, sleepy withdrawal, selective inattentiveness and

concern. In this coping process, the initial experience was anticipated by the mark of immature and unconscious mechanisms which were compatible with these subjects' resources and possibilities in this experience<sup>(12)</sup>

Proceeding to the second category, the movement printed in this experience is perceived.

2<sup>nd</sup> Category – I had to accept it

During the interviews, it was observed that the subjects did not have another escape in this dilemmatic situation, thus having to, somehow, accept the condition of being ostomized.

Sub-category- It is accepted because there is no other option

A remarkable aspect was the resignation contained in the statements. There was also evidence of the beginning of coping in motion to be focused on the problem. Many individuals accepted the ostomy because they had no other option, emphasizing that even though it was difficult to live with the pouch, they were alive and no longer felt that they were ill, suffering pain or facing the possibility of imminent death. Some statements also showed a look into reality, for the severity of their problem led them to the following feelings.

*... Ah, I'm resigned, you know, it's as they said: You are alive, operated, if you didn't have that, you might not be able to be here today!. E1*

*... I was suffering a lot, it hurt a lot, and now I don't feel anything else, thank God I'm fine, I just have to be resigned, you know... I'm peaceful; I just have to resign, don't I? What can I do? You mustn't get desperate; you must hold your head up and face it! E2*

Gastrointestinal physiological alterations, care for the pouch and difficulties to deal with the new situation led ostomates to picture their limitations and changes that took place in their daily lives<sup>(3)</sup>

Sub-category – Acknowledgment of the severity of the problem helps with acceptance

An important emerging question was the notion of the severity of the problem experienced by the individual, which enabled better acceptance of being ostomized.

*... I was feeling bad, you know, and the doctors said that the problem was this, that the problem was that.. then, one*

day, I went to see a specialist in my town, and he said: 'Your problem can be cured, but not here! You have to go somewhere else' ... I was resigned... I think that 4 years after my surgery, this area was itching, and I lifted my blouse... I saw the little scratch... then I thought: My God, I was entirely open, wasn't I? ... but I was never desperate. I faced it! I think that this has helped me a lot, you know. E7

Although they showed common characteristics, the ostomates had their own needs and responses. Hence, the reaction to the problems caused by the stoma is related to each individual's personal conditions as well as to external variations, such as the quality of family, financial and care support received during all phases of the surgical treatment that generated the stoma<sup>(11-12)</sup>

Various authors and professional experience show that individuals oscillate between coping and giving up. Coping, generally active, may oppose to non-coping. This is what was observed in most cases and particularly at the beginning of each case as occurring in this study. Nevertheless, after the initial shock and each person's peculiar duration, the coping process begins<sup>(12-13)</sup>

In this study, the strategies used focused on the described emotion from the attempt to replace or regulate emotional stress stemming from defensive processes, which makes people avoid consciously confronting the reality from the threat. But there were also other problem-centered strategies with efforts to manage, administrate or somehow change problems or improve the relationship between people and the environment. They focused on reality, in an attempt to remove or attenuate the stressing source. In fact, there was a choice of alternatives and action<sup>(6)</sup>.

Such fact could be evidenced in the categories and subcategories shown, and it could also be observed in the movement expressed in the category below, where life was perceived as a possibility to find forms to cope with situations.

### 3<sup>rd</sup> Category – I have to live with the ostomy

It was shown that the ostomates do not live with the stoma in the sense of having chosen it, but rather that they endure it. The potential to live and endure is recovered, thus adding meaning to this reality. Therefore, the stoma is not part of these individuals' life project, but in this reality, they have been led to change their life habits and to reconsider their wishes and possibilities.

### Sub-category – Being helped to handle the pouch

Some individuals reported to have been helped with handling the pouch due to difficulty in doing so, but as time passed, most of the undertook self-care. The statements report this experience:

... At the beginning, I was afraid to touch it, like this, to clean it ... Then I would go to the health care unit. I kept doing it for one month after the surgery. I gradually got used to it ... E3

... I handle it myself. At the beginning a nurse did it; he was my neighbor. But then I realized that I no longer needed it, and now I do it myself! E6

### Sub-category – Everyday activities take place whenever possible

The continuity of daily activity performance and the search for alternatives to be able to perform other desired actions were observed in some reports:

... I go out as I used to. I come here by myself; I drive; I drive my wife to the doctor's; I drive my granddaughter; I look after my grandson. I do the same things at home; I drive, anything, I find things to do at home. I just can't make physical efforts; the doctor told me not to, so I don't lift heavy things! And if I have to do anything, I do it sitting down. E5

.... We have to look for alternatives as far as possible. I think it's sad not to be able to go to church because going to religious services on Sundays is my duty as a Christian. I have found an alternative: whenever I go, I sit near the pipe organ, the choir! (laughter)... I just keep looking for alternatives! E11

Functional possibilities after beginning to use the pouch are associated with the determination of perspectives by the patient himself and encouraging social interactions<sup>(3,14)</sup>

In the category *I have to live with the stoma*, contact with reality and life was observed, and although it was not these individuals' choice, this reality aspect offered them the possibility to implement problem-solving coping strategies. The problem was not solved due to the impossibility imposed by the condition of being ill, but the relationship with health care service was intensified and the limits to these individuals' lives were demarcated. The behaviors were subtle, but they enabled the assumption that there were problem solving strategies.

The coping concept is corroborated in this study by the evidence of the occurrence of a dynamic process which changed according to evaluations and re-evaluations that were continuously performed by the ostomates.



The ostomates' trajectories were evinced by these individuals' experience of going through the coping process, is not a behavior consisting of a single dimension. Nevertheless, it consists of a wide range of known behaviors and perceptions, distributed in various levels which comprise, in the last instance, their coping repertoire, with a wide spectrum of options showing their own relevance, since these were the elected forms for coping. Each individual presented his peculiar resources, which consisted of their experiences and influenced their personal responses<sup>(15)</sup>.

## FINAL REMARKS

The set of coping modes used to deal with the various stressors related to the condition of being ostomized, including a large number of responses, was shown by the wealth of elements contained in the interviews.

The beginning of the event was well demarcated by defense mechanisms, where minimization and relativization strategies with indirect patterns were presented in the interviews, showing evidence of the difficult experience and of the initial impact. The forms of coping with and being in the process which enabled individuals to go ahead while facing such adversity are the confirmation of the reality still perceived under this condition.

At this moment, "I did not choose it" was stated and revealed by feelings of fear and difficulty and discourses such as "there's no other way". The nomination of the disease and of the device which would be part of this person were expressed in the interviews as "that thing, stuff, I had it on" and the memory of the exact date when one was informed

about the ostomy reflected the intensity of this experience.

The way chosen by the doctor to inform the patient also seemed to show a lack of conditions, personal and institutional unpreparedness, where these people could be offered the option to have their will guaranteed with support for the impact to be suffered.

In this synthesis, categories "I had to accept it" and "I have to live with the ostomy" are distinguished, since that was where the coexistence of problem-solving coping strategies and emotion-focused coping strategies were shown in the coping process by subtle behaviors. The revealed experience of people living with ostomy was presented in a beautiful movement and its meanings, with a notion of limits to one's reality, although with intense life in this process of becoming ill and coping with it.

For this reason, it is expected that the findings stemming from the results in this study can contribute to reflection and knowledge application by care giving and teaching professionals working with ostomates. It is also expected that they can:

Identify, in the light of the coping framework, the coping strategies used by ostomates at a certain moment, understanding that it is an experiential process; mediate relationships among ostomates, family members or significant persons with the purpose to establish interlocution so as to recognize available resources, thus providing support to such patients; provide care to ostomates by perceiving them as people beings in the course of their lives, where technical knowledge is important, and although they might not be stomatherapists, they will be able to take hold of theoretical and particularly of human-interaction elements which will guarantee the care-giving process.

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