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BIOSOCIODEMOGRAPHIC AND DIGITAL PROFILE OF PARTICIPANTS IN AN ONLINE EDUCATIONAL INTERVENTION ON COLOSTOMY

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ABSTRACT

Objective: To identify the biosociodemographic and digital profile of people with colostomy and caregivers who participated in the online educational intervention on colostomy. **Method:** Cross-sectional study carried out with 20 people with colostomy and 32 caregivers, in the period of September/November 2020, in an integrated health center in Teresina, Piauí, Brazil. Sociodemographic and clinical characterization instruments, computer and internet access, and basic digital proficiency submitted to statistical analysis were used. **Results:** Among people with colostomy and caregivers, 60% were male and 75% female. Temporary colostomy (55%) with bright red color and regular shape (80%) predominated. Most caregivers had a job (46.9%), and 8 hours/week were dedicated to care. The degree of digital proficiency was low (76.9%). **Conclusion:** The identification of the biosociodemographic and digital profile of the participants can contribute to the adoption of educational strategies according to digital maturity or the need for support for the use of technologies, to optimize health care and qualify the assistance provided.

DESCRIPTORS: Patient education as topic. Caregivers. Colostomy. Internet-based intervention. Nursing. Enterostomal therapy.

PERFIL BIOSSOCIODEMOGRÁFICO E DIGITAL DE PARTICIPANTES DE UMA INTERVENÇÃO EDUCATIVA ONLINE SOBRE COLOSTOMIA

RESUMO

Objetivo: Identificar o perfil biossociodemográfico e digital das pessoas com colostomia e dos cuidadores que participaram da intervenção educativa online sobre colostomia. **Método:** Estudo transversal realizado com 20 pessoas com colostomia e 32 cuidadores, no período de setembro/novembro de 2020, em um centro integrado de saúde de Teresina, Piauí. Utilizaram-se instrumentos de caracterização sociodemográfica e clínica, acesso ao computador e à internet e proficiência digital básica, todos submetidos à análise estatística. **Resultados:** Das pessoas com colostomia e cuidadores, 60% eram do sexo masculino e 75% do feminino. Predominou a colostomia temporária (55%) de cor vermelho vivo e formato regular (80%). A maioria dos cuidadores tinha ocupação laboral (46,9%), e 8 horas/semanais eram dedicadas ao cuidado. O grau de proficiência digital foi baixo (76,9%). **Conclusão:** A identificação do perfil biossociodemográfico e digital dos participantes pode contribuir na adoção de estratégias educativas conforme a maturidade digital ou a necessidade de suporte para o uso de tecnologias, para otimização do cuidado em saúde e qualificação da assistência prestada.

DESCRITORES: Educação de pacientes como assunto. Cuidadores. Colostomia. Intervenção baseada em internet. Enfermagem. Estomaterapia.

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PERFIL BIOSOCIODEMOGRÁFICO Y DIGITAL DE LOS PARTICIPANTES EN UNA INTERVENCIÓN EDUCATIVA ONLINE SOBRE COLOSTOMÍA

RESUMEN

Objetivo: Identificar el perfil biosociodemográfico y digital de personas con colostomía y cuidadores que participarían de la intervención educativa en línea sobre colostomía. **Método:** Estudio transversal, realizado con 20 personas con colostomía y 32 cuidadores, en el período de septiembre/noviembre de 2020, en un Centro Integrado de Salud de Teresina, Piauí. Se utilizaron instrumentos de caracterización sociodemográfica y clínica, acceso a computador e internet y competencia digital básica sometidos a análisis estadístico. **Resultados:** La mayoría de las personas con colostomía y cuidadores eran hombres (60%) y mujeres (75%), respectivamente. Predominó la colostomía temporal (55%) de color rojo vivo y forma regular (80%). La mayoría de los cuidadores tenían trabajo (46,9%), y se dedicaban al cuidado 8 horas/semana. El grado de competencia digital fue bajo (76,9%). **Conclusión:** La identificación del perfil biosociodemográfico y digital de los participantes puede contribuir para la adopción de estrategias educativas de acuerdo con la madurez digital o la necesidad de apoyo para el uso de tecnologías, para optimizar la atención en salud y calificar la asistencia brindada.

DESCRIPTORES: Educación del paciente como asunto. Cuidadores. Colostomía. Intervención basada en la internet. Enfermería. Estomaterapia.

INTRODUCTION

Epidemiological changes in the Brazilian scenario resulting from accelerated urbanization and globalization are reflected in the increase in chronic non-communicable diseases, accidents, violence and the number of people who need ostomies[1]. It is estimated that in Brazil, in 2018, there were approximately 207,000 people with stomas[2].

The colostomy is a type of intestinal elimination ostomy that consists of a surgical intervention to exteriorize a segment of the colon through the abdominal wall, creating a stoma for the exit of feces and flatus[3].

Online educational interventions seem adequate for people with stomas who have difficulties in adaptation, self-care, social interaction and return to periodic consultations due to economic and transport barriers[4,5]. Furthermore, caregivers must receive health education and ongoing support from preoperative to home care[6].

Studies show that accessing information via the Internet can provide adequate support and be cost-effective for people with stomas and caregivers[7,8]. In Brazilian households, there is a trend towards growth in internet access via cell phones and microcomputers[9], which may favor online educational interventions. In this context, the virtual learning environment (VLE) is a viable and innovative technology that has synchronous and asynchronous tools that can be used to offer online educational interventions to health professionals and other users.[10,11].

Although there are online educational interventions for people with stomas and caregivers[7,12], their developers should have bothered to identify the bio-socio-demographic and digital profile of the participants before building them, to support them with an appropriate design for the target audience.

Thus, identifying the bio-sociodemographic profile of people with stomas is essential for planning care and future educational interventions to improve health services[3].In addition, it is believed that knowledge of the bio-sociodemographic and digital profile of people with colostomy and caregivers may be relevant in providing information for planning and implementing an online educational intervention, favoring the care and adaptive process of these people to the new condition imposed by the ostomy.

Given the above, this study is the first stage of a macro research project entitled Development, Validation and Evaluation of Intervention in a Virtual Learning Environment for People with Colostomy and Caregivers. For its development, the researchers needed to identify the bio-sociodemographic and digital profiles of people with colostomy and caregivers who would participate in the online educational intervention. Therefore, the following question was asked: what is the bio-sociodemographic and digital profile of people with a colostomy and caregivers participating in an online educational intervention? Thus, this study aimed to identify the bio-sociodemographic and digital profiles of people with colostomy and caregivers who participated in an online educational intervention.

METHODS

A cross-sectional, descriptive study with a quantitative approach carried out in a care program for people with a stoma at an integrated health center in Teresina, Piauí, from September to November 2019, after approval by the Research Ethics Committee (Opinion No. .189), according to Resolution of the National Health Council nº 466/2012 and its complements.

The population consisted of all people with a colostomy (n = 161) registered in the care program for people with a stoma at an integrated health center in Teresina. In cases where people with a colostomy couldn't join, the caregivers were invited. The sample was obtained by convenience and comprised 20 (38%) people with colostomy and 32 (62%) caregivers. The inclusion criteria for people with a colostomy were: age equal to or greater than 18 years; having the cognitive capacity to answer the study questions, verified by the Mini-Mental State Examination (MMSE); exclusively having a temporary or permanent colostomy; having a fixed residence in the capital of Piauí; and have a computer or smartphone with internet access. As exclusion criteria, there were: having psychiatric illnesses proven by medical reports.

Concerning caregivers, those who met the following criteria were included: age equal to or greater than 18 years; cognitive ability to answer the study questions; being the person who contributes to the direct care of the person with a colostomy; reside in the capital of Piauí; and have a computer or smartphone with internet access. The exclusion criterion was the same as for people with a colostomy.

People with a colostomy were located by surveying the electronic records of the care program for people with a stoma at the Teresina Integrated Health Center. Notably, the exclusive participation of people with a colostomy was due to the inclusion of specific topics related to the colostomy, such as guidance on intestinal irrigation.

A total of 142 potential participants were approached. The researcher's first contact with potential study participants was at the institution, weekly in the morning, during the care provided by the stoma therapist nurse and the nursing technician. After this contact, the study's objectives and the invitation to participate in the research were placed. Next, the inclusion criteria were verified, and for that, it was necessary to apply the MMSE. Afterward, people with a colostomy and caregivers who met the inclusion criteria and agreed to participate in the study physically signed the Free and Informed Consent Form, were registered in the VLE, where the online educational intervention was hosted, and received a login and access password. Then, a face-to-face moment before the online educational intervention was carried out with people with a colostomy and caregivers to familiarize them and remove doubts. However, depending on their difficulty accessing the online educational intervention, other face-to-face meetings took place at the center or at home, as the participants requested.

Also, a group on the WhatsApp application was created to facilitate communication between the study participants and the researcher, available during the four months of the online educational intervention. Through the WhatsApp group, the participants also received a tutorial on navigating the online educational intervention for consultation in case of doubts. This tutorial was also available on the VLE.

The instruments used were: bio-sociodemographic and clinical characterization of people with a colostomy, with 30 semi-structured questions; sociodemographic description of caregivers, consisting of 20 semi-structured questions; and computer and internet access for the person with a colostomy and the caregiver, with six semi-structured questions[13]. The instrument for measuring basic digital proficiency (BDP)[14] had eight items related to knowledge and skills in using the computer and the Internet, necessary and sufficient to perform basic tasks, on a five-point Likert-type scale, with the extremes ", totally disagree" and "totally agree"[14]. The interview time of the participants was, on average, 20 minutes.

The collected data were entered and compiled in the Excel 2013 version 15.0 program and then exported and analyzed in the Statistical Package for Social Sciences (SPSS) version 22 program. Descriptive statistics were performed.

For qualitative variables, absolute frequency and percentage were used, and for quantitative variables, measures of variance (mean and median) and dispersion (standard deviation – SD – and interquartile intervals). The significance level used for the statistical analysis was 5% ($p \leq 0.05$).

RESULTS

Of the 20 people with a colostomy, the majority were male (12; 60%), and the mean age was 42.4 years (SD ± 15.3). There was a predominance of people with colostomy with high school education (9; 45%), followed by the elementary school (5; 25%), postgraduate (4; 20%), functional literacy (1; 5%) and higher (1; 5%). Ten (50%) were married/in a stable relationship, seven (35%) were single, two (10%) were separated/divorced, and one (5%) was widowed. Most had children (14; 70%) and lived with partners and children (7; 35%); with family members without a partner (6; 30%); with a partner, child(ren) and/or other family members (4; 20%); alone (2; 10%); and with partner(s) with marital ties and without child(ren) (1; 50%). The average monthly income was R$ 2,136.7 (± R$ 2,177.3).

Of the 32 caregivers, the majority were female (24; 75%), and the mean age was 41.9 years (SD ± 12.1). As for education, 13 (40.6%) had high school, 12 (37.5%) higher education, five (15.6%) elementary school and two (6.3%) graduated. Sixteen (50%) caregivers were single, 15 (46.9%) were married/in a stable relationship, and one (3.1%) was separated/divorced. Regarding the family situation, the caregivers lived with their partner(s) and child(ren) (13; 40.6); with family members without a partner (12; 37.5); with a partner, child(ren) and/or other family members (3; 9.4); lived alone (2; 6.3); with a partner(s) with marital ties and without child(ren) (1; 3.1); and with another person(s) without blood ties and/or marital ties (1; 3.1). The average monthly income was R$ 2,115.9 (± R$ 1,546.7).

The clinical characterization of people with a colostomy is shown in Table 1.

Table 1. Clinical characterization of people with a colostomy (n = 20). Teresina, Piauí, 2019.

Variables	N	%	Md (P25-P75)
Causes of colostomy*			
Colorectal cancer	7	36.8	
Trauma	3	15.8	
Inflammatory bowel diseases	2	10.5	
Acute abdomen	2	10.5	
Others	5	26.3	
Permanence			
Temporary	11	55	
Location			
Lower left quadrant	7	35	
Lower right quadrant	7	35	
Upper left quadrant	3	15	
Upper right quadrant	3	15	
Color			
Bright red	16	80	
Pink	3	15	
Pale red	1	5	
Shape			
Regular	16	80	

continue...

Table 1. Continuation…

Variables	N	%	Md (P25-P75)
Implantation			
Flat	9	45	
Protruding	9	45	
Withdrawn	2	10	
Stoma complications			
No	16	80	
Peristomal skin complications			
No	11	55	
Colostomy preparation time			1,5 (0,8–3) years

*Characterization information was not obtained in its entirety. Those who answered the question were considered; Md: median; P25-P75: interquartile range.

As for the type of collector equipment, open (drainable) (19; 95%) and one-piece (16; 80%) predominated. People with a colostomy who had no difficulties in self-care (16; 80%) or limitations to perform activities of daily living prevailed (13; 65%). The median frequency of emptying the collection equipment was three times daily (3 – 5.8).

The care and occupational characteristics and the health conditions of the caregivers are shown in Table 2.

Table 2. Distribution of caregivers, according to care and occupational characteristics and health conditions (n = 32). Teresina, Piauí, 2019.

Variable	N	%	Md (P25-P75)
Caregiver time			**1 (0.3–6) years**
Hours per week for care			**8 (4.5–24) hours/week**
Lives in the same household			
Yes	19	59.4	
Degree of kinship*			
Mother		8	25.8
Father	4	12.9	
Sibling	4	12.9	
Spouse	4	12.9	
Grandparent	4	12.9	
Child	2	6.5	
Parents-In-law	1	3.2	
Others	4	12.9	
Employment status			
Employee	15	46.9	
Unemployed	9	28.1	
Domestic Skills	4	12.5	
Autonomous	3	9.4	
Retired	1	3.1	
Hours of sleep per day			**6 (5–7.8)**
Sleep is			
Interrupted	**22**	**68.8**	
Health problem			
No	**23**	**71.9**	

*Characterization information was not obtained in its entirety. Those who answered the question were considered; Md: median; P25-P75: interquartile range..

All 52 (100%) study participants had internet access. Of these, 17 (85%) people with colostomy and 26 (81.3%) caregivers used the Internet daily—almost all, 51 (98.1%), predominantly accessed the Internet from home. Most (30; 57.7%) did not own a computer, and of those who did, 13 (25.5%) used it daily. The online educational intervention was predominantly accessed via cell phone by 85% of people with a colostomy and 84% of caregivers. The BPD was low for most participants (40; 76.9%), followed by moderate (9.6), as shown in Table 3.

Table 3. Basic digital proficiency (BDP) of people with colostomy and caregivers who participated in the online educational intervention (n = 52). Teresina, Piauí, 2019.

BDP	Subject type		Total n (%)
	Person with ostomy n (%)	Caregiver n (%)	
Low	15 (75)	25 (78.1)	40 (76.9)
Moderate	2 (10)	3 (9.4)	5 (9.6)
High	1 (5)	0 (0)	1 (1.9)
Very high	2 (10)	4 (12.5)	6 (11.5)

DISCUSSION

The person with a stoma has the right to receive specialized care, with adequate information in hospitals and primary care[15]; however, there are barriers to follow-up and, consequently, gaps in education and follow-up that can affect people in managing their health[16]. Identifying the bio-sociodemographic and digital profile before implementing educational interventions can be a relevant tool for planning a technological resource that addresses the needs of people with colostomy and caregivers, and that enables the democratization of access to knowledge.

Thus, the study was directed to two user categories: people with colostomy and caregivers, with a more significant predominance of the latter. At the outpatient clinic, there were more demands from family members/caregivers to receive collection and adjuvant equipment. Research reveals that people have a more significant impact on the news that they will receive a stoma, to the detriment of diagnosing one of its causes, such as cancer, for example[4]. The fear of social stigma makes them keep the ostomy a secret[17]. The factors mentioned above, as well as the limitation of the health status caused by the disease that caused the stoma, may be responsible for the low demand of these people in the outpatient clinic and the non-adherence to participation in this research.

Similar to the profile of people with stomas in previous studies[14,18], most people with colostomy in this study were male and had a mean age of 42.4 years. Among the participants, colorectal cancer was the first cause of making colostomy, corroborating the findings in the literature.[17,18].

Concerning education, most people with a colostomy completed high school. Study shows that people with ostomy with higher education have a better perception of quality of life in the psychological and spiritual spheres[14]. Concerning the average monthly income of people with colostomy and caregivers, the study indicated that most were low-income. This finding aligns with the results of other studies.[14,19,20], in which the presence of the stoma impacts the socioeconomic context[20]. Study shows improvement in the biopsychological aspect and quality of life associated with higher income[14].

The clinical aspects regarding the bright red color and regular shape colostomy characteristics correspond to the literature recommendation [21]. The median time of ostomy and follow-up at the outpatient clinic indicates a recent period with the colostomy, similar to another study in which people with ostomies had used the collection equipment for one or two years[4]. Notably, the process of accepting the ostomy before themselves and society and other factors may be related to the time that people have the stoma[4].

The open (drainable) and one-piece systems predominated concerning the collection equipment. The type of collection equipment is corroborated in a study carried out with patients enrolled in an assistance program for people with stomas in Teresina, in which the drainable one-piece collection equipment was the most distributed and presented a significant association with the monthly cost, as the two-piece bag was more expensive, showing a relationship with increased costs[19].

Among caregivers, women were predominant, in line with findings in the literature.[6,19]. The mean age of 41.9 years corroborates with a previous study [19]. As for education, close results were found for middle and higher levels, contrary to those found in the literature, in which most participants had less than eight years of schooling[19]. A study points out the need to identify the educational level for adaptations in the transfer of guidelines on health education to facilitate the understanding by the individual[19].

The role of caregiver is recent, and few hours a week are devoted to caring, which may mean that people with a colostomy are less dependent on care. Responsibility for the care demands of people with ostomy influences the social and financial life of the caregiver, who refuses opportunities for professional growth or leisure to prioritize the person to care for[20].

Regarding the caregiver's degree of kinship, the mother was predominant, and most lived in the same household. This finding aligns with a previous study [20], in which the maternal figure was responsible for the care and financially accountable for health expenses.

The predominance of caregivers with work occupations opposed the research report in which caregivers mainly were unemployed and sold material goods to pay for health care[20]. Concerning sleeping habits, it can be assumed that sleep quality was unsatisfactory due to interruptions. A previous study on the home caregiver context found that few caregivers had help, generating stress, overload and abandonment of the spouse[20]. Thus, throughout the care process, family members suffer a deterioration in their quality of life[20].

Most caregivers did not have health problems, which may be linked to the average age of the participants; however, the study points out that the needs and demands attributed to the role of caregiver, such as loneliness, increased stress and limited social support, can result in health problems[8].In this sense, interventions based on the Internet can imply satisfactory health conditions for caregivers due to the promotion of well-being caused by the support of digital tools[8].

In the technological field, all people with colostomy and caregivers had access to the Internet, the smartphone was the most used means of entry, and most did not have a computer. This fact may reflect the national scenario, which shows a significant growth in the population using mobile phones to access the Internet and a sharp decline in using microcomputers to access the Internet[2].

On the other hand, the BDP was low in both user categories, demonstrating less affinity and skill in handling digital equipment; however, a study shows that an educational intervention, via computer, despite the low prevalence of use and regardless of literacy level, was considered feasible, as patients preferred using this technological resource to a traditional method of education[22].

The difficulty related to the low BDP of the participants required more time to get used to the VLE and often face-to-face assistance to access the online educational intervention, which may have influenced the low adherence of participants and the low demand of people with colostomy in outpatient clinics. So, the invitation to participate in the study was extended to caregivers who attended the health service and scheduled appointments according to availability and the place chosen by the person with a colostomy.

A limitation of this study was the sample size, which needed to allow the generalization of the results. The self-reported capacity for self-care is a possible information bias since it needs to be evaluated in practice.

The study contributes to nursing and health services insofar as knowledge of the bio-sociodemographic and digital characteristics can subsidize the assistance and application of educational technologies to support and guide people with colostomy and caregivers seeking to meet the needs of these users to encourage learning and improve quality of life. Knowledge of digital proficiency before applying an educational strategy enables professionals to create mechanisms to overcome user access obstacles.

CONCLUSION

It showed that people with colostomy and caregivers have low incomes and average education. Despite the recent ostomy time, most did not present complications or difficulty in self-care. Caregivers required less care time and had a job.

The degree of BDP was low among study participants; however, most accessed the online educational intervention via smartphone, a practical device. In this way, there is an approximation with the digital medium, and the training of these people and their assistance made using the VLE feasible. In addition, all participants had access to the Internet, which can help them use technological resources to obtain information.

It is considered, therefore, that knowledge about the characteristics of people with colostomy and caregivers can contribute to the adoption of educational strategies according to digital maturity or the need for support for the use of technologies to optimize health care and qualification of assistance provided to this clientele, to meet the needs of these users, encourage learning and promote quality of life.

AUTHORS' CONTRIBUTION

Formal Analysis: Monteiro AKC and Andrade EMLR; **Conceptualization:** Monteiro AKC and Andrade EMLR; Data Healing: Monteiro AKC and Andrade EMLR; **Methodology:** Monteiro AKC and Andrade EMLR; **Writing - First Version:** Monteiro AKC, Monteiro AKC, Matias RS, Brasileiro YBAS, Gouveia MTO, Araujo Filho ACA and Andrade EMLR; **Writing - Reviewing & Editing:** Monteiro AKC, Monteiro AKC, Matias RS, Brasileiro YBAS, Gouveia MTO, Araujo Filho ACA and Andrade EMLR; **Supervision:** Monteiro AKC, Monteiro AKC, Matias RS, Brasileiro YBAS, Gouveia MTO, Araujo Filho ACA and Andrade EMLR; **Validation:** Monteiro AKC, Monteiro AKC, Matias RS, Brasileiro YBAS, Gouveia MTO, Araujo Filho ACA and Andrade EMLR; **Visualization:** Monteiro AKC, Monteiro AKC, Matias RS, Brasileiro YBAS, Gouveia MTO, Araujo Filho ACA and Andrade EMLR.

DATA AVAILABILITY STATEMENT

Data is available upon request.

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