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REVIEW ARTICLE

Social networks, apps and videos for people with intestinal ostomy, tracheostomy and caregivers: from informal networks to communities of practice

Redes sociales, apps y videos para personas con ostomía intestinal, traqueotomía y cuidadores: de redes informales a comunidades de práctica

Redes sociais, aplicativos e vídeos para pessoas com estomia intestinal, traqueostomia e cuidadores: das redes informais para as comunidades de prática

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Abstract

This article seeks to describe the evidence on social networks as informal online networks aimed at people with tracheostomy, intestinal ostomy and their caregivers, providing evidence of how online Communities of Practice (CPo) could use social networks, supported self-care apps and videos. An integrative review was carried out in all six stages, with a timeline search between 2010 and 2021 in the LILACS, PUBMED, CINAHL, SCOPUS and Web of Science databases. After analyzing 314 articles, the 17 articles included in the sample were explored in 4 categories, still using the framework of the social scientist Étienne Wenger, who coined the term CPo. Thus, there were only informal networks and not communities of practice, nor synchronous use of technological resources in them, so community patterns were sought in existing informal networks, considering the benefits generated for people with ostomy and caregivers when accessing videos, applications and software from future communities of practice. Finally, the seven principles to cultivate them for the profile studied are exposed, relying on the existing informal networks and a research agenda around this unexplored nationally and internationally.

Descriptors: Ostomy; Social Media; Internet-Based Intervention; Learning Health System; Self Care.

Resumén

Este artículo busca describir la evidencia sobre las redes sociales como redes informales en línea dirigidas a personas con traqueostomía, ostomía intestinal y sus cuidadores, brindando evidencia de cómo las Comunidades de Práctica (CPo) en línea podrían usar las redes sociales, las aplicaciones de autocuidado respaldadas y los videos. Se realizó una revisión integradora en las seis etapas, con una línea de tiempo de búsqueda entre 2010 y 2021 en las bases de datos LILACS, PUBMED, CINAHL, SCOPUS y Web of Science. Después de analizar 314 artículos, los 17 artículos incluidos en la muestra fueron explorados en 4 categorías utilizando el marco del científico social Étienne Wenger, quien acuñó el término CPo. Así, solo existían redes informales y no comunidades de práctica, ni uso sincrónico de recursos tecnológicos en ellas, por lo que se buscaron patrones comunitarios en las redes informales existentes, considerando además los beneficios que genera para las personas con ostomía y cuidadores al acceder a videos, aplicaciones y software. de futuras comunidades de práctica. Finalmente, se exponen los siete principios para cultivarlos para el perfil estudiado, apoyándose en las redes informales existentes y una agenda de investigación en torno a este recorte inexplorado a nivel nacional e internacional.

Descriptores: Estomía; Medios de Comunicación Sociales; Intervención Basada en la Internet; Aprendizaje del Sistema de Salud; Autocuidado.

Resumo

Este artigo busca descrever as evidências sobre redes sociais como redes informais online destinadas a pessoas com traqueostomia, estomia intestinal e seus cuidadores, lançando evidências de como Comunidades de Prática on-line (CPo) poderiam usar redes sociais, aplicativos de autocuidado apoiado e vídeos. Efetuou-se revisão integrativa na totalidade de seis etapas, com busca em linha temporal entre 2010 e 2021 nas bases LILACS, PUBMED, CINAHL, SCOPUS e *Web of Science*. Após análise de 314 artigos, os 17 artigos inclusos para a amostra foram explorados em 4 categorias empregando ainda o referencial do cientista social Étienne Wenger que cunhou o termo CPo. Destarte, verificaram-se apenas redes informais e não comunidades de prática, tampouco uso síncrono dos recursos tecnológicos nas mesmas, portanto buscaram-se padrões de comunidades nas redes informais existentes ponderando ainda os benefícios gerados as pessoas com estomia e cuidadores ao acessarem vídeos, aplicativos e *softwares* a partir de futuras comunidades de prática. Por fim, expõem-se os sete princípios para cultivá-las para o perfil estudado contando com as redes informais já existentes e uma agenda de pesquisa em torno deste recorte inexplorado nacionalmente e internacionalmente.

Descritores: Estomia; Mídias Sociais; Intervenção Baseada em Internet; Sistema de Aprendizagem em Saúde; Autocuidado.

Introduction

Intestinal stomas are an artificial opening in the abdomen to divert the flow of feces out of the body temporarily or permanently, requiring a fixed collection device. Two areas of the intestine form a stoma: the ileum (small intestine), which results in a loop ileostomy, or the colon (large intestine), which results in a colostomy[1].

The diseases that require this surgical treatment are colorectal cancer, ulcerative colitis, Crohn's disease, pelvic cancer, congenital diseases, diverticular disease, familial adenomatous polyposis, among others. Tracheostomies, which are performed to help patients breathe, whether temporary or permanent, involve removing the larynx and separating the airways from the mouth, nose, and esophagus, usually because of cancer[1,2].

Structured interventions with stomatherapist nurses and the provision of printed material or soft-hard care technologies after the newly stomized patient is discharged and returned to his home are promising initiatives for self-management in the extra-hospital environment. The perioperative period is when health education is primarily passed on and complicating this moment are the lack of care systematization, pain, nausea, fatigue and emotional suffering, giving rise to a teaching path in which guidelines and support for social adjustment are provided online on a lasting basis[3-6].

In this way, online social engagement is defended in exchanges with significant others (stomized people) and cyberspace balances the space versus time relationship and increases cultural exchange despite lacking personal contact. It is undeniable that mutual engagement in a practice, negotiation of it and the routines established around the commitment to learn are advantages of online communities of practice (CPo) that can permeate self-care supported in health[7-9].

The advent of CPo is the transposition of the concepts of Étienne Charles Wenger and Jean Lave to cyberspace, the construct of the “Situated Learning Theory” is carried out through them and through legitimate peripheral participation. Due to the complexity of supported self-care and knowing that its deviations lead to readmissions after the surgical procedure, computer-assisted or smartphone-assisted education bringing together the use of videos, applications, software and support on social networks is urgent, and the versatility of PCo makes it convenient for these technologies are available in your structure to be viewed or downloaded[9-12].

Communities of practice differ from support groups and informal networks. Health support groups are composed of patients with chronic diseases and for ostomy patients they are relevant for the encouragement, inspiration and hope for their components, the topics of discussion of such spaces include the facilitation of topics mediated by medical oncologist and surgeon, clinical psychologist, exercise physiologist, nutritionist and stoma therapist nurse[13].

Informal networks are a set of relationships that have no mission while the CPo will bring together multiple teams for something, usually the practice-knowledge dyad. These exist to build knowledge and learning from meetings and commitment to participate in the exchange of knowledge constituted in a domain, the components are from different geographic locations, boasting their own identity and directing certain questions related to the practice[14-16].

The dimensions of a CPo are engagement in a domain, imagination and alignment[17]. There are also standards for CPo identification according to Wenger and Wenger-Trayner[14]: Problem solving (SP), Requesting information (SI), Seeking experiences (BE), Reusing resources (RR), Coordinating and finding synergy (CES), Building arguments (CA), Building trust (IC), Discussing personal development and (DDPC), Document projects (DP), Organize visits (OV) and Map Knowledge and Identify Holes (MCIB).

Successful examples exist in the business field and in organizational learning in companies; virtual collaborative environments for students and teachers, providing opportunities for proximity to information technology for synchronous and asynchronous teaching; in establishing a “digital ecology” with interaction followed by private reflection; in addition to Facebook© being used as an informal network to obtain information by people with cochlear implants, high blood pressure and Crohn's disease[8,10,15,16,18,19].

In view of the above, the objective is to describe the evidence on social networks as informal online networks aimed at people with tracheostomy, intestinal ostomy and their caregivers, launching evidence of how online communities of practice could use social networks, supported self-care and videos.

Methodology

The Integrative Review (IR) was used with identification of the study question, criteria for inclusion and exclusion of studies, information identified, categorization, evaluation of studies, interpretation of data and synthesis of knowledge[20]. The following are motivators for a discussion of the state of scientific production: focused themes; methodological designs; innovations, restrictions in the field of knowledge, research contributions and identifies contributions to the construction of theories and practical models[21].

It is asserted that more than one research question can be used in IR[22]. The chosen questions were: What is the evidence on social networks as informal online networks aimed at people with tracheostomy and intestinal ostomy and their caregivers?; How can online communities of practice aimed at people with tracheostomy and intestinal ostomy and their caregivers use social media, supported self-care apps and videos for their composition?

Descriptors in Health Sciences (DECS), Medical Subject Headings (MESH), CINAHL Headings and the uncontrolled term “community of practice” were used combined with the Boolean operator AND, as shown in Chart 1.

The inclusion filters were English, Portuguese and Spanish, timeline from 2010 to 2021, and other review studies, informal networks of health professionals and research that touched on the topic were excluded.

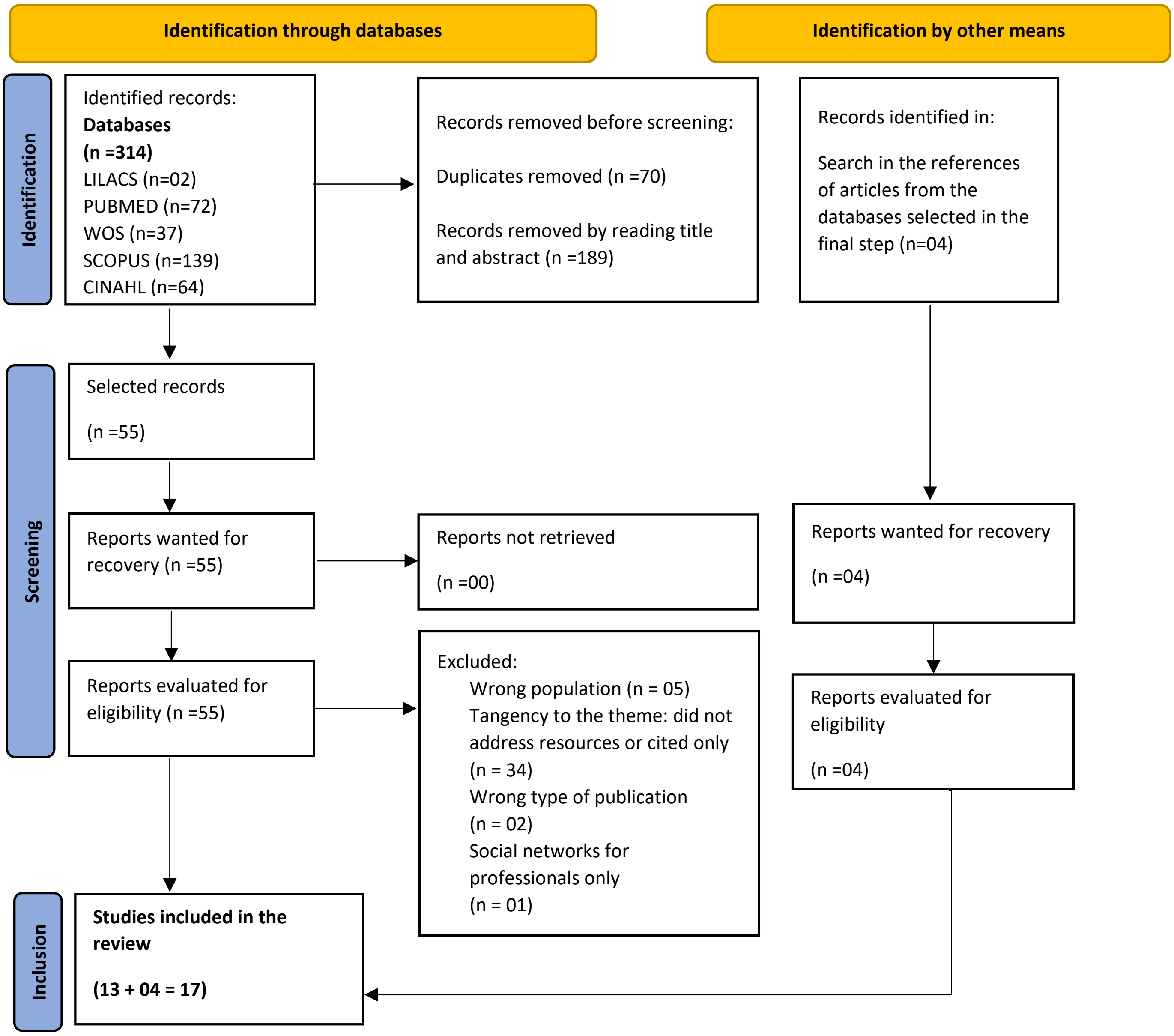
Chart 1. Database search strategy. Ribeirão Preto, SP, Brazil, 2021

DeCS and MeSH combinations	Data base
Grupos de autoajuda AND estomia / grupos de treinamento de sensibilização AND estomia / intervenção baseada em internet AND estomia / mídias sociais AND estomia / estomia AND comunidade de prática	**LILACS**
Grupos de autoajuda AND colostomia / grupos de treinamento de sensibilização AND colostomia / intervenção baseada em internet AND colostomia / mídias sociais AND colostomia / colostomia AND comunidade de prática	
Grupos de autoajuda AND ileostomia / grupos de treinamento de sensibilização AND ileostomia / intervenção baseada em internet AND ileostomia / mídias sociais AND ileostomia / ileostomia AND comunidade de prática	
Grupos de autoajuda AND traqueostomia / grupos de treinamento de sensibilização AND traqueostomia / intervenção baseada em internet AND traqueostomia / mídias sociais AND traqueostomia / traqueostomia AND comunidade de prática	
Learning Health System AND ostomy / Self-Help Groups AND ostomy / Sensitivity Training Groups AND ostomy / Social Media AND ostomy / Internet-Based Intervention AND ostomy / Ostomy AND community networks / Ostomy AND community of practice	**PUBMED, SCOPUS, WoS**
Learning Health System AND colostomy / Self-Help Groups AND colostomy/ Sensitivity Training Groups AND colostomy / Social Media AND colostomy / Internet-Based Intervention AND colostomy / Community Networks AND colostomy / Colostomy AND community of practice	
Learning Health System AND ileostomy / Self-Help Groups AND ileostomy / Sensitivity Training Groups AND ileostomy / Social Media AND ileostomy / Internet-Based Intervention AND ileostomy / Community Networks AND ileostomy / ileostomy AND community of practice	
Learning Health System AND tracheostomy / Self-Help Groups AND tracheostomy / Sensitivity Training Groups AND tracheostomy / Social Media AND tracheostomy / Internet-Based Intervention AND tracheostomy / Internet-Based Intervention AND tracheostomy / Community Networks AND tracheostomy / tracheostomy AND community of practice	
Learning Health System AND ostomy / Community Networks AND ostomy/ Social Media AND ostomy/ Internet-Based Intervention AND ostomy/ Support Groups AND ostomy / Ostomy AND community of practice	**CINAHL**
Learning Health System AND colostomy/ Community Networks AND colostomy/ Social Media AND colostomy/ Internet-Based Intervention AND colostomy/ Support Groups AND colostomy / Colostomy AND community of practice	
Learning Health System AND ileostomy/ Community Networks AND ileostomy/ Social Media AND ileostomy/ Internet-Based Intervention AND ileostomy/ Support Groups AND ileostomy / Ileostomy AND community of practice	
Learning Health System AND tracheostomy/ Community Networks AND tracheostomy/ Social Media AND tracheostomy/ Internet-Based Intervention AND tracheostomy/ Support Groups AND tracheostomy / Tracheostomy AND community of practice	

The management took place through the Rayyan application and the PRISMA year 2020 recommendation was used to detail the search steps[23]. The references of the selected articles were checked in order to find other publications that met the objectives.

There was a need to be analyzed with the alignment of a theory[21]. Wenger and Wenger-Trayner patterns were used for analysis[14] these being: SP, SI, BE, RR, CES, CA, IC, DDPC, DP, OV and MCIB and concepts relevant to the CPo as seven principles to cultivate them[24]. The evaluation of the seven levels of evidence respected: level I for systematic review or meta-analysis, level II for randomized controlled trial, level III for controlled trial without randomization, level IV for case-control studies or cohort studies, level V for metasynthesis , level VI for qualitative studies and level VII for expert opinions[25]. The flowchart for the search and selection of studies is presented (Figure 1)

Figure 1. Flowchart of search and selection of studies. Ribeirão Preto, SP, Brazil, 2021



Source: PRISMA Recommendation 2020[23].

Results

The 314 publications were identified and after eligibility in the screening, the final sample consisted of 17 articles, of which 04 were searched in the references of the 13 publications.

As for the origin of the 17 publications: 2 studies from China (P7 and P12), 2 studies from India (P2 and P17), 3 studies from Brazil (P3, P10 and P16), 1 study from Iran (P6) and 9 studies from United States of America (P1, P4, P5, P8, P9, P11, P13, P14, P15). It culminated in a level of evidence of VI for 11 studies, III for three studies and II for three studies. It was found that videos and applications have not been resources coupled in CPo (Chart 2).

Chart 2. Synoptic table of studies included in the IR. Ribeirão Preto, SP, Brazil, 2021

(Code)	Authorship/ Year/ Base/ Country	Participants	Method/Level of evidence
(P1)	Madan *et al.*/ 2011/ SCOPUS/ USA	Adolescents with tracheostomy	Descriptive transversal / LE = VI
(P2)	Halemani; Shashidhara; D'Souza *et al.* / 2021 / PUBMED/ India	Caregivers of children with colostomy	Quasi-experimental / LE = III
(P3)	Silva *et al.* / 2020/ CINAHL/ Brazil	People with a stoma and caregivers	Quantitative, descriptive, with descriptive statistics and Kruskal-Wallis test / LE = VI

(P4)	Bedra *et al.*/ 2013/ SCOPUS/ USA	People recently ileostomized	Descriptive transversal with intervention / LE = VI
(P5)	Rosa et al./ 2019/ identificado a partir de SILVA *et al.*/ USA	Caregivers and people with a stoma	Educational technology development study carried out in 2 phases: production and validation / LE = VI
(P6)	Farahani, Dorri, Yousefi/ 2019/ identificado a partir de Silva *et al.*/ Iran	People with colostomy, duodenostomy, jejunostomy, or ileostomy	3-phase development study, including software development and creation, validity and modification / LE = VI
(P7)	Wang *et al.*/ 2018/ PUBMED/ China	People with colostomy, ileostomy and urostomy	Randomized controlled trial / LE = II
(P8)	Huestis *et al.*/ 2020/ CINAHL/ USA	Family caregivers of children with tracheostomy	Data-based theory study / LE = VI
(P9)	Frohlich; Zmyslinski-Seelig/ 2016/ SCOPUS/ USA	People with a stoma	Thematic analysis of messages communicated in online support groups / LE = VI
(P10)	Stragliotto *et al.*/ 2017/ identificado a partir de Silva *et al.*/ Brazil	Colostomized people and caregivers	Descriptive and qualitative approach / LE = VI
(P11)	Meyer-Macaulay *et al.* / 2021/ SCOPUS/ USA	Biological or adoptive parents, family members, and home nurses or respiratory therapists of children with tracheostomy and mechanical ventilation at home	Qualitative with content analysis of texts by caregivers of children with tracheostomy and respiratory supports as expressed on the Internet, in the light of the mid-range nursing theory of uncertainty in Mishel's disease / LE = VI
(P12)	Xia/ 2020/ CINAHL/ China	Colostomized people	Single-blind randomized clinical trial / LE = II
(P13)	Rademacher/ 2018/ SCOPUS/ USA	People with a stoma	Exploratory qualitative case study, on six news stories aimed at mass audiences after Google search by Bethany Townsend Ostomy Selfie / LE = VI
(P14)	Cherney *et al.*/ 2020/ SCOPUS/ USA	Caregivers and people with recent tracheostomy to safe discharge home	Quasi-experimental / LE = III
(P15)	Crawford *et al.*/ 2012/ SCOPUS/ USA	Adults aged 21 years and over with colostomy or ileostomy	Randomized controlled trial / LE = II
(P16)	Dalmolin *et al.*/ 2016/ LILACS/ Brazil	Caregivers and people with a stoma	Descriptive with a qualitative approach / LE = VI
(P17)	Dabas *et al.*/ 2016/ identificado a partir de Halemani; Shashidhara; D'Souza/ India	Caregivers of colostomized children	Group pre-test and post-test regarding a video teaching program related to pediatric colostomy / LE = III

With the exception of one study (P3) that extensively verified the videos posted on Youtube© about self-care during the exchange of ostomy bags, four studies with video-type resources were interventions coupled to the phases of randomized controlled, quasi-experimental and randomized design studies and time series with pre-test and post-test (P15), video to strengthen the primary caregiver's confidence in the child's colostomy care (P2), video development for caregivers (P17), implementation of "Trach Trail" care protocol ” which includes an informative video (P14). Another 2 studies with a qualitative approach included videos in their design (P10 and P16) and another was characterized as validation (P5).

Facebook© was the most mentioned media in studies on the experience of adolescents with tracheostomies or parents of children with tracheostomy, sharing network experiences with other users through Facebook© (P1 and P8), in the P11 study with parents and family caregivers of children living with tracheostomy in addition to Facebook©, the forum community where users vote on content (also interacting with external links) – Reedit, was researched. Two other studies examined interaction between significant others and stigma in comments on photos of people with stomas on Facebook© (P9 and P13).

Other cyberspace-based resources were explored in the randomized design (P12), such as WeChat© (multiplatform instant messaging service developed by Tencent in China), blog and QQ (the most popular instant messaging program in China). Applications and software were evidenced: for people with ileostomy with interactive education (P4), prototyping of a software for patient education based on the theoretical principles of the cognitive theory of multimedia (P6) and a home self-management mobile application on psychosocial adjustment , self-efficacy and stoma-related complications (P7).

No PCo was found according to Wenger's “Identity of communities”[17] which implies the use of concepts, vocabulary and tools appropriate for its denomination. It was noted the lack of interface of video resources, media/social networks and applications for CPo composition. However, it is considered that publications on informal networks that provide evidence on CPo patterns were captured. The description of informal networks in P1, P8, P9, P11 and P13 stands out (Chart 3).

Chart 3. Analysis of IR articles. Ribeirão Preto, SP, Brazil, 2021

Códe	Technological resource used or analyzed	Learning or exchanging with significant others	Standards for identifying communities of practice
P1	Social media – Facebook©	Yes	BE, IC
P2	Video on colostomy care, including anatomy and physiology of the human digestive system, colostomy care, diet management, and complication prevention	No	
P3	Videos of 4-20 minutes present on the Youtube© website about the exchange of intestinal ostomy collection equipment are analyzed	No	
P4	Computer-assisted education system installed on a touchscreen tablet	No	
P5	Scripted video about (con)living with colostomy and cancer	No	
P6	Software for people with ostomies to promote self-care after surgery to promote fecal diversion	No	
P7	Mobile app for home care	No	
P8	Social media – Facebook©	Yes	SP, SI, BE, CES, CA
P9	Website and Social Media – Facebook©	Yes	BE, IC, CA
P10	Educational video	No	
P11	Internet-based resources: public forums and blogs written by caregivers – six resources were sampled, two were Q&A-style forums (“Facebook©” and “Reddit©”), three were blogs written by a single author and one was an online magazine written by and for parents of children with chronic illnesses	Yes	SP, SI, BE, CES
P12	WeChat©, blog, QQ	No	
P13	Social media – Facebook©	Yes	BE, IC, CA

P14	Multifaceted Trach Trail Intervention that includes an informative video	No	
P15	DVD for patient instructions	No	
P16	Scripted video about (con)living with colostomy and cancer	No	
P17	Video teaching program	No	

Discussion

Information networks for ostomy-caregivers: when will we reach PCo?

Informal networks only group and pass on information without mandatory joint initiatives around a learning-practice. The interaction through Facebook© indicated important aspects of “Participation in learning systems” and “Ways of belonging” (local interaction and global participation). However, evidently the evidence was null regarding the “Presence of an internal leader” and “Social engagement” – doing and talking together producing artifacts with the help of nurses and doctors (documents, norms, symbols, stories and tools)[15,17].

Interactions of ostomized people in cyberspace on Twitter©, Instagram and Snapchat, denormalize the relationship between people with ostomies in relation to the non-ostomized public and as “medicalized bodies” as they are commonly seen[26]. The posts in Facebook© groups were aimed at giving, selling or exchanging equipment and products, acquiring security in the exchange of the cannula or collector, seeking support, information, news and updating the participants' lives.

The term “Online Health and Photo Sharing Communities” reports individual initiatives involving self-acceptance: provocative images of Jessica Grossman showing her ostomy while narrating her life at university; the viral reaction to Bethany Townsend's selfie that clearly showed two visible ostomy pouches covering much of her abdomen, with 12 million views and 246,000 likes on Facebook©; four adolescents with tracheostomy (diagnosed with neuromuscular respiratory failure, grade III tracheal stenosis, ventilator dependence secondary to a chest wall deformity and upper airway obstruction secondary to neurofibromatosis), accessed groups on Facebook© and three felt safe when post pictures of themselves talking about health[26-28].

In the existence of a CPo, which was not verified in the research, its patterns are interconnected and thus the patterns were not found in the informal networks: Reuse resources, Discuss development, Document projects, Organize visits and Map knowledge identifying holes. However, 6 CPo patterns were identified in informal networks: Seeking experiences, Building trust, Solving problems, Asking for information, Coordinating and finding synergy and Building an argument.

1) Seeking experiences: Effective and uncomplicated communication encourages people with chronic problems, living socially isolated or not, to share their stories in a network. The experiences will vary according to the condition that caused the stoma to be made, but even so, there are common points: lack of normality in relation to other people (“typical parents” and their children without a chronic condition), their negative impacts and the need for restoration of life, disagreements and distrust and experience with the family[14,28,29];

Those who post their experiences and comment on the experiences of others share post-surgical stories, connect through stories of pets, tattoos, talk about the impact of cancer/ostomy on their careers and jointly reflect that the function ostomy is to allow a better life like a second chance. Transition from medical provider recommendations, clinical and life situation perceptions, divergent and conflicting expectations, lack of collaboration or information, unsolicited treatment advice as experimental or complementary such as medical cannabis, Ayurvedic and Chinese medicine, and dietary changes[26.27,29,30].

Emotional support experiences are given via comments on the forums applauding resilience, reporting inspiring moments and narrating stories of overcoming, aiming at self-reflection on challenges such as leaks, increased flatulence and peristomal skin irritation. Exposing such experiences favors a change of perspective and adequacy, in the sense that they implicitly think that they will only be able to expose their bags in a bathroom and take selfies in public places (such as beaches), forces the “significant others” (re)think among themselves the social standards that reject any positive aspects of exposing bodies with collection bags and even make them wonder why the health system does not offer colorful or more elegant bags[26].

2) Increase trust: Facebook© support allows the experience of adolescents with tracheostomies to reverberate in an “online community of convenient access”, increasing perceived social support, awareness and self-confidence. A similar effect was seen in the viral selfie boosting trust[14,26,28];

A sense of self-reflection endorses this elevation of trust via photo sharing on networks, as they reflect on the “love” and frustrations of carrying an intestinal ostomy bag. This fact is verified with reports that involve humor when treating the ostomy (as in the comment that the person had named his stoma as “Stella stoma” after the surgery), thanks for the bravery of shy people to share photos too, thanks for showing how much an ostomy can be beautiful or those who felt depressed even years after the surgical treatment[27].

3) Troubleshooting and Requesting Information: In the case of parents of children with tracheostomy, clinical problems, uncertainty, loss of "normality" arise, coping, support providers, resourcefulness in care, having an internal or external control center, burden, financial worries, relationship mitigation, conflict, trauma, and resilience[14,29].

Knowing this, asking for information is a constant given the lack of education on topics such as infection, dermatitis treatment, which products and equipment are the most used, where they could be found or donated. The description of delivery points and suppliers is noticeable, but this does not prevent problems such as that of parents of tracheostomized children who were practically forced not to change their children's tubes as often as indicated by professionals. Informal networks are often characterized by forums for parents to provide resources for their peers saying what health professionals did not have the opportunity to say, these are critical examples after tracheostomy: how to configure the ventilator at home?, adequate storage of medical supplies and how to support child mobility. Ingenious solutions are given for travel, exposure to water and how to allow the child to crawl using the fan. Within informal networks, the term "structure providers" is given to those who provide information in the face of the range of problems and uncertainties[29,30].

4) Coordinate and find synergy: For the task of taking care of a child with a tracheostomy or even taking care of the tracheostomy he had all his life, groups are relatively safe points to look for news and update questions. Gradually finding the necessary synergy, they deal with the lack of an internal locus of control and acquire the resourcefulness to face physical and emotional problems in the family, however in this IR the coordination of efforts in favor of some care product was not verified in the informal networks[14,29,30];
5) Build an argument: Posting comments indicating recovery, happiness, saying the person is "great" or proud, builds within the informal online network supporting arguments after the opportunity to explore issues about infection, treatment of peristomal skin irritation and other clinical factors. It is asserted that in smaller networks the feeling of belonging and being helped is more intense[14,29,30].

Being a catalyst for a greater mission, building awareness and inclusion statements to the outside public, is one of the intentions of disseminating photos in the online health community. Showing ostomy bags, scars, tattoos, socializing or engaging in physical activities build a challenging argument for the stigmas of social isolation and inactivity that these people suffer. More than stimulating the ego, social media challenges the idea that the lives of people with ostomies are less active, reporting struggles and self-confident body images[26,27].

Consequently, the development of PCo for colostomized, ileostomized and tracheostomized people is distant according to the scientific literature, therefore, it is emphasized that they are not what was verified: several electronic tools and a series of communications without a guide[15]. Knowing that the evidence for them is a seemingly unexplored path for people with a stoma, their patterns were not fully realized.

It is argued that the informal networks described are similar to the concept of E-group, sharing asynchronously between its participants. Furthermore, the aspects of "Imagination" and "Alignment" would also be necessary, which direct self-care to practical problems, supporting the coordination, validation and auditing of the PCo by health professionals. The patterns not found go back to the systematic involvement for the production of tools and routines demanding goals and direction that are not within the scope of informal online networks, the very occurrence of shared practice was not visualized, but the sharing of experiences and problems that to a certain extent allowed resolution of acceptance and clinical issues[10,16,17].

Audiovisual resources: why not add them to the CPo?

Resources would be aggregated as links in the rooms and are already being aggregated in the forums of informal networks. The videos are classified as theoretical, practical and theoretical-practical, and the term "interaction" was used to refer to the way in which people and caregivers engage with audiovisual technologies, due to the approach to reality and basic reflection on the ostomies. More than an audiovisual resource, videos are multidimensional resources linked to teaching-learning pedagogical practices[5,31,32].

The video is a tool for those with no experience in handling the effluent collection bag, especially after hospital discharge. Educational scenarios based on real facts were well received by caregivers, with emphasis on improving the quality of life of the caregiver-child ostomized by acquiring practical skills and knowledge, and it is suggested that such technologies should not use the caregiver only as a vehicle, as well as instrumentalize it to observe and record changes and intercurrences in a critical way[5,33-36].

After the analytical sieve of a Brazilian research team, 32 videos for intestinal ostomies were analyzed, indicating that: 15 demonstrate the exchange of one-piece pouch and 20 the exchange of two pieces (three videos reported the exchange of two types). Being videos presented mostly by people with and addressing various topics of self-care, coming from useful platforms, such as Google© and Youtube©[31].

In this IR, a variety of scripts were found: (1) a 9-minute teaching video explaining the basic anatomy of the intestines, colostomy indications, signs of a healthy stoma, cleaning, stoma dressing and complications, before the video was shown. they did not wash their hands, they did not clean the stoma from the outside to the inside, nor did they protect the stoma region with a cloth soaked in suitable products while the bag was not yet attached; (2) video with an introduction, handling, new way of looking at life and testimony from a family member, lasting just over 8 minutes[5]; (3) handling, cleaning outside the home, ways to perform the exchange and proper cutting of the plate to the size of the stoma without errors, caution to avoid peristomal injuries and durability issues[33,35].

The "learning by repetition of techniques" is achieved by the combination of individual instructions and DVD, being an instruction controlled at the user's pleasure. It was confirmed that the method of Instruction for Nurses associated with the educational DVD (2 individual sessions and 1 lesson on DVD) was as effective as the “Traditional Nurses Instruction” (3 individual sessions given by a specialist nurse) in education[6].

Another successful experience of a North American study involving video implementing multimodal education and supported self-care on tracheostomy was the Trach Trail, developed with the Iowa Model of Evidence-Based Practice in 7 steps: select a topic, form a team, search for evidence, classify it, develop a standard of practice, implement evidence-based practice, and evaluate the results. There is an initial meeting with the clinical practice nurse, supervisor, family caregivers and respiratory therapist, defining the Trach Trail schedule, including a terminology glossary, educational booklet, the basic care video and access to the hospital’s “GetWellNetwork”.[37].

However, limitations and future points to be improved in the videos are emphasized: showing what the rights of these users are, citing places where to look for supplies and equipment, various ways of managing the ostomy, when the family is not with some users and citing the proper removal of the intestinal stoma collection equipment. Furthermore, verbal guidance and illustrations will still be necessary to increase the potency of the educational care video[5,31,32].

Software and applications: why not download from CPo?

The software that supports video galleries, on the other hand, needs to undergo a thorough validation by specialists in this production, taking into account: how the video will be displayed, choice of subtle background music, there are no ambiguities, adequate font size, fewer clicks to move to the next screen, contain a “Back” button every time, anatomy and physiology, nutritional training, detailed images (such as ostomy necrosis to let them know that necrotic changes appearing in white and black are critical) and tracking of when access from home[12,38].

The functional modules of other applications stand out: 1. Filling in basic personal and medical information and scheduling an appointment with the specialist nurse (periodically 1, 3 and 6 months after discharge); 2. Diagnosis by photography in which specialist nurses make a diagnosis based on the users' stoma photographs sent via the application (periodically 1, 3 and 6 months after discharge); and 3. Contact nurses for support, complementary to outpatient follow-up[11]. The Iranian software galleries had 22 videos/slideshows with 56.1 GB of memory, and from the initial menu, eight content modules are accessed, where each alternate section gives a step-by-step guide on self-care. An interesting fact is the availability of this software in the wards during the postoperative period[38].

Subjects with an affinity for the daily use of a computer, tablet or e-reader are easier to handle and are more interested in this modality called “continuous hospital integration care” or “improved care follow-up”, which brings together multimedia information for people with stomas. After discharge, the patient contacted the team through WeChat©, blog, phone or QQ, immediately expressing problems, the caregiver was also encouraged to talk in real time via the software[11,12,36].

In a study supervised by researchers and an experienced programmer, the following were sent by text, voice or video via the application: step-by-step guidelines on stoma care and measures to prevent complications; reports of successful self-care experiences of others with an ostomy; promoting acceptance of a stoma; recommendations for relieving negative emotions such as anxiety and depression. For six months, if they had any problems after discharge, they would contact counseling or individual support via the mobile application and, if the experts judged that self-care consistently and lastingly was good, they were exempted from fixed outpatient follow-up[11].

In the supported self-care scenario, new studies must be developed to produce and validate online digital resources (mobile or not) in hospital-to-home transition care in rehabilitation, expanding the types of population for which the applications are intended[11,31].

RI contributions to potential CPo

Interpreting the approximations and distances between informal networks and communities from the reference point[24], it is known that many fall apart and so that this does not happen, seven principles are encouraged although they are not recipes:

1) Design for evolution: start as simple structures and fewer elements than a traditional organization, benefiting from existing networks such as those found in RI, its core must remain engaged in one or more practices or topics through a website on which links and materials.
2) Open dialogue between the “inside” and “outside”: the flow of ideas must be bidirectional. From the inside, the results and the heart of the domain are appreciated with the development of techniques and ideas, but collaborations with other external organizations should not be closed and its design foresees that multiple structures and personnel are added.
3) Invite for different levels of participation: design the most different types and levels of participation. There is a public forum and a small central group where the nucleus is located with the leadership, moderator(s) and assistant, being the fostering members (10 to 15%). The small active group are those who regularly or occasionally participate in the forums without the regularity of the core (15 to 20%). The large portion are peripheral members who rarely participate and only watch the participation of others because they feel contemplated by the explanations or feel that they

lack authority on the topic. Contrary to what it seems, they are essential and not passive in learning, they have private insights and in their own way they learn a lot. Outside components are preferably "intellectual neighbors" contributing sporadically at the invitation of the nucleus. As the CPo is fluid, its boundaries adhere to this scope and the rooms or forums from the website have ways of co-opting people to the core.

4) Development of public and private spaces: Considering that, especially in the field of stomas, technical discussions, exploring problems and ideas, must have the necessary funneling going from private to public even online, to base face-to-face events in the future, the website you will need public and private spaces in your meetings and forums.
5) Value Focus: CPo's grow with a sense of the value of the practice they develop. Value is changeable and a central element, these are ways of monitoring value: 1) advising system engineers to expand or ascertain the extent of the CPo; 2) create events or debates to discover or reinforce this value; 3) encourage members to talk about their impact on their lives.
6) Combining familiarity and emotion: using regular meetings and using the website as the main domain, points must be clarified: 1) there are no mandatory processes; 2) the CPo is a free place; 3) the PCO is a neutral place and should not cause fear in its components, especially when dealing with stigmatizing or sensitive topics such as sex, fecal effluents, blood or secretions.
7) Create a rhythm: activities and practice require rhythm so as not to exhaust participants. Ostomized patients go through ruptures, challenges and new sensations sequentially, especially in the postoperative weeks, and the nucleus needs to be aware that time and cadence and interactions influence practice.

Conclusion

It was found that Facebook© groups have been used for stoma management and self-care practice in Informal Networks, which are not characterized by systematic knowledge negotiations like PCo. As limitations, the use of self-care applications and software and videos was not focused on in isolation, but the possibility of synchronous use - revealing the non-existence of this use. At the same time, the search strategy did not include people with urostomy and gastrostomy.

The IR did not find applications, software and online videos coupled, thus, the scientific literature was critically analyzed with evidence and possibilities on an unexplored topic, allowing for the coupling of audiovisual resources such as videos and download of software and mobile applications in the domain of CPo.

Primarily, social (informal) online support networks also have a profusion of patterns such as seeking experiences, building trust, problem solving, requesting information, coordinating and finding synergy and building a case especially in international studies. Future CPos could use the network of contacts of social networks from their own domain, a website, or from the presence of an internal leader and health provider(s) in the informal network itself, engaging members around the learning of one or more practices with well-defined goals and always requesting feedback. From there, the production of elements and even important tools or documents would take place. It is also known from the study of Wenger's work that the CPo use existing structures such as forums and informal networks.

Secondly, despite being excellent teaching and self-care tools, applications, videos and software encourage individual learning, fixation and training of the practice(s) passed on by the CPo core, not constituting in no way as the isolated solution to the range of teaching-learning demands. In-person or online feedback must be requested by a health provider, as well as an understanding of the existence of more or less agile people in the learning path at CPo.

All explanations so far are possibilities. Next steps for a future research agenda on PCo for ostomy patients, I would consider: the validation of elements of one of them carried out by experts and target audience; equipment and technical network necessary to carry out self-care supported online and support subsidizing rehabilitation; network for data security, information and website profiles; training of users with a-functional literacy or with little mastery of technological resources and diagnosis of the needs of people with stomas and their caregivers in cyberspace.

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