

DIGITAL HEALTH AND SELF-CARE IN PEOPLE WITH INTESTINAL OSTOMIES: AN INTEGRATIVE REVIEW

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ABSTRACT

Objective: synthesize the scientific production related to digital health in ostomies to promote self-care. **Method:** integrative review with research in online databases, seeking to answer the following guiding question: What are the digital approaches used to teach self-care to patients with ostomy identified in the publications? **Results:** six different ways of using digital health to promote self-care in people living with intestinal ostomies were identified. Five were published in the National Library of Medicine (MEDLINE) database and one published in the databases Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS) and Base de Dados de Enfermagem da Biblioteca Virtual em Saúde (BDENF), in the period from 2017 to 2020. **Conclusion:** the six approaches studied can be used simultaneously in individuals with ostomies and can be considered complementary, as they act in different aspects of the individual's routine, with the ultimate goal being to improve the quality of life of the person with an intestinal ostomy.

DESCRIPTORS: Ostomy. Internet access. Health education. Distance education. Stomatherapy.

SAÚDE DIGITAL E AUTOCUIDADO EM PESSOAS COM ESTOMIAS INTESTINAIS: REVISÃO INTEGRATIVA

RESUMO

Objetivo: sintetizar a produção científica relacionada à saúde digital em estomias para a promoção do autocuidado. **Método:** revisão integrativa com pesquisa em bases de dados on-line, buscando responder a seguinte questão norteadora: Quais são as abordagens digitais utilizadas para o ensino do autocuidado de pacientes com estomia identificadas nas publicações? **Resultados:** foram identificadas seis diferentes maneiras de empregar a saúde digital para promover o autocuidado em pessoas vivendo com estomias intestinais. Cinco foram publicadas na base de dados da *National Library of Medicine* (MEDLINE) e uma publicada nas bases de dados Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS) e Base de Dados de Enfermagem da Biblioteca Virtual em Saúde (BDENF), no período de 2017 a 2020. **Conclusão:** as seis abordagens estudadas podem ser utilizadas simultaneamente em indivíduos com estomias e podem ser consideradas complementares, pois têm ação em diferentes aspectos da rotina do indivíduo, sendo o objetivo final a melhoria da qualidade de vida da pessoa com estomia intestinal.

DESCRIPTORES: Estomia. Acesso à internet. Educação em saúde. Educação à distância. Estomaterapia.

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SALUD DIGITAL Y AUTOCUIDADO EN PERSONAS CON OSTOMÍAS INTESTINALES: UNA REVISIÓN INTEGRADORA

RESUMEN

Objetivo: sintetizar la producción científica relacionada a la salud digital en ostomías para la promoción del autocuidado. **Método:** revisión integradora con investigación en bases de datos on-line, buscando la respuesta a la siguiente pregunta guía: ¿Cuáles son los abordajes digitales utilizados e identificadas en las publicaciones para la enseñanza del autocuidado en pacientes con ostomía? **Resultados:** se identificaron seis diferentes maneras de emplear la salud digital para promover el autocuidado en personas que viven con ostomía intestinal. Cinco fueron publicadas en la base de datos de la *National Library of Medicine* (MEDLINE) y una publicada en las bases de datos Literatura Latinoamericana y del Caribe en Ciencias de la Salud (LILACS) y en la Base de Datos de Enfermería de la Biblioteca Virtual en Salud (BDENF), en el periodo de 2017 a 2020. **Conclusión:** los seis abordajes estudiados pueden ser utilizados simultáneamente en individuos con ostomía y pueden ser considerados complementarios, ya que actúan en diferentes aspectos de la rutina del individuo, siendo el objetivo final la mejora de la calidad de vida de la persona con ostomía intestinal.

DESCRIPTORES: Ostomía. Acceso a internet. Educación en salud. Educación a distancia. Estomaterapia.

INTRODUCTION

The presence of an ostomy brings with it changes in the physiology, self-esteem and body image of the person with an ostomy, the most striking being the loss of control over eliminations. Controlling the sphincters is a condition considered essential for social interaction, and the loss of this function can lead to isolation, believing that they are incapable of resuming the daily activities performed before the surgery¹.

Changes in lifestyle habits, such as food, hygiene, sleep and elimination control, associated with the need to use collecting devices, require adaptation to the change in the process of living². However, the person is faced with changes in their daily lives that can condition family, affective, work and social life to care for the ostomy¹.

Each patient understands their condition and care in a unique way. In addition, the family support network has its own organization and interrelationships, and taking care of these patients and preparing them for self-care requires nurses' sensitivity and the ability to make themselves understood³.

Some patients need support to resume daily life and the health team must be prepared to accommodate the care needs and promote better adaptation of those involved to the new routine of life. With support, the changes caused by the condition of a person with an ostomy can be better understood and the adaptation will be less suffered^{4,5}.

Health professionals can significantly contribute to improving the quality of life of individuals with ostomy as they plan care, include health education in their care process and develop the person's skills for self-care⁶. Thus, educational approaches in the process of living with an ostomy can play a decisive role in the physiological, psychological and social adaptation of individuals and their families^{3,4,7,8}.

Health education practices seek the subjects' autonomy, so that they are authors of their health and disease trajectory. By developing autonomy, the person takes responsibility for decisions related to their health, incorporating actions for self-care^{3,9,10}.

Nursing currently has a vast field of technological resources to assist in patients' self-care actions, which in addition to providing information, help establish routines. Information and Communication Technologies (ICTs) have been used globally in personal, educational, business and healthcare contexts. ICTs are communication tools that facilitate the transmission of information by digital means¹¹. The use of these tools in the teaching-learning process strengthens the construction of knowledge and expands the potential of this process¹².

Internet-connected information systems are in common and routine use, mainly through cell phones and computers. This ease of access to information fosters life in today's society. In a study that evaluated the use of mobile applications for healthcare, found evidence that the use of this type of technology is important for the population. The use of these technologies supports actions to monitor, inform, rehabilitate and assist people, helping them to live well and with quality of life¹¹.

Digital health is understood as the use of ICTs to promote health for everyone, everywhere. It incorporates e-Health, Telemedicine, Telehealth and Mobile Health, in addition to recent advances in technology such as new concepts, social networking applications, Internet of Things (IoT), Artificial Intelligence (AI), among others¹³.

Due to the need for specific care for patients with ostomy and considering the ease of access promoted by digital health, it is relevant to investigate the progress of published studies dealing with the topic of digital health aimed at patients living with intestinal ostomy. Bringing to the knowledge of professionals technological updates in the area of health education for patients with ostomy.

This study aims to synthesize the scientific production related to digital health in ostomy for the promotion of self-care. It is understood that the study results allow us to verify what has been used in the practice of health professionals to promote self-care, support approaches to care for people with an ostomy and guide investigations based on the panorama presented.

METHOD

Integrative review that aims to identify trends or evidence that support the proposed study. This type of study has the potential to provide a comprehensive understanding of the problems researched by using a rigorous and systematic method when analyzing the publications found.¹⁴ Integrative reviews include multiple data sources that provide a thorough understanding of the topic of interest¹⁴.

This manuscript followed the guidelines of the Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0) for its construction.

The steps for its realization include six phases: elaboration of the research question; search and definition of the sample through the selected descriptors; data collect; analysis of results; discussion; and dissemination¹⁴.

To collect evidence, a survey was carried out on the topic of digital health in ostomy to answer the following guiding question: What are the digital approaches used to teach self-care to patients with ostomy identified in the publications?

The search was carried out in July 2021 in the portal's databases Biblioteca Virtual em Saúde (BVS – BIREME).

In the search strategy, the association of descriptors was used: ostomy, internet access, health education and distance education, searched in the descriptors in Ciência da Saúde (DeCS), of the BIREME system. The Boolean operator "AND" was used, a time frame criterion from 2016 to 2021.

The inclusion criteria were to be an original article and available in full online. Theses, dissertations and articles without an abstract or incomplete were excluded. For this review, articles that addressed digital technologies for teaching and training professionals working in self-care were excluded.

Studies of digital technologies planned for direct use by ostomy users and their families were analyzed, with the aim of promoting self-care.

The analysis was carried out according to the steps proposed by Mendes et al.¹⁵, which include: identification of the theme and selection of the hypothesis or research question, establishment of criteria for inclusion and exclusion of studies, definition of information to be extracted from selected studies, evaluation of studies included in the integrative review, interpretation of results and presentation of the synthesis of knowledge.

The studies included in the sample were evaluated using a script with information on year of publication, title, authors, journal and methodological design.

RESULTS

The data sampling process is shown in Table 1.

Table 1. Distribution of scientific publications according to descriptors and databases. Porto Alegre (RS) – 2021.

Databases	Descriptors			Total Articles by database
	(ostomy) AND (internet access)	(ostomy) AND (health education)	(ostomy) AND (distance education)	
BDENF	0	32	4	36
LILACS	0	30	3	33
MEDLINE	8	57	4	69
Total articles by descriptor association	8	119	11	138

BDENF = Base de Dados de Enfermagem da Biblioteca Virtual em Saúde; LILACS = Literatura Latino-Americana e do Caribe em Ciências da Saúde; MEDLINE = National Library of Medicine.

A thorough reading of the pre-selected articles was carried out, which culminated in the selection of articles, with six comprising the final review sample.

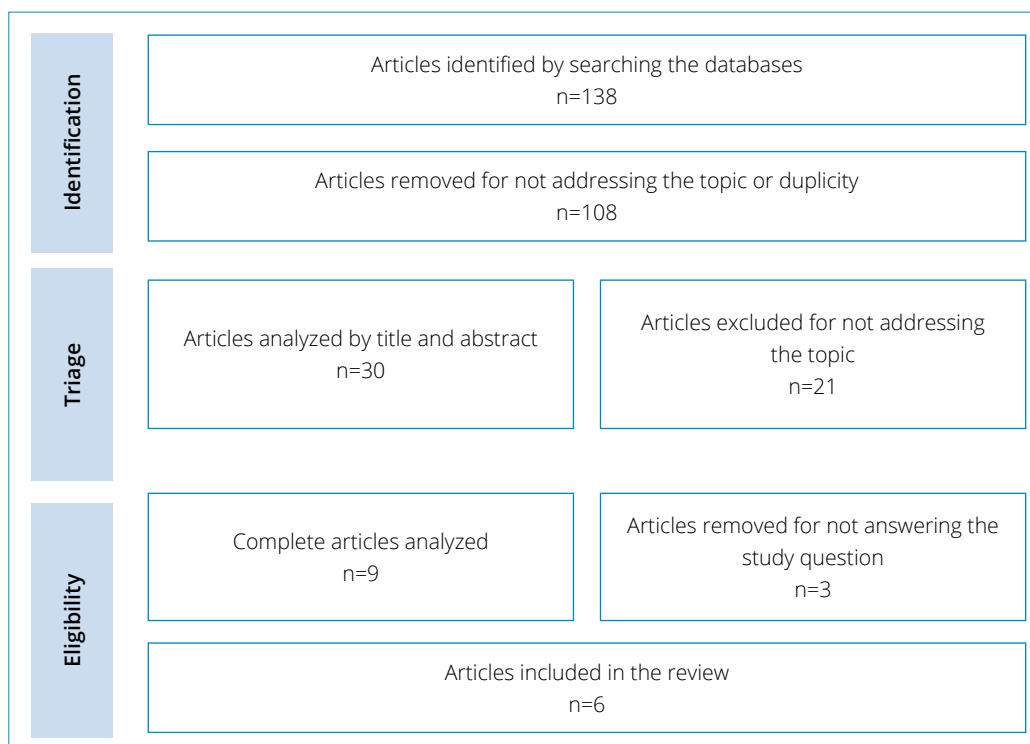


Figure 1. Process of data collection and selection of studies that make up the sample. Porto Alegre (RS) – 2021.

Of the six eligible articles, five were published in the National Library of Medicine (MEDLINE) database and one published in the databases *Literatura Latino-Americana e do Caribe em Ciências da Saúde* (LILACS) and *Base de Dados de Enfermagem da Biblioteca Virtual em Saúde* (BDENF).

The results were organized according to author, title, year, journal of publication, country of origin, objective, digital technology addressed and level of evidence, shown in Table 2.

Table 2. Synopsis of articles included in the integrative review, Porto Alegre (RS) – 2021.

Authors	Article title	Journal / year of publication	Objective	Digital Technology addressed	Level of Evidence GRADE
Pittman J, Nichols T, Rawl SM ¹⁶	Evaluation of Web-Based Ostomy Patient Support Resources.	<i>J Wound Ostomy Continence Nurs.</i> ; 2017.	Evaluate the patient support resources currently available on the web, at no cost, designed for people with recent ostomies.	Ostomy information sites available for free on the internet.	Low
Rouholiman D, Gamble JG, Dobrota SD, Encisco EM, Shah AG, Grajales I et al ¹⁷	Improving Health-Related Quality of Life of Patients With an Ostomy Using a Novel Digital Wearable Device: Protocol for a Pilot Study.	<i>JMIR Res Protoc.</i> ; 2018	Assess the quality of life of ostomy patients using the Ostom-i alert sensor, a portable, wearable, Bluetooth-connected biosensor that facilitates easier ways to exit the ostomy bag.	Automated portable sensor with alert on the patient's personal cell phone when detecting the presence of volume in the collection bag.	—
Sun V, Ercolano E, McCorkle R, Grant M, Wendel CS, Tallman NJ, Passero F, Raza S, Cidav Z, Holcomb M, Weinstein RS, Hornbrook MC, Krouse RS ¹⁸	Ostomy telehealth for cancer survivors: Design of the Ostomy Self-management Training (OSMT) randomized trial.	<i>Contemp Clin Trials.</i> ; 2018.	Describes the study design of a telehealth-based ostomy self-management (OSMT) training program for cancer survivors and their caregivers.	Online course through the Zoom platform, given to patients with ostomies and their caregivers.	—
White T, Watts P, Morris M, Moss J ¹⁹	Virtual Postoperative Visits for New Ostomates.	<i>Comput Inform Nurs.</i> ; 2019.	Define the feasibility of virtual post-operative consultations to answer specific questions that patients want to address and record these patients' satisfaction with the consultations in the virtual format.	Teleconsultation for self-care training for patients with ostomies.	Low
Indrebø KL, Aasprang A, Olsen T, Andersen JR ²⁰	A new model of patient-reported outcome monitoring with a clinical feedback system in ostomy care: rationale, description and evaluation protocol.	<i>Health Qual Life Outcomes.</i> ; 2020.	Describe a new ostomy model, in which a clinical feedback system is implemented in order to improve the adaptation process of patients with an ostomy. Present a plan to assess patients' experience with the system and its clinical outcomes.	Virtual instrument with a questionnaire about the knowledge and experience of the patient with an ostomy. The answers are forwarded to the nurses who use the system's calculations to address the issues most difficult for the patient during the consultation.	Moderate
Silva BWAC, do O LB, Araújo AKD, Medeiros MBC, Melo VL, Sena JF, Costa IKF ²¹	<i>Análise de vídeos de autocuidado no YouTube sobre troca de bolsas de estomias intestinais.</i>	Rev Rene (Online); 2020.	Analyze YouTube videos about self-care during the exchange of ostomy bags. Quantitative and descriptive research methods, carried out on Google. Descriptive statistics and the Kruskal-Wallis test were used.	Educational videos for colostomy bag exchanges.	Moderate

Regarding the year of publication, two publications were identified in 2020, one in 2019, two in 2018 and one in 2017. Of the published studies, one was developed in Brazil, one in Norway and four in the United States of America (USA). Of these articles, four had descriptive quantitative research as a methodological design, a randomized study.

The six different possibilities of digital health approach for the care of patients with ostomy identified in this study are presented in Table 3.

Table 3. Description of digital technologies for the self-care of patients with ostomy found in the articles studied, Porto Alegre (RS) – 2021.

Digital technology addressed	Description
Educational videos for changing colostomy bags published on YouTube.	Videos produced and published on YouTube with content aimed at changing the collector device in intestinal ostomy. They were analyzed using a checklist built according to the theoretical content of the <i>Cartilha Educativa Para o Cuidado da Pessoa com Estomia Intestinal</i> . (Educational Booklet for the Care of Persons with Intestinal Ostomy.)
Virtual questionnaire that makes it possible to calculate the patient's needs to be addressed during care.	Web-based questionnaire for routine results monitoring (ROM) with clinical feedback system (CFS)
Teleconsultation.	Pilot study to implement teleconsultation with a stoma therapist for patients with intestinal ostomy between the 2nd and 7th day after hospital discharge.
Virtual, distance, synchronous course for learning about self-care in ostomies.	Online course designed for training in self-care and improving the quality of life for ostomy patients and caregivers. Total 5 sessions of 2 hours duration. There are 3 sessions for patients, 1 session for caregivers and 1 session for both groups.
Ostomy information sites.	Quality analysis of content freely available on the web to improve self-care in ostomy patients.
Effluent disposal warning sensor in collection bag.	Ostom-i, a portable Bluetooth biosensor that facilitates ostomy bag exit measurements. Analysis of the quality of life of patients with ostomy after using the device.

DISCUSSION

A guide to care for people with an ostomy during the Covid-19 pandemic was recently published. This guide reports the importance of technological updating for the care of patients with ostomy in order to offer new care modalities, with a view to maintaining support for care, even with the need for social distance. The time has come to innovate, audit and evaluate new and different ways to provide the care service to patients with ostomies. Ensuring that services provide equity of access, remaining flexible to everyone's needs triggers the planning of future services, considering a wide range of strategies to bring users closer together²². Thus, it appears that advances and improvements in the use of digital health technologies need to be continued.

Telehealth is an example of evolving digital health technology that can be used as a complementary tool to face-to-face consultations. For people who have recently undergone an ostomy, the immediate postoperative period is a delicate transitional moment between hospital discharge and the usual initial clinical follow-up. Sensitive, educational, and timely interventions should be prioritized to help these patients return as close to their normal function as possible.¹⁷ In this sense, the use of videoconferencing and telehealth equipment for postoperative visits allows for an adequate examination of the patient, speeds up care, reduces anxiety and monitors acute complications. It is a tool to empower each patient and provide them with a better level of health¹⁷.

In the same line of technology for care, using Telehealth, a preliminary randomized clinical trial tested the effectiveness of a training program in ostomies. The program aims to awaken the individual to self-care in a patient with an ostomy due to cancer¹⁸. This program provides goal setting and problem solving approaches to increase autonomy. Four group sessions are offered via videoconference, in real time, administered by stomal therapy nurses. An additional session is also offered to caregivers to meet their needs regarding ostomy care. This technology enabled users from three different geographic areas, in two time zones, and from their own homes to participate in the study¹⁸.

This virtual approach, in the form of real-time support groups, has high potential to positively impact the unique physical, psychological, social and spiritual needs of cancer survivors living with a permanent ostomy. The course is built on a solid theoretical and practical understanding of the issues facing ostomy survivors. It's large, adaptable, accessible, simple, low-intensity, and reproducible. Contributing to the study design, process, and approach to telehealth, the authors infer that future efforts to disseminate the intervention in diverse clinical and community settings will be successful¹⁸.

The participation of ostomy patients in support groups demonstrates great value in the adaptation process. Provides the sharing of questions and experiences of participants and can include patients and their families¹⁹. The approach through virtual means allows this interpersonal contact to remain even in situations where moving to the meeting is impossible.

The degree of satisfaction and well-being of the patient with ostomy is related to the way in which this individual adapts to his new condition. Health care, therefore, must consider the expectations, anxieties and needs of the patient in a way that facilitates the formation of a bond between them and the health professional¹⁹.

In this context, a technology created for clinical feedback of the patient with an ostomy can be considered a tool to facilitate attachment. By admitting that sometimes patients with stoma have difficulties in reporting their problems, this tool allows for a greater understanding of the needs of this individual. It is an intervention via an online system in which the patient answers a questionnaire, at home, before the face-to-face consultation. The system includes self-reported measures for adaptation to life with an ostomy and health-related quality of life. In addition, experiences and patient satisfaction are recorded through the clinical feedback system²⁰.

Measurements are electronically evaluated before each clinical visit, at 3, 6 and 12 months after surgery. Scores are instantly analyzed and presented graphically for use during the query. The patient and the stomal therapist can discuss the results. This technology aims to assess the patient's adaptation to the use of an ostomy. Equipment or skin lesions are not evaluated²⁰.

With a different technological approach, but also with the intention of improving the quality of life of the ostomy patient, the Ostom-i alert sensor was developed. This sensor is a portable device designed to facilitate the adaptation of patients with ostomy bags. The sensor issues an elimination alert in the collection bag and provides anticipation of bag exchanges, and is connected via Bluetooth to the user's smartphone¹⁷.

The vast majority of people have access to the internet using computers or smartphones²¹. This fact makes it easier for many patients with ostomy to seek guidance on websites aimed at this type of audience. One of the main reasons for this search is the fact that the hospital stay has been reduced for surgery. In ostomy surgeries, time is very limited for planning the discharge and preparing the patient and family for home care¹⁶.

In one of the studies included in this review, the evaluation of free sites available on the internet for consulting content related to ostomies was carried out. The study reports that this type of technology is accessed by both young adults and the elderly, and most often using tablets or smartphones. It was found that in all four sites evaluated, the content available met the best practices/professional standards for education of patients with ostomy. The most important difference between the sites was the ways in which the content is presented, which vary in the way it is organized¹⁶.

As for the websites, it can be concluded that this type of web-based resource, when accurate and reliable, can be a very viable option for educating the patient with an ostomy, especially if the preparation of the patient and family for hospital discharge was limited.

Another content model available on the web and widely accessed by users are the videos produced to teach self-care to patients with stoma. These technological products are very popular and easy to reach.²¹ The popularity of videos published on Youtube motivated researchers to evaluate the quality of videos about changing the colostomy bag.

The lack of guidance regarding the ostomy, especially regarding the exchange of the bag, is the main difficulty reported by patients with an ostomy. This digital technology was considered a relevant means of dissemination to reach this population and important for the learning of self-care²¹.

A limitation of this study is the small number of publications included in the research. Although it is common knowledge that numerous digital technologies are being used with ostomy patients, a large part of the material produced found in published databases was related to the teaching or training of health professionals and academics.

However, the studies presented address facilitating technologies for teaching/learning self-care in ostomy patients, as they constitute alternatives to overcome some barriers that hinder this process.

CONCLUSION

Through the analysis of selected articles, it was possible to identify six different ways of using digital health to promote self-care in people living with intestinal ostomy. All resources used are viable and possible to be replicated in different locations, some with greater accessibility and using technological resources already inserted in the daily lives of users.

The six approaches studied can be used simultaneously in individuals with an ostomy and can be considered complementary, as they act in different aspects of the individual's routine, with the ultimate objective being to improve the quality of life of the person with an intestinal ostomy.

The study confirmed what the existing literature says, which points to digital health as an access alternative, improving the care process and promoting the quality of life of patients with an ostomy. All digital technologies studied were identified as alternatives for improving patient care. These are tools that encourage self-care and were used to support face-to-face care. They facilitate the patient's access to care, but they do not replace the nursing consultation and face-to-face patient assessment.

Future studies with research in different databases are suggested, as well as feasibility studies for the implementation of these technologies in nursing care services for patients with ostomy.

AUTHORS' CONTRIBUTION

Conceptualization: Pozebom NV; **Methodology:** Viégas K and Pozebom NV; **Research:** Pozebom NV; **Writing – First version:** Pozebom NV; **Writing – Reviewing & Editing:** Pozebom NV and Viégas K; **Resources:** Pozebom NV and Viégas K; **Supervision:** Viégas K.

DATA STATEMENT AVAILABILITY

Data will be made available on request.

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