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# Popular care, self-care, and adaptation in rural dyads with intestinal elimination ostomies

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**Abstract**

Popular care, self-care, and adaptation in rural dyads with elimination ostomies Objective: To analyze popular care, self-care, and adaptation in rural care dyads with bowel elimination ostomies. Methods: Qualitative ethnographic study, with snowball sampling, in-depth interviews, and field notes; coding performed with qualitative software. Results: 8 dyads participated; 198 quotations, 54 codes, and 8 categories were identified: cultural adaptation and popular care, meanings, corporeality, emotional adaptation, activities of daily living, feeding, instrumental knowledge, and life project. Conclusions: The dyads go through adaptation processes in which they implement popular care from their resources, to mitigate access barriers and socioeconomic difficulties. From the point of view of health care, it is necessary to identify the needs of each dyad and the popular care applied, to validate safe practices and negotiate concerning those that are risky. Keywords: Nursing. Perceptions. Patients. Ostomy. Caregivers. Culture. Self-care.

## Introduction

People who require an elimination ostomy as part of their treatment face changes in their body that impact the roles they fulfill, also affecting their primary caregivers and families.[1] The Federation of Incontinent and Ostomized Persons' Associations (FAIS) estimates that around two million people worldwide have an ostomy. However, it is difficult to obtain an exact figure due to the lack of records and data from some countries.[2,3] In Colombia, there is no national registry of ostomized patients, but according to data from the Colombian Association of Ostomized Persons, there will be between 15,000 and 30,000 ostomized individuals by 2021.[3]

Care dyads require long-term adaptation processes, as this condition impacts psychological, social, and sexual dimensions,[4] generating uncontrollable feelings of uncertainty,[5] as people must learn to be aware of and accustomed to changes and restrictions in their daily lives.[6] Ostomies constitute a physical change that affects body image and self- esteem,[7] along with a decrease in sexual desire,[4] making it necessary to consider an integral approach in the management of ostomized individuals.

Follow-up and health education processes must necessarily be personalized, considering the socioeconomic and cultural contexts of these individuals.[8] The popular care and self-care employed by dyads living with a permanent elimination ostomy demonstrate the adaptations they make, with particular significance in addressing the rural population of Cundiboyacense, given its agrarian connotation. According to Leininger, care that takes cultural aspects into account is defined as: "the values, beliefs, and lifestyle patterns that are professionally and popularly learned and transmitted".[9] Thus, to contribute to the study of this phenomenon, this research seeks to analyze popular care, self-care, and adaptation in rural care dyads regarding the management of permanent elimination ostomies.

## Methods

A qualitative ethnographic study[10] using snowball sampling was conducted until theoretical saturation of the information was reached, according to the research objectives.[11] Care dyads were included, consisting of a person with a temporary or permanent elimination ostomy, of any gender, who had undergone surgery more than three months prior, was of

legal age, and had a primary caregiver (either a family member or another type of relationship) who was also of legal age, both residing in rural areas of the Cundiboyacense region.

Initial contact and invitation to participate in the study were made via telephone, during which home visits to the rural residences of these care dyads in the Cundiboyacense region were scheduled. Subsequently, in-person visits were conducted, and after the informed consent process (which included conducting interviews, audio recording, and photographic documentation), in-depth interviews were carried out using a guiding questionnaire developed from the specific objectives of the study. These interviews were audio-recorded and lasted approximately one hour. Two dyads required two sessions, while one visit was sufficient for the rest.

The collected information was transcribed verbatim, reflecting the participants' statements, and field notes were also taken. All these findings were processed through qualitative analysis, which included open coding to freely identify individual emerging thematic codes from each interview, followed by axial coding to organize these codes into thematically related categories and subcategories. This analytical process took place over several synchronous sessions, in which all the researchers contributed, ensuring the triangulation of different researchers in the data analysis. Subsequently, a word cloud and resulting theoretical frameworks were generated using the Atlas TI 8.0 software.

For the development of this study, prior approval was obtained from the Ethics Committee of the project received prior approval from the Research Ethics Committee of the institution managing the project. This study was considered to be of minimal risk since sensitive topics were addressed during the interviews, for which the researchers were qualified to provide psychological first aid. However, these risks did not materialize. Throughout the entire study, the principles of scientific integrity were respected at each stage of the research.

## Results

The study included the participation of 8 care dyads, comprising 16 individuals: 8 ostomized patients of different ages and genders (4 women and 4 men; 2 young adults, 3 adults, and 3 elderly adults), and their 8 family caregivers. Notably, 7 of the caregivers were first-degree relatives (3 spouses, 2 children, and 2 parents), while in 1 case, the caregiver was a neighbor and friend of the patient. All participants resided in rural areas of the Cundiboyacense region, and 7 of the dyads were part of the subsidized health care system.

The interviews with participants led to the identification of 198 excerpts, which were structured into 54 codes. These codes, in turn, formed the foundation for 8 main categories described below.

Cultural adaptation and popular care refer to the activities implemented for ostomy care as expressed by the care dyads, adapted to the rural context in which they live (in terms of language and the products used for care). These activities stem from their ancestral cultural beliefs and values, which are rooted in their communities' practices for managing various types of wounds. The dyads have purposefully adapted these practices to ostomy care.

Ostomy patients and their family caregivers adapt their ancestral knowledge of skin care using the resources available in their environment. This adaptation helps them cope with barriers such as limited access to medical devices and specialized consultations, geographic obstacles, socioeconomic challenges, and lack of training in instrumental care. They utilize everyday products they perceive as helpful for managing these issues to heal, reduce inflammation, alleviate pain, clean, and for other uses, leading to popular care practices and self-care that allow them to cope with their new health situation.

These popular care practices include odor mitigation, translating technical terms into more familiar language, creating closure devices, washing and reusing the bag, using topical solutions, transparent tape as an adhesive, and applying products such as anise, "Jabon Rey" soap, talcum powder, vinegar, liquid soap, wipes, and creams around the ostomy. For example: "*I make a little cream, some rice, and a little potato to help set the little tummy [the ostomy], to manage it properly and carefully*" D9: O_6-9:21 (6980:7054). "*Sometimes I take off the entire bag to wash it and keep it clean, as I've also seen others do…* [E: What do you wash it with?] *I wash it with water, soap, and vinegar*" D5: O_4-5:42 (12780:12937). "*I would take a shower with 'Jabon Rey,' because they say 'Jabon Rey' is good for everything, for wounds*" D3: O_1-3:56 (10318:10525). "*Sprinkle some baby powder in the bag, the kind you use for babies, so it doesn't smell bad*" D1: O_3-1:33 (6600:6693).

For these dyads, having an ostomy carries ambivalent meanings depending on the stage of the adaptation process they are in. It evolves from being seen as a divine challenge or test, to feelings of hopelessness, a return to the care of infancy, something unexpected, and finally as something positive that contributes to health improvement. Accepting the new body means recognizing and reinterpreting the body, which causes suffering, anxiety, and impacts the caregiver. However, over time, there is a positive acceptance of the body and the recognition of the ostomy as an autonomous organ: "*It's a very tough challenge that God gives someone… but it was God's will, and we have to accept it, and we move forward with God's help*" D1: O_3-1:24 (4828:4877). "*Because after 21 years, I had to go back to dealing with a small baby again, with baths and everything, for his care*" D1: O_3-1:14 (3462:3582).

Some care dyads also provide evidence of achieving emotional adaptation, demonstrating progress in a positive and constructive process of living with an ostomy. This includes aspects that help manage having an ostomy, such as maintaining a good attitude, a willingness to learn, and developing resilience. In this way, the ostomy is seen as a facilitator in dealing with each pathological process and as a permanent new reality, especially in the case of a permanent ostomy: "*But for those people who have to live with this for life, the only thing I have to say is to keep a positive attitude and morale, because I understand that having a bag hanging there isn't pleasant, but you have to keep moving forward*" D1: O_3-1:70 (16300:16657).

This adaptation is reflected in daily activities, through reintegration into everyday life, which includes household chores, changes in clothing style, and acceptance/resignation. Adaptation is also evident in changes to diet, as necessary modifications to both the type of food and how it is prepared are required: "Because it's not easy for someone to see you with that bag, so at first it's uncomfortable. In my case, I like to

wear these big sweaters to cover it up, to hide it a bit, because it's always uncomfortable" D1: O_3-1:42 (8628:8870). "*But the food has to be special at first, now I eat everything and it doesn't harm me, I've been eating everything for a while, and I haven't had a blockage in a while*" D9: O_6-9:23 (7057:7235).

Another indication of positive progress in the adaptation process is the acquisition of instrumental knowledge by the dyad. This becomes evident when there is ownership of the self-care of the person with the ostomy, highlighting the importance of care, understanding of intestinal function, the use of skin care products, recognition of the characteristics of the stoma, and awareness of warning signs: "*It's manageable now, but it requires steps and strict care because you can't neglect it, like if it starts to come off or something like that*" D1: O_3-1:5 (1735:1882).

Regarding future life projects, it is identified how these care dyads are motivated to value life, and how their loved ones inspire them to have a future projection in family, academic, and work areas: "*He helped me so much, my son, to move forward, to study, to work. The best thing I've had in my life is him, and my husband and my son*" D3: O_1-3:70 (13764:14001). "*I also studied something in aesthetics, and we opened a psychology practice, but with aesthetics because, in hair salons, people vent more than they do with psychology*" D2: O_2-2:148 (60911:62233).

## Discussion

From a cultural care perspective, the values, beliefs, and cultural practices of these care dyads are recognized[12] as a field of study, a framework that allows for assertive and transformative care, enabling the recognition of these people, their knowledge, and their creativity[13] as they adapt to contexts where there are geographic and access barriers to both health devices and specialized care, issues that are exacerbated in remote rural areas, where socioeconomic and information access limitations are frequent.

In this regard, in Western Australia, healthcare teams encounter a significant gap in the delivery of products and struggle against the stoic culture of the rural population living with ostomies.[14] This population employs popular care and self-care practices, such as using plastic bags fastened with rubber bands, which in the long term resulted in complications, such as granulomas that made it difficult to apply medical devices.[14] Rachel Spector, on the other hand, has developed the Health Traditions model, which links practices derived from communities with the maintenance, protection, and restoration of physical, mental, and spiritual health in each culture.[15] This is exemplified by the study of Tao Hui et al., who analyze care from the Chinese cultural perspective, finding that autonomy in changing devices prevails, with little acceptance of a family member taking charge of care. Conversely to the results with participants from Cundiboyacá, who adhered to the recommendations of surgeons and nurses from the beginning of their surgery. Their popular care practices involve the value of acting autonomously, taking responsibility for their body and ailments with minimal help from family members.[16]

Ostomy patients and their caregivers must be understood as holistic beings who live in their own social and cultural structures, which define what it means to be healthy[17] and what cultural care practices should be applied to health. This complexity is enriched by approaches such as Madeleine Leininger's theory of diversity and universality in nursing care, which explores unknown dimensions in nursing,[18] facilitating care from a culturally competent perspective. Thus, it is necessary to have culturally competent nursing professionals, defined by Campinha-Bacote as "the ability and willingness to work effectively within the cultural context of the family, addressing the identified popular care practices,"[19] so that care providers can advance in their cultural competence to provide assertive and contextualized care.[20]

As identified in the participants' narratives, the adaptation process requires emotional support and assistance in developing technical skills to manage the ostomy.[12] Individuals integrate adaptation strategies that involve behavioral efforts to overcome these limitations, including deciding whether to disclose or hide their stomas to others, based on the possibility of acceptance or rejection, using internal resources, and seeking and receiving external support.[22] Progressing in adaptation requires mitigating negative thoughts and fostering social interactions,[23] increasing leisure activities, and having access to support groups and psychological support.[24]

Additionally, as part of these adaptation strategies, spirituality, resilience,[25] and having people involved in their care are essential.[26] Thus, comprehensive care consultations are necessary to achieve an adaptation process for ostomy patients to this new condition and to promote their quality of life,[27] where aspects such as self-image and self-esteem are addressed, as they are key factors for overall well- being and their health-related perceptions.[28]

Educational needs are of great importance in the adaptation process to this new health condition, focusing on efficient education, meaning that patients understand the information,[29] which helps manage preoperative anxiety.[30] In this regard, patient education should focus on a set of skills, including ostomy care, how and when to empty and change the bag,[31] and knowledge about the risk factors that cause peristomal moisture.[32] This type of education should also target caregivers, utilizing other strategies such as telemedicine,[33] with programs that promote self-care and self-management for ostomy patients.[34,35]

The second phase of the study encountered limitations, including difficulty in accessing participants due to their residences being in remote and often hard-to-reach locations. Additionally, the need for future phases of comprehensive intervention in these communities, with a broader participant reach, is recognized.

## Conclusions

Care dyads undergo adaptation processes in which they implement popular care and self-care using available resources as a strategy to mitigate access barriers and socioeconomic difficulties. Health and nursing services must identify the care needs of each dyad, in addition to recognizing popular care practices, validating safe care practices, and negotiating on those identified as presenting evident risks in their application.

To facilitate the adaptation process of care dyads when carrying an ostomy, emotional support must be provided by healthcare professionals, along with assistance in acquiring

instrumental care skills, acceptance of the new body image, and new dietary practices. This requires close and continuous support from an interdisciplinary team, including nursing, psychology, medicine, nutrition, social work, among others, allowing these dyads to gradually resolve their doubts and acquire the necessary care competencies.

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