



## ORIGINALES

### Characterization of patients with an ileostomy that are treated on a reference service for patients with an ostomy

Caracterização dos ileostomizados atendidos em um serviço de referência de ostomizados

Caracterización de ileostomizados atendidos en un servicio de referencia de ostomizados

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### ABSTRACT

**Objective:** To characterize the patients with ileostomies who are registered in the Ostomy Association of Rio Grande do Norte.

**Material and Method:** Retrospective exploratory study, with quantitative approach, based on the data obtained from the registration forms of 97 people with an ostomy, on the period of November, 2013 to January 2014, from an Ostomy Association that belongs to the state of Rio Grande do Norte, Brazil.

**Results:** There were mainly female patients, with an average age of 57.08 years, white/brown, married, coming from the oriental coastal zone, with incomplete basic education, retired and with one minimum wage. Regarding the duration and reason for the ileostomies' confection, the tumor of rectum/neoplasia of rectum/cancer of rectum was the main cause and most of them were temporary.

**Conclusion:** The knowledge about these patient's profiles allows to identify their needs, stimulating the multidisciplinary team to make use of conducts that can help the patients to live with the ostomy.

**Keywords:** Ostomy; Ileostomy; Health Profile

## RESUMO

**Objetivo:** Caracterizar os pacientes ileostomizados cadastrados na Associação dos Ostomizados do Rio Grande do Norte.

**Material e Método:** Estudo exploratório retrospectivo, com abordagem quantitativa, baseado nos dados obtidos das fichas cadastrais de 97 pessoas com ostomias, no período de novembro de 2013 a janeiro de 2014, em uma associação de ostomizados no estado do Rio Grande do Norte, RN, Brasil

**Resultados:** Predominaram pacientes do sexo feminino, com média de idade de 57,08 anos, branco/pardo, casados, procedentes da zona litoral oriental, ensino fundamental incompleto, aposentados e 1 salário mínimo. Quanto à duração e motivo para confecção das ileostomias, o tumor de reto/neoplasia de reto/câncer de reto foi a principal causa e a maioria delas eram temporárias.

**Conclusão:** O conhecimento do perfil desses pacientes permite a identificação das necessidades dos ostomizados, estimulando a equipe multiprofissional à execução de condutas que auxiliem o pacientes a aceitar e conviver com a estomia.

**Palavras-chave:** Estomia; Ileostomia; Perfil de saúde.

## RESUMEN

**Objetivo:** Caracterizar a los pacientes ileostomizados registrados en la Asociación de Ostomizados de Río Grande del Norte.

**Material y Métodos:** Estudio exploratorio, retrospectivo, con abordaje cuantitativo, basado en datos obtenidos de las fichas de inscripción de 97 personas con ostomías, en el periodo de noviembre de 2013 a enero de 2014, en una asociación de ostomizados en el estado de Rio Grande del Norte, RN, Brasil.

**Resultados:** Predominaron pacientes de sexo femenino, con edad media de 57,08 años, blanco/pardo, casados, procedentes de la zona costera del este, educación primaria incompleta, jubilados y con 1 salario mínimo. En cuanto a la duración y motivo del origen de la ileostomía, el tumor de recto/neoplasia de recto/cáncer de recto fue la causa principal y la mayoría de ellas fueron temporales.

**Conclusión:** El conocimiento del perfil de estos pacientes permite la identificación de las necesidades de los ostomizados, estimulando al equipo multidisciplinar para implementar comportamientos que ayuden a los pacientes a aceptar y vivir con la ostomía.

**Palabras clave:** Ostomía; Ileostomía; Perfil de la Salud

## INTRODUCTION

Ostomy is a surgical procedure that has as purpose to externalize a bowel's part through the abdominal wall resulting on an opening, named as stoma, that allows the evacuation of waste, the entrance of food or medical treatment. The variety of ostomies differ according to the affected body segment, this way, the ostomies that are made on the digestive system with the purpose of elimination, are divided in colostomies and ileostomies, being made respectively in the colon (large intestine) and small intestine<sup>(1)</sup>.

An ileostomy is made to treat problems that impairs the gastrointestinal system and that disable the definitive or temporary use of the other system segments in question. Frequently, an ileostomy's confection is made for medical treatment, being needed to externalize one part of the small intestine, the ileus. The ileostomy is located on the right lower quadrant and there is no presence of sphincter that voluntarily controls the evacuation, so, a pouch is needed to store the intestine's content<sup>(2)</sup>.

Depending on the disease's etiology, the intestine's stomas are classified regarding the permanence time in definitive or temporary. The temporary stomas are accomplished to protect an anastomosis and its closure occurs on a short period of time when the problem that led to its making is solved. On the definitive stomas, an intestine's segment is removed and are produced when there is no possibility to reestablish the normal intestinal flow, usually in cases of cancer<sup>(3)</sup>.

About the indications for the accomplishment of an ileostomy, it is possible to highlight the colon and rectum cancer and the ulcerative colitis<sup>(4)</sup>. According to data from the National Institute of Cancer, the colon and rectum cancer show themselves as the third most incident type of malignant neoplasia among men, with 746 thousand of new cases, and the second among women, with 614 thousand of new cases in 2012. It was estimated that in 2014 it would occur 580 thousand of new cancer cases in Brazil, and the colon and rectum cancer would be the fourth most incident in the Brazilian population reaching about 33 thousand people<sup>(5)</sup>.

After the ostomy's realization, the patient come across a few changes regarding their organism's operation, these changes on physiology and anatomy frequently impact on a negative way in the quality of life and the individual's well-being, because it affects him biologically and psychologically, being of extreme importance to have an emotional support in order to obtain a better and bigger adaption to the new reality<sup>(6)</sup>.

Although it is present in the professional practice, the archive of available materials, publications and information about the theme, is still scarce in Rio Grande do Norte. There are no published studies that involve the issue in stake and the health profile of those patients still is unknown.

Therefore, the current characterization has its relevance at the measure that it can ease the health team's action planning, especially the nurse, since, they provide subsidies for the planning and implementation of actions that benefits the care to the people with ileostomies, with the intention of facilitating their adaptive process, through directed educational, advertising and of early diagnostic activities, giving an effective service with quality, as well as the improvement on the patient's quality of life, supported in scientific knowledge. In addition to this, it is highlighted the absence of official data from the Ministry of Health regarding the situation of people with an ostomy in Brazil, just as the lack of a health profile of these patients<sup>(7)</sup>.

The accomplishment of this study had as motivating factor some questions about the amount of people with ileostomies, the main problems that led to the fulfilment of this surgical procedure, allowing to sketch their health profile from the available data in the Ostomy Association of Rio Grande do Norte.

From what has been exposed, this study aimed to characterize the patients with an ileostomy, enrolled in the Ostomy Association of Rio Grande do Norte, which serves not only the capital, but all cities of the state.

## **MATERIAL AND METHOD**

It is about a retrospective exploratory study, with a quantitative approach, made in the Ostomy Association of Rio Grande do Norte, that is the state's reference center in respect of the distribution of materials, follow-up and treatment of patients with

ostomies, all this relied on the accomplishment of nursing consultations that made possible to identify and treat potential complications.

The presented population in the study was made of 97 people with active ileostomies registered in the association since 1991, year of its foundation, that attended to the following inclusion conditions, to have active registration form in the Association, be served at the Ostomy Association of Rio Grande do Norte and as exclusion conditions, the incomplete forms.

The data gathering was done between the months of November, 2013 to January, 2014, from one research instrument developed by the researchers, upon a printed document denominated as "registration forms", one individual instrument for each patient available in the association where the following variables were contemplated: institution's situation (active, inactive, reversion, death), admission date, gender, race, hometown, neighborhood, country of birth, birth date, education level, marital status, family income, type of member, profession/occupation, surgery date, reason for making the ostomy, hospital, type of bag, ostomy type and duration, adhesive, pouch's type and style.

For the research's elaboration, the quoted variables were analyzed accordingly to the age group in consequence of the population's aging. In accordance if the IBGE, the elderly's population represents an amount of approximately 20,590,000 people above 60 years old <sup>(8)</sup>.

After the data gathering, the data was digitalized in a database on the spreadsheet from Microsoft Excel 2007, that after correction were exported and analyzed in the statistical program SPSS (Statistical Package for the Social Sciences), version 20.0 to treat the results, having as type of analysis the descriptive statistic with absolute and relative frequencies.

Considering that research projects that involves human beings need an analysis made by the Committee of Ethics in Research, the current study was submitted to the fulfilment of the ethical principles included in the Resolution 466/12. Therefore, it was evaluated by the Committee of Ethics in Research/UFRN (Protocol n. 421.342/13), meeting all requirements for the research on human beings, having the identity and privacy of the patients preserved and the extracted information was used exclusively for this study.

## **RESULTS**

On the study's period it was obtained data of 97 patients with ileostomies. The chart I shows data corresponding to the sociodemographic characterization, distributed in accordance with the age group, showing a female predominance, white/brown skin color and married. In addition to this, the participants' age varied from 18 to 98 years, with an average of 57.08 years old and standard deviation of +/- 17.7.

About the sociodemographic data, distributed from the age group, there were mainly women (53.60%) regardless of age; race, white and brown (45.36%) respectively; and marital status, married (45.36%), followed by singles (28.86%), being most of them up to 59 years old, accordingly to chart I.

**Chart I** – Sociodemographic data of patients submitted to ileostomy. Natal, 2014.

<b>Variables</b>	<b>Up to 59 years n (%)</b>	<b>&gt;59 years n (%)</b>	<b>Total n (%)</b>
<b>Gender</b>			
Female	26 (26.80)	26 (26.80)	52 (53.60)
Male	26 (26.80)	19 (19.60)	45 (46.40)
<b>Race</b>			
White	20 (20.61)	24 (24.74)	44 (45.36)
Brown	27 (27.83)	17 (17.52)	44 (45.36)
Black	1 (1.03)	2 (2.06)	3 (3.09)
Yellow	2 (2.06)	1 (1.03)	3 (3.09)
Ignored	2 (2.06)	1 (1.03)	3 (3.09)
<b>Marital status</b>			
Married	25 (25.77)	19 (19.58)	44 (45.36)
Widow	2 (2.06)	14 (14.43)	16 (16.49)
Single	20 (20.61)	8 (8.24)	28 (28.86)
Separated	3 (3.09)	0 (0.00)	3 (3.09)
Ignored	2 (2.06)	4 (4.12)	6 (6.20)
<b>Total</b>	<b>52 (53.60)</b>	<b>45 (46.40)</b>	<b>97 (100.00)</b>

Regarding the education level and family income, it was highlighted the amount of patients that had incomplete primary school (32.98%), high school (25.77%), illiterate (15.46%), and illiterates who are above 59 years old and with who have ileostomy (12.37%). About the family income, it was emphasized a large amount of patients with up to one minimum wage (65.97%) as shown on chart 2.

**Chart II** – Sociodemographic data of patients submitted to ileostomy. Natal, 2014.

<b>Variables</b>	<b>Up to 59 years n (%)</b>	<b>&gt;59 years n (%)</b>	<b>Total n (%)</b>
<b>Education level</b>			
Illiterate	3 (3.09)	12 (12.37)	15 (15.46)
Incomplete primary school	15 (15.46)	17 (17.52)	32 (32.98)
Primary school	10 (10.30)	4 (4.12)	14 (14.43)
Incomplete high school	2 (2.06)	0 (0.00)	2 (2.06)
High school	14 (14.43)	11 (11.34)	25 (25.77)
Incomplete College	2 (2.06)	0 (0.00)	2 (2.06)
College education	5 (5.15)	1 (1.03)	6 (6.20)
Ignored	1 (1.03)	0 (0.00)	1 (1.03)
<b>Family income (on minimum wage)</b>			
≥ 1	35 (36.08)	29 (29.89)	64 (65.97)
2 – 5	12 (12.37)	9 (9.30)	21 (21.64)
> 6	1 (1.03)	3 (3.09)	4 (4.12)
Ignored	2 (2.06)	4 (4.12)	6 (6.20)
No income	2 (2.06)	0 (0.00)	2 (2.06)
<b>Total</b>	<b>52 (53.60)</b>	<b>45 (46.40)</b>	<b>97 (100.00)</b>

The data regarding the profession/occupation showed that most of the researched are retired (27.83%) and do household work (12.37%) as exposed on chart 3. It is emphasized the amount of forms that did not had this information (35.05%).

**Chart III** – Data of patients with an ileostomy related to the profession/occupation.

Variables	Up to 59 years n (%)	>59 years n (%)	Total n (%)
<b>Profession/Occupation</b>			
Retired	10 (10.30)	17 (17.52)	27 (27.83)
Do household work	5 (5.15)	7 (7.21)	12 (12.37)
Farmer/Fisherman	6 (6.20)	2 (2.06)	8 (8.24)
Professor	2 (2.06)	2 (2.06)	4 (4.12)
Others	8 (8.24)	4 (4.12)	12 (12.37)
Ignored	21 (21.64)	13 (13.40)	34 (35.05)
<b>Total</b>	<b>52 (53.60)</b>	<b>45 (46.40)</b>	<b>97 (100.00)</b>

In relation to the ostomy's duration, the ones with temporary ileostomy prevailed (59.79%), of those being 36.08% in the age group of 59 years old. And about the definitive ileostomies (35.05%), it was observed that there were many patients above 59 years old (18.55%). The patient's average surgery time was of 1 year, with standard deviation of 5.38 years. The admission type on the Ostomy Association had an average of 1 year and standard deviation of 3.9 years.

Concerning the ileostomy's confection, the rectum tumor was the most prevailed one (35.04%). Subsequently, one observes the colon cancer (14.44%), the inflammatory intestinal disease and the colon's adenocarcinoma, both with 9.27%, accordingly to the chart 4. One highlights that the diagnosis who showed only one case were grouped and received the denomination "Others".

**Chart IV** – Characterization related to the ostomy of the patients with an ileostomy from the Ostomy Association of Rio Grande do Norte, based on the diagnostic. Natal, 2014.

Variables	Up to 59 years n (%)	>59 years n (%)	Total n (%)
<b>Diagnostic</b>			
Tumor of rectum/neoplasia of rectum/cancer of rectum	13 (13.40)	21 (21.64)	34 (35.05)
Tumor in the intestine	7 (7.21)	9 (9.27)	16 (16.49)
Colon's Adenocarcinoma	3 (3.09)	6 (6.20)	9 (9.27)
Inflammatory intestinal disease	8 (8.24)	1 (1.03)	9 (9.27)
Wound by gunshot/Wound by melee weapon	5 (5.15)	2 (2.06)	7 (7.21)
Familiar polyposis	4 (4.12)	1 (1.03)	5 (5.20)
Sigmoid's puncture	3 (3.09)	0 (0.00)	3 (3.09)
Tumor in the uterine cervix	1 (1.03)	1 (1.03)	2 (2.06)
Acute abdomen	2 (2.06)	0 (0.00)	2 (2.06)
Others	6 (6.20)	4 (4.12)	10 (10.30)
<b>Total</b>	<b>52 (53.60)</b>	<b>45 (46.40)</b>	<b>97 (100.00)</b>

Regarding the source, most of the people with an ileostomy is concentrated in the oriental coastal zone (53.60%), followed by the countryside (12.40%) and Mossoró (12.40%), respectively.

## DISCUSSION

Based on the found results, the most affected gender by problems that led to the ostomy's confection was female, endorsing the researched data, which revealed that in 2010 there were 190,755,799 inhabitants in Brazil, from this total, 51% of the population are women<sup>(8)</sup>. In addition to this, the data from the National Institute of Cancer reveals that about 17,530 women would develop colorectal neoplasia in 2014, on the other hand, only 15,070 men would be affected<sup>(5)</sup>. Similar results were found on other studies, showing that 63.2% were female<sup>(7, 9)</sup>.

The gender difference translates what the impact of the ostomy's making may cause in the patient's daily routine. The women have a larger adaptive capacity related to the ostomy's self-care, in contrast, the men have difficulty when taking care of their ostomy, needing the help of their companions<sup>(10)</sup>. About the negative feelings in respect to the body image, women have a greater tendency of developing psychological problems involved with self-image disorders, on the other side, men did not report any negative changes related to their body<sup>(11)</sup>.

Regarding the marital status, one observes that most of the people with an ileostomy are married (45,36%). It is possible to highlight the significance of such information because the companion's support is shown as a relevant and fundamental factor for the psychosocial adaption of women, exerting positive effects on their quality of life, since, they not only receive instrumental support, but also can notice that the ostomy's

presence does not diminish the woman's "value" and does not change the feeling that the husband feels for his wife<sup>(12)</sup>. In the same way, when there is no support from the husband, there is a negative impact on the women's adaptive process, which will undergo negative changes on the sexuality patterns during the wedding, resulting on the diminishing on the quality of life<sup>(10, 13)</sup>.

In relation to the age, the research shows that the ostomy's confection is more present on people who are with or under 59 years, such fact is due to the technological advances that each time provides more early diagnosis and faster surgical treatment<sup>(15)</sup>. Allied with this, it also has been showing association between the feeding and the colorectal cancer's development. The modern society have the easiness of fast foods, that are poor on fibers, vitamins and minerals, increasing the tendency to develop gastrointestinal diseases<sup>(15)</sup>. However, divergent results were demonstrated, where 178 patients with an ileostomy had more than 59 years, representing 65,2% of the researched. This is mainly due to the increase on the population's life expectancy and technological advances for treatment<sup>(16)</sup>.

Most of the researched patients had incomplete primary school (32.98%). The education levels have direct relation to the knowledge about risk factors and life habits for the development of chronic diseases<sup>(17)</sup>. Furthermore, the education levels are related to the self – evaluation of the health state, in such a way that people with lower education showed 300% more chance to have a bad self – evaluation, when compared to the ones with high education<sup>(18)</sup>. Combined with this, the education level, influence on the treatment's adherence, concerning the ostomy and the low education ends up impairing the treatment's adherence for prevention of complications, since, it is more difficult for them to learn about the ostomy's care<sup>(19)</sup>.

Endorsing the presented data, some authors still discuss that this result might have religious influence for considering that the participants with low education level face the situations as a fact imposed by God, this makes them adapt to the situation faster. Meanwhile the individuals with higher education level tend to prevent diseases and improve their health, accepting professional support to be more adapted and thus, ensuring a better quality of life<sup>(10)</sup>.

From the family income's point of view, the study showed that 65.97% of the participants have up to 1 minimum wage, confirming the data presented on another research that revealed the relation between the education level and the income. Therefore, the low education level justifies the family income detected on this study, as the education level is directly associated with the income, because it is believed that people with higher education possess more opportunities of being well paid<sup>(9)</sup>.

Associated with this, the accomplishment of an ostomy requires expenses for the patient, because now he must set aside part of his salary to pay for the ostomy's costs, this way, people with low acquisitive power may have difficulties in acquiring the needed material for their self – care, implying in the decrease of their quality of life and wellbeing when the person with an ostomy confront difficulties to fulfil his needs<sup>(20, 24)</sup>.

Regarding the occupation, one verifies that most of the people with ileostomies are retired (27.83%). This information is justified by the fact that many of them had an employment relationship before the ostomy's accomplishment and drifted away from labor for not having conditions, comfort and privacy to take care of their ostomy on the



work field, so, they chose to abandon their activities<sup>(10)</sup>. In addition to those factors, it is believed that this also happens due to the loss of will to work<sup>(9)</sup>.

About the ostomy's duration, most of them showed temporary ileostomy (59.79%). Individuals with temporary ostomy occasionally do not feel significant impact on the ostomy's confection and their adaptive process is minimized, since, their ostomy will be eventually closed, unlike those that possess definitive ostomy, because they will remain with it during their life<sup>(10)</sup>. People with ostomies discussed strategies for the care with the ostomy highlighting the need to continuously adapt to several situations that might negatively affect the individual's quality of life<sup>(21)</sup>.

One observes that from the moment the hospital beds are occupied for the ostomy's confection, there is a delay on the procedure's development that allows to reconstruct the intestinal flow, this way, people with temporary ostomies that remain on this situation for several years, have their ostomy turned into definitive<sup>(7)</sup>.

About the precedence, the oriental coastal zone showed a larger amount of attended patients. This zone is where most of the state's populations is gathered (48.50%), justifying such result<sup>(22)</sup>.

Regarding the reason for making the ileostomy, the tumor of rectum/Neoplasia of rectum/cancer of rectum was the main cause, corroborating with the data the estimated that, in the year of 2014, it would occur around 580 thousand of new cancer cases in Brazil and the cancer of colon and rectum would affect roughly 33 thousand people, being the fourth most incident in the population<sup>(4)</sup>. Other researches enhance this information for showing similar results in different regions of Brazil<sup>(23, 24)</sup>. One highlights the relevance of educative actions directed to health developed by the multidisciplinary team, with the purpose of encouraging the practice of physical exercises, healthy feeding, absence of cigars, since, those practices influence on tumor's development<sup>(7)</sup>.

Among the handicaps of this study, one emphasizes the lack of information on the patient's registration forms, in addition to the fact of them, occasionally, being obtained through third parties, which may have provided incomplete or mistaken data.

## **CONCLUSION**

This study allowed to characterize the people with ileostomies registered in the Ostomy Association of Rio Grande do Norte in the period of November, 2013 to January, 2014. From those patient's profile description, it was possible to conclude that most of the people with ostomies were women, white, married, retired, from the oriental coastal zone, with incomplete primary school and family income of up to 1 minimum wage. About the reason and duration, most of them had temporary ostomy and the main reason for the ileostomy's confection was tumor/neoplasia/cancer of rectum.

This research offers important results, because it provides subsidies for the health team, especially the nurse, to support the patient with an ostomy, from the knowledge of their characteristics and needs, encouraging them to develop actions guided toward this kind of public, through directed educative actions, and giving them the commitment to make this patient accept and live with the ileostomy, clarifying doubts for a better adaption to this process, acting as mediator to improve those people's

quality of life. In addition to this, this study enables the dissemination of the obtained data, subsidizing the construction of future investigations, allowing to know better this clientele and to optimize the deployed public resources.

One of the research's limitations was centered in the lack of information of the registration forms. Confronting this, one emphasizes the importance of this study to instigate the nurses to make larger investments on this problem's solution, considering their importance on the subsidy of the care process to the client in a holistic, individualized and continuous manner.

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