

# PROFILE OF UROSTOMIZED PATIENTS REGISTERED IN AN ASSOCIATION OF OSTOMATES

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**ABSTRACT:** The objective in this study was to investigate the profile of urostomized patients registered in the Association of Ostomates of Rio Grande do Norte. A descriptive and retrospective study was developed between October 2013 and February 2014, through information collected from the registration forms of 53 urostomized patients. The highest concentration of urostomized patients is located in the Eastern coastal region of the state (60.4%), over 59 years of age (73.6%), mulatto (50.9%), male (54.7%), married (52.9%), who finished primary education (35.9%), gain one minimum wage (56.6%) and were diagnosed with bladder tumor (47.2%). The results provide specific information on the urostomized patients. Through the analysis of social and demographic data and information about the living conditions, this population's problems can be listed in order of priority, contributing to health promotion and optimizing time and financial resources.

**DESCRIPTORS:** Nursing; Stoma; Health profile.

## PERFIL DOS UROSTOMIZADOS CADASTRADOS EM UMA ASSOCIAÇÃO DE OSTOMIZADOS

**RESUMO:** O objetivo deste estudo foi investigar o perfil dos urostomizados cadastrados na Associação dos Ostomizados do Rio Grande do Norte. Trata-se de um estudo descritivo, retrospectivo, desenvolvido entre outubro de 2013 a fevereiro de 2014, mediante informações colhidas nas fichas cadastrais de 53 pessoas com urostomia. A maior concentração de urostomizados cadastrados está localizada na zona litoral oriental do estado (60,4%), com idade superior a 59 anos (73,6%), pardos (50,9%), do sexo masculino (54,7%), casados (52,9%), com ensino fundamental (35,9%), com renda de um salário mínimo (56,6%) e com diagnóstico de neoplasia de bexiga (47,2%). Os resultados obtidos fornecem informações específicas sobre os urostomizados. Através da análise de informações sociais e demográficas e das condições de vida, é possível listar e priorizar os problemas desta população, colaborando, com a promoção da saúde, otimizando tempo e recursos financeiros.

**DESCRIPTORES:** Enfermagem; Estomia; Perfil de saúde.

## PERFIL DE LOS UROSTOMIZADOS REGISTRADOS EN UNA ASOCIACIÓN DE OSTOMIZADOS

**RESUMEN:** El objetivo de este estudio fue investigar el perfil de los urostomizados registrados en la Asociación de los Ostomizados de Rio Grande del Norte. Es un estudio descriptivo, retrospectivo, desarrollado entre octubre de 2013 y febrero de 2014, con informaciones obtenidas en las fichas de registro de 53 personas con urostomía. La mayor concentración de urostomizados registrados está ubicada en la zona litoral oriental del estado (60,4%), con edad superior a 59 años (73,6%), pardos (50,9%), del sexo masculino (54,7%), casados (52,9%), enseñanza fundamental (35,9%), renta de un salario mínimo (56,6%) y con diagnóstico de neoplasia de vejiga (47,2%). Los resultados obtenidos ofrecen informaciones específicas sobre los urostomizados. Por medio del análisis de informaciones sociales y demográficas y de las condiciones de vida, es posible enunciar y priorizar los problemas de esta población, colaborando con la promoción de la salud, optimizando tiempo y recursos financieros.

**DESCRIPTORES:** Enfermería; Estomía; Perfil de salud.

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## INTRODUCTION

Changes in the functioning of the urinary or intestinal apparatus can result in the creation of a stoma<sup>(1)</sup>, due to the need to deviate the normal traffic of physiological eliminations. A stoma is an artificially creating opening in the gastrointestinal (GI) or urinary tract, where the body residuals would come out, in a body surface. This is a deliberate opening, made in an intestinal segment, deviating the flow of feces or urine. No sensory nerves transmit to the stoma, so that feelings like pain cannot be felt<sup>(2)</sup>.

Urostomy relates to when a segment of the small intestine is used to constitute a channel between the urethra and the abdominal wall, to allow the urine to run out beyond its natural course<sup>(3)</sup>.

The estimated number of stoma patients in the United States of America in 2013 is approximately 700 thousand<sup>(4)</sup>. In Brazil, there are about 33,864 stoma patients<sup>(5)</sup>, about 700 of whom live in Rio Grande do Norte (RN)<sup>(6)</sup>.

Independently of the stoma type, the patients may feel different, as the mutilation in the body and the use of the collector bag entail the need to reconstruct their identity. The loss of an organ, loss of self-esteem and self-concept resulting from the body image, loss of one's social status, depression, repulsion and feeling of uselessness are some of the anxieties urostomized patients experience. Other factors are changes in sexual life, reduced libido and concerns with the elimination of smells, feces or urine during the sexual intercourse. At that moment, the support of family members and friends, as well as of health professionals, is fundamental for the urostomized subjects<sup>(7)</sup>.

In Rio Grande do Norte, registered stoma patients receive support from the Association of Stoma Patients of Rio Grande do Norte (AORN), founded in 1991, which has more than 800 active attending members at the time this paper was elaborated, helping to promote the stoma patients' reintegration in daily life<sup>(8)</sup>. Despite the existence of referral centers in the Northeast, the collection of research material on the topic remains scarce.

Publications on the theme in RN are restricted and these patients' profile is limited, arousing reflections and raising the following research problem: What is the profile of urostomized patients registered in AORN?

In that context, the objective in this study was to investigate the profile of active urostomized patients registered in AORN. Based on the identified profile, this study will enable the health team, especially the nurse, to improve the comprehensive planning of care actions through the knowledge the professionals interpret and through which they establish new guidelines for their practices, besides promoting the enhancement of the professional-patient relationship.

## METHOD

A descriptive and retrospective study was developed between October 2013 and February 2014 in the AORN, which covers all cities in the state. The study population comprises all active urostomized patients registered in the association's database.

The data were obtained by consulting the print document called individual registration form for each stoma patient, completed when (s) he attended the association for registration and could pick up the stoma bags.

The study variables were: sex, color, origin, marital status, income, profession/occupation, education, diagnosis, motive for the ostomy, type of stoma and duration of the ostomy. For the database and analysis, statistical treatment was used in the software Microsoft Office Excel 2010® with descriptive statistics.

In compliance with National Health Council Resolution 466/12, the printed forms were consulted with the authorization of the association's board and approval by the Research Ethics Committee/UFRN (CAAE 19866413.3.0000.5537). All ethical premises for research involving human beings were complied with.

## RESULTS

Among the 697 active patients registered in AORN, 53 (7.6%) had urostomies. In this group, n=39 (73.6%) were over 59 years of age, n=29 (54.7%) were male, n=27 (50.9%) of mulatto origin and n=28 (52.9%) were married, according to Table 1. The large percentage of registration forms without complete information is highlighted, considered as missing data in this study.

As regards education, the number of patients with primary education is highlighted, with a predominance of urostomized patients over 59 years of age, n=19 (35.9%). Data on the profession demonstrated that n=14 (26.4%) were retired, pensioners or gained social benefits. Concerning the income, n=30 (56.6%) gained up to one minimum wage (MW), as displayed in Table 2.

Concerning the cause of the urostomy, Table 3 demonstrates that n=25 (47.2%) had been diagnosed with bladder tumor. One patient, however, had a urostomy with ileostomy, with

a diagnosis related to urothelial carcinoma. Six patients had a urostomy with colostomy with a diagnosis of rectal tumor. As regards the duration, n=50 (94.3%) of the patients had definitive stomas, n=38 (71.7%) in the age range over 59 years.

As regards the region with the highest concentration of urostomized members, it was verified that the majority was located in the Eastern coastal region n=32 (60.4%), followed by the Mossoró region n=9 (17%), as demonstrated in Figure 1.

Table 1 – Sociodemographic characteristics of urostomy patients according to age range. Natal, Brazil, 2014

Sociodemographic characteristics	Up to 59 years		> 59 years		Total	
	n	%	n	%	n	%
<b>Sex</b>						
Male	8	15,1	21	39,6	29	54,7
Female	6	11,3	18	34	24	45,3
<b>Color</b>						
White	7	13,2	13	24,5	20	37,7
Mulatto	6	11,3	21	39,6	27	50,9
Black	1	1,9	4	7,6	5	9,5
Missing	0	0	1	1,9	1	1,9
<b>Marital status</b>						
Married	7	13,2	21	39,6	28	52,9
Single	6	11,3	5	9,5	11	20,7
Widowed	1	1,9	8	15,1	9	17
Separated	0	0	4	7,5	4	7,5
Missing	0	0	1	1,9	1	1,9
<b>Total</b>	14	26,4	39	73,6	53	100

Tabela 2 - Características sociodemográficas de pacientes com urostomia segundo a faixa etária. Natal-RN-Brasil, 2014

Sociodemographic characteristics	Up to 59 years		> 59 years		Total	
	n	%	n	%	n	%
<b>Education</b>						
Illiterate	4	7,5	13	24,5	17	32
Primary education	9	17	19	35,9	28	52,9
Unfinished secondary education	1	1,9	1	1,9	2	3,8
Higher education	0	0	4	7,5	4	7,5
Missing	0	0	2	3,8	2	3,8
<b>Profession</b>						
Retired/pensioner/beneficiary	3	5,7	11	20,7	14	26,4
Housewife	3	5,7	4	7,5	7	13,2
Other	3	5,7	2	3,8	5	9,5
Farmer/fisherman	0	0	3	5,7	3	5,7
Soldier/seaman	1	1,9	1	1,9	2	3,8
Driver	0	0	1	1,9	1	1,9
Public servant	0	0	1	1,9	1	1,9
Missing	4	7,5	16	30,1	20	37,6
<b>Family income</b>						
0 Mw	1	1,9	2	3,8	3	5,7
Up to 1 mw	12	22,6	18	33,9	30	56,6
Up to 2 mw	0	0	9	17	9	17
Up to 3 mw	1	1,9	3	5,7	4	7,5
≥ 5 Mw	0	0	4	7,5	4	7,5
Missing	0	0	3	5,7	3	5,7
<b>Total</b>	<b>14</b>	<b>26,4</b>	<b>39</b>	<b>73,6</b>	<b>53</b>	<b>100</b>

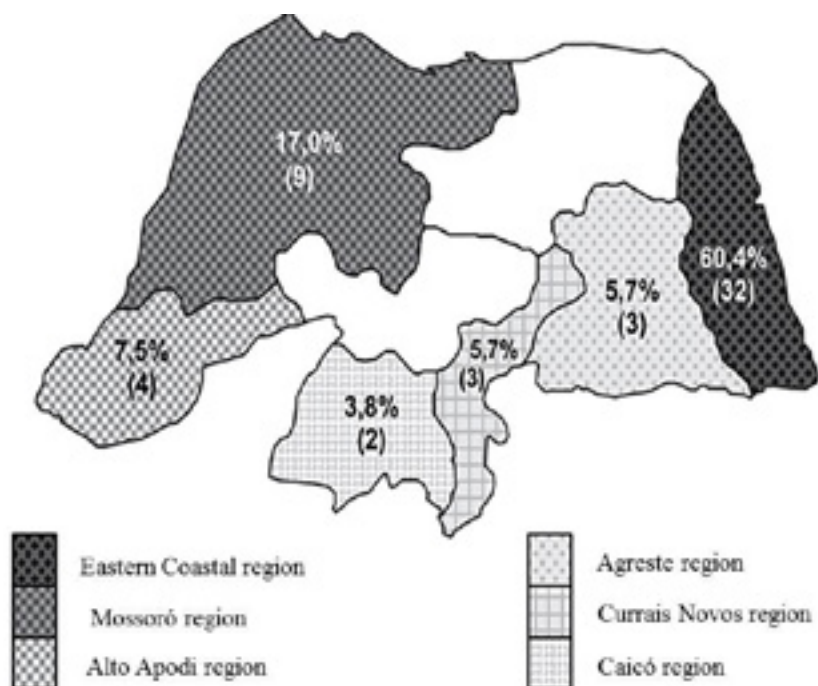


Figure 1 – Geographic map of Rio Grande do Norte, showing the distribution of urostomized patients registered in AORN. Natal, Brazil, 2014

Table 3 – Distribution of urostomized patients regarding the diagnosis and duration of the stoma. Natal, Brazil, 2014

Variable	Up to 59 years		> 59 years		Total	
	n	%	n	%	n	%
<b>Diagnosis</b>						
Rectal tumor	1	1,9	2	3,8	3	5,7
Uterine cervix tumor	1	1,9	2	3,8	3	5,7
(Intestinal) colon tumor	1	1,9	0	0	1	1,9
Bladder lesion	1	1,9	3	5,7	4	7,5
Vesicovaginal fistula	1	1,9	1	1,9	2	3,8
Bladder tumor	4	7,5	21	39,6	25	47,2
Chronic kidney failure	1	1,9	0	0	1	1,9
Urothelial carcinoma	1	1,9	3	5,7	4	7,5
Hydronephrosis	1	1,9	0	0	1	1,9
Firearm related injury	2	3,8	0	0	2	3,8
Uterine cervix tumor/ vesicovaginal injury	0	0	1	1,9	1	1,9
Prostatic cyst	0	0	1	1,9	1	1,9
Rectovaginal fistula	0	0	1	1,9	1	1,9
Carcinoma	0	0	1	1,9	1	1,9
Urethral carcinoma	0	0	1	1,9	1	1,9
Extensive pelvic injury	0	0	1	1,9	1	1,9
Kidney tumor	0	0	1	1,9	1	1,9
Duration	0	0	1	1,9	1	1,9
<b>Permanent</b>						
Temporary	12	22,6	38	71,7	50	94,3
Missing	2	3,8	0	0	2	3,8
Total	0	0	1	1,9	1	1,9
<b>Total</b>	<b>14</b>	<b>26,4</b>	<b>39</b>	<b>73,6</b>	<b>53</b>	<b>100</b>

## DISCUSSION

The demographic data presented in this study illustrate the demographic transition process that is ongoing in Brazil, characterizing the population aging as a relevant fact in the healthcare context, as it also demonstrates a transition in the care model, characterized by the growing need for hospital care and its respective complexity levels. Different factors affect the elderly's quality of life (QoL), some of which are related to the sociodemographic characteristics, such as age range, economic class, education, marital status and occupational situation, and others associated to the health conditions, i.e. the Body Mass Index (BMI) classification, health problems and medication use<sup>(9-10)</sup>.

Concerning the marital status, the majority in this study is married. In that sense, the partner is a fundamental component in the stoma patients'

adaptation process, in view of the countless physical and psychological modifications after the procedure. Based on their joint life, the family members can provide important information, such as habits and preferences, which help to formulate and execute a therapeutic plan, and to interpret how it should be put in practice, not only during the adaptation phase, but in any phase of the health/disease process<sup>(11-12)</sup>.

Thus, in view of the reports of the stoma patients who mention feeling shame, fear, insecurity and constraint, the family is a source of support to promote enhanced self-esteem and the stoma patient's reinsertion in society<sup>(13)</sup>.

The urostomized patients' low education level in this study can represent an obstacle for them to understand their health condition and to accomplish self-care actions, as most of the interviewed individuals fit into the primary education category. The access to information and

health services, as well as to other community-based resources, are directly related to the socioeconomic and cultural level. Therefore, the knowledge influences the need for routine tests with a view to the early detection of cancer, for example, in the search for care and opportunities to have access to medical/hospital resources<sup>(14)</sup>.

Most of the urostomized patients were retired, followed by farmers and housewives. After the enactment of Federal Law 5.296, which classifies stoma patients as physically disabled, these clients are included in the retirement system, in combination with the other laws that regulate the rights of disabled people in Brazil, in the federal, state and municipal spheres<sup>(15)</sup>.

Among these rights, social support for the elderly and disabled stands out, represented by the Organic Law of Social Services (LOAS), which offers a monthly benefit of one month, based on the proof that they have no means to provide for their own maintenance or have it provided for by their family; exemption of income tax charges on disability benefit; withdrawal of contributions from the Social Integration Plan (PIS) and from the Brazilian Governance Severance Indemnity Fund (FGTS); exemption of the Value-Added Tax on Goods and Services (ICMS) and the Tax on Industrialized Products (IPI) in the purchase of an adapted care; exemption of the Motor Vehicle Tax (IPVA) for adapted vehicles; disease aid; BPC-LOAS (Continuous Cash Benefit Program); free municipal, intercity and interstate bus tickets<sup>(15)</sup>.

With regard to financial matters, it should be highlighted that the urostomy represents an additional source of spending. The ways in which it affects health can be understood based on the income use for the purchase of goods and health services, housing conditions and education<sup>(16)</sup>.

About the diagnoses associated with the urostomy, bladder tumor stands out. The appearance of a tumor can cause suffering and pain to individuals, generating emotional instability while experiencing a new condition and its treatment<sup>(17)</sup>. Various risk factors can be associated with the incidence of this tumor. Smoking is underlined as the main risk factor for its development, with a risk two to four times higher than for non-smokers, with a double risk if this tumor is related to both smoking and overweight<sup>(18-19)</sup>.

The occupational risks are represented in the literature as another risk factor, in function of the exposure to a range of chemical products, including polycyclic aromatic hydrocarbons, formaldehydes and solvents. The genetic load, urinary tract infections and age are additional factors favoring this tumor<sup>(20-22)</sup>.

Stomas can be classified as temporary or permanent. The latter are the majority among the types demonstrated in this study, in line with international studies that found the same result. The stoma patients' adaptation process requires time and the development of specific skills for self-care and to overcome the obstacles this new physical, psychological and physiological condition causes. In that sense, people with permanent stomas differ from temporary stomas because of the permanent need for this adjustment, in which the time influences the way these people face the situation<sup>(23-24)</sup>.

Concerning the urostomized members' region of origin, a high population density of this group was identified in the state capital, as well as the nearby regions, based on which this data is associated with the location of the AORN, favoring the access to physical and human resources, and with the population of the Eastern coastal region (48.5% of the population in RN)<sup>(25)</sup>. Similarly, this information provokes a reflection on the difficulty of other urostomized patients in the other regions of the state to get access to the state association and, consequently, to orientations about care and management of ostomy bags, as well as to their provision.

## CONCLUSION

Male and mulatto patients who lived with a fixed partner and were over 59 years of age prevailed. The family income was one minimum wage, possibly associated with the fact that they were over 59 years of age and included in the group of retired people, pensioners or receiving social benefits. As regards education, primary education was predominant among the urostomized patients. Concerning the demographic distribution, the patients in this study showed a high concentration in the Eastern coastal region of RN.

It is important to highlight that, as presented in

the results, one of the research limitations was the lack of information on the investigated patients' registration form with regard to some study variables, such as: color, age, income, education, profession, diagnosis and stoma type, which in some cases were not completed and considered as missing data in this study.

Considering the theme urostomy, this research can support reflections and encourage the development of future research, as the literature on this area remains scarce. Nevertheless, the patients' profile will support clinical practice, through the identification of the stoma population's particularities, contributing to health promotion and optimizing the time and financial resources.

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