

Living With an Intestinal Stoma: A Qualitative Systematic Review

Qualitative Health Research
2019, Vol. 29(9) 1255–1265
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DOI: 10.1177/1049732318820933
journals.sagepub.com/home/qhr



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Abstract

The main aim of this article is to explore the experiences and life situations of people living with intestinal stomas. Previous studies indicated the need to investigate the concerns of ostomy patients and how these concerns can affect their quality of life and their approaches to the comprehensive conceptualization of the bodily changes. A qualitative systematic review and metasynthesis design was carried out by using the main scientific databases. Original articles from 2002 to 2015 were selected based on their qualitative methodology. Methodological quality was evaluated using the Critical Appraisal Skills Program. The findings were synthesized using the metasynthesis procedure of Sandelowski. The final number of articles included was 95 and 1,982 participants. Regarding the metasummary, the data generated 191 thematic statements that were organized into eight categories. The findings support an explanatory model of the experience of people with ostomy based on three aspects: Acceptance, Adaptation, and Autonomy.

Keywords

nursing; patient perspectives; stoma care; qualitative approaches; qualitative; metasynthesis; international approach

Introduction

Many diseases lead to the creation of an intestinal stoma; however, colorectal cancer is the primary cause. According to the American Cancer Society (2017), the estimated 2017 rates of new cases of colorectal cancer in the United States were 71,420 among men and 64,010 among women. In Europe, this type of cancer is the most common and the second leading cause of mortality among both sexes, with 446,000 new cases diagnosed each year (Siegel, DeSantis, & Jemal, 2014). Therefore, the number of people who are susceptible to having an intestinal stoma is considerable.

Several studies have indicated the need to research the concerns of patients with ostomy and how stomas affect their quality of life (Popek et al., 2010; Wilson, Birks, & Alexander, 2010). Other authors have requested studies that provide a comprehensive conceptualization of the bodily changes associated with stomas (Li, 2009; Thorpe, McArthur, & Richardson, 2009) as well as studies following a similar perspective and research design that enable a better analysis of the data (Recalla et al., 2013). In this sense, qualitative research represents an opportunity to respond to these demands because it offers a methodology that allows us to understand and explore the experiences of people who are living with an intestinal stoma.

Recently, numerous qualitative studies have been published across different countries. One limitation associated with qualitative research is the difficulty of transferring their findings to different contexts because sociocultural characteristics condition patient responses. Therefore, a qualitative study synthesis represents an opportunity to search for common elements across different contexts in a way that generates data interpretations with a high potential for transferability, especially if the studies reviewed are representative at the international level (Kenderian, Stephens, & Jatoui, 2014; Recalla et al., 2013). As a frame of reference, this study uses a model previously called the Triple A model (Bonill-de-las-Nieves, 2011), which emerged from a qualitative research study and aims to explain the process that ostomized patients follow, beginning directly after surgical intervention.

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The Review

Aim

The purpose of this review was to explore the experiences of people with intestinal stomas by synthesizing the results of qualitative studies. In addition, this study sought to identify the factors that influence the coping process.

Method

A qualitative systematic review with an extended synthesis procedure was developed following the metasynthesis guidelines proposed by Sandelowski, Barroso, and Voils (2007). Studies published in English, Spanish, or Portuguese were included from 2002 to 2015. Original qualitative articles that explored the perspective of people with intestinal stomas were selected. Studies of pediatric populations were excluded. The intention of the current project was to provide a broad view of the study phenomenon, including works from across a wide geographical context. As such, various databases and search sources were used, including PubMed, CINAHL, Web of Knowledge, Scopus, SciELO (Spain and Latin America), CUIDEN (Spain and Latin America), Lilacs (Latin America), and Google Scholar (English and Spanish versions). Medical Subject Headings (MeSH) were used as descriptors for English-language articles, and Health Sciences Descriptors (DeCS; *Descriptores de Ciencias de la Salud* in Spanish) were used as descriptors for Portuguese and Spanish articles. Free terms were also used. The English terms used were colostomy, ileostomy, ostomy, peritoneal stomata, qualitative research, and surgical stomas. The Portuguese terms used were *colostomia*, *ileostomia*, *estomia*, and *estomas peritoneais*. Finally, the Spanish terms used were *colostomías*, *estomas peritoneales*, *estomas quirúrgicos*, *ileostomía*, *investigación cualitativa*, and *ostomía*.

Search

Initially, an expansive search was conducted with descriptors referring to ostomy (Finfgeld-Connett & Johnson, 2013) to obtain the general results of the investigations in this field.

Subsequently, this search was finalized by applying the design and population criteria discussed above. This procedure was performed using the filters offered by the databases. We mainly used the filter of time span and type of study, when available in the database, or by combining the thematic descriptors with a design descriptor. The inclusion criteria were mostly applied after reading the title and the abstract of the records found (more information about the filters can be found in Appendix). The articles were selected after reading the title and abstract

during the identification phase, reading the full text during the screening phase, and evaluating the quality of studies for the review during the final selection phase. An example of the search string followed in one of the chosen databases (PubMed) for the term “Surgical stomas” (one of the terms) can be seen here: (“Surgical stomas”[MeSH Terms] OR “Surgical stomas”[All Fields]) AND (Journal Article{ptyp} OR Meta-Analysis{ptyp} OR Review{ptyp} OR systematic{sb}) AND (“loattrfull text”[sb] AND hasabstract[text]) AND (“2002/01/01”[PDAT]: “2015/12/31”[PDAT]) AND “humans”[MeSH Terms] AND (English[lang] OR Portuguese[lang] OR Spanish[lang]) (Appendix). Supplementary Figure 1 shows the selection flowchart. The search was carried out in March 2016.

Critical Evaluation

The articles were evaluated via peer review. A double criterion was applied. On one hand, an evaluation of the methodological quality was conducted using the Critical Appraisal Skills Program (CASP) Qualitative Research Checklist (May 31, 2013). On the other hand, following the proposal of Sandelowski et al. (2007), the quality of the findings was prioritized to obtain valid data for the metasynthesis. Two reviewers independent from previous reviewers resolved the discrepancies found in the checklist items. The result of this evaluation is shown in Supplementary Table 1.

Ultimately, 95 articles were included in this review.

Data Extraction

Relevant data (country, number of participants, scope of study, type of study, and methodology) were extracted from the articles. The major characteristics of the selected studies are shown in Supplementary Table 2. For the synthesis, quotes from the participants, descriptions created by the authors, or both were extracted from each article to provide an account of the results. Interpretations based on the data were not included. Each study was used as a unit of analysis, and the text extracted from each of them was imported for analysis using Atlas.ti 7.0. software.

Synthesis

Initially, the extracted text was studied line by line and coded based on a scheme of categories and codes (Table 1) previously defined in a preliminary study developed by the research team (Bonill-de-las-Nieves, 2011; Bonill-de-las-Nieves et al., 2014; Bonill-de-las-Nieves et al., 2013; Hueso-Montoro et al., 2016). After the text was coded, the guidelines of the metasynthesis of Sandelowski et al. (2007) were followed. Specifically, metasummaries were

Table 1. Categories and Codes.

Categories	Codes
Description of the disease process and creation of the stoma	Symptoms
	Diagnosis
	Complications
	Surgery
	Postoperative period
	Chemotherapy, Radiotherapy Changes
Factors that determine coping with the news of the ostomy	How the patient receives the news
	Reconstruction
Significance and experience of the new body reality	Immediate reactions after seeing the stoma
	Experiences with the stoma Future
Care received and relationship with health professionals	Information
	Care management
	Follow-up
	Treatment received
	Demands or proposals for improvement
Strategies developed to cope with the situation	Self-care: Irrigations, Feeding, Hygiene, Change of the Ostomy Bag, Devices, Dreams, Leaks, and Gases
	Body image
	Information found on the Internet
	Peer group
Effect on and participation of the family during the process	Perceived family support
	Family experiences
	Sexual relations
Social and work effect	Social impact
	Perceived social support
	Workplace impact

Note. Scheme based on the results of previous studies by the research team: Bonill-de-las-Nieves (2011); Bonill-de-las-Nieves et al. (2014); Bonill-de-las-Nieves et al. (2013); Hueso-Montoro et al. (2016).

conducted in each category. The summaries were developed based on simple phrases extracted from the data that were later grouped into thematic statements that categorized them in a higher rank.

A report including the entire process was generated from each category and used as the basis for the final results report. Each report collected the following data: category, code, thematic statement, references, and significant quotes from the participants. In addition, the effect size (ES) of each thematic statement was calculated, dividing the number of articles in which it appeared by the total number of articles reviewed. This was done to guide the synthesis process and to more clearly define the proposed theoretical model. Importantly, selecting a strategy for the synthesis of qualitative studies was difficult when there was heterogeneity. The guidelines of Sandelowski,

Docherty, and Emden (1997) were followed because they offered procedures that were easy to apply to the intended objective and allowed quantitative indicators to be obtained that were useful for the synthesis process.

Ethical Considerations

No ethical approvals were required as this was a systematic review of existing qualitative evidence.

Results

In total, 1,982 participants from Australia, Brazil, China, Denmark, Iran, Portugal, Spain, Sweden, United Kingdom, Uruguay, and the United States were included within the 95 selected studies. Participants from the hospital environment composed 18.55% of the sample, whereas 81.44% were from the community setting.

Regarding the metasummary, the data generated 543 phrases that were grouped into 191 thematic statements. The statements were organized into eight categories. As previously mentioned, initially, a scheme with seven categories that originated from a previous study was used, but a scheme with eight categories was generated after coding. The final categories were “Description of the disease process and creation of the stoma,” “Factors that determine coping with the news of the ostomy,” “Significance and experience of the new body reality,” “Appreciating other aspects of life after the change,” “Strategies developed to cope with the situation,” “Social and work effect,” “Effect on and participation of the family during the process,” and “Care received and relationship with health professionals.”

The most significant changes regarding the previous scheme were that the category “Appreciating other aspects of life after the change” was initially a code within the “Description of the disease process and creation of the stoma” category but was transformed into an independent category. In addition, two emerging codes arose: “Spirituality” was included in the category “Strategies developed to cope with the situation,” and “Finances” was included as a code within the category “Factors that determine coping with the news of the ostomy.”

Below are the most relevant findings of each category, using the most prototypical thematic statements. The results were completed using the ES that appears in parentheses and are shown in Supplementary Table 3.

Description of the Disease Process and Creation of the Stoma

Colorectal cancer is usually the diagnosis that most frequently results in an ostomy. An aspect that worried the patients concerned the diagnosis and symptomatology.

The delay in diagnosis produced a lack of credibility with regard to the health care system (ES = 4.21¹). As such, culture acted as a clear determinant. Patients' perceptions of disease were culturally influenced, which affected their symptomatology and even their treatment. Therefore, some patients self-medicated or resorted to traditional or alternative medicines as opposed to the conventional health care system (ES = 4.21²). As a patient from Mato Grosso (Brazil) in Maruyama and Zago's (2005) study explained, "I attributed it to hemorrhoids, [so] I self-medicated [by] taking Indian chestnut."

Regarding the influence of sex, different studies have explained how the cultural construct of masculinity in certain societies causes, determines, and imposes the reactions of men to the diagnosis (ES = 7.36¹).

Generating a suitable environment and using culturally adapted language to communicate the diagnosis was another suggestion that arose from the studies that were analyzed (ES = 7.36²). The timing of the surgical intervention was also a key element in the description of the disease process. Feelings of nervousness and emotional fragility occurred before the intervention. Presurgical anxiety, with or without previous surgical experience, was frequently manifested in these patients (ES = 10.52¹). A patient in the study of Notter and Burnard (2006) related the following: "My mind just couldn't let go, and every time I moved or breathed it couldn't be ignored . . . I'll never forget it, and it's not like childbirth [this participant had previously had two children], fading as soon as it's over. I'll never forget it; never . . ." Likewise, the historical-cultural development of the body within different societies was another factor to consider (ES = 3.16).

During the postoperative period, the analyzed studies indicated the importance of working with patients on their perceived problems and self-image after the operation. Positive attitudes minimized later conflicts between the environment and the person (ES = 13.68) because patients were able to face these problems. They developed mechanisms, such as educating themselves, to do that. Finally, one of the central codes in this category focused on complications. Flatulence, the location of the stoma, and the impossibility of performing activities of daily living (e.g., carrying weight, playing football, or swimming) provoked restlessness and fear in the patients (ES = 10.52²). Patients feared possible subsequent surgeries, disease recurrence, and physiopathological alterations resulting from the stoma (e.g., hernias and prolapses; ES = 10.52³).

Some studies showed that the patients preferred pain or the discomfort associated with going to the bathroom over colostomy bag installation; in other cases, however, not carrying a spare stoma bag produced insecurity (ES = 3.16). Another complication was associated with intercourse, specifically in relation to fertility, fecundity, and sexual relationships (ES = 4.21³). One participant from the study of

Mendes et al. (2014) stated the following: "The ostomy is a big problem for those who are single. During sex, it is very difficult; I have not had an erection for a long time. It will always depend on the bag, and you have to always have a bag for emergency changes that can occur at any time."

Factors That Determine Coping With the News of the Ostomy

Different studies explained that life experiences, previous illnesses, and patients' self-awareness can condition the way in which patients react to the news of a stoma (ES = 11.57). Knowing that the stoma was reversible provided patients with a better predisposition, which improved their perceptions of their quality of life (ES = 4.21). When a patient received the news, contact with trained and informed professionals and contact with other patients was essential. Patients must know the consequences of the entire procedure and the possibility of reconstruction (ES = 5.26). One of the participants in the study by Perry-Woodford (2013) explained it as follows:

I can't remember anyone saying to me [that] it might fail or you know, it might not be okay for you. It was something I did not expect. I just thought once it was done, it would be okay. But it wasn't.

Significance and Experience of the New Body Reality

The uncertainty and worry derived from the disease and the creation of the stoma were maintained for some time after the intervention. After the acute phase, patients must cope with changes to both their body image and their behavior and emotional responses. They experienced physical and psychological changes, including weight loss, loss of evacuation control, and apathy due to the many hospital admissions (ES = 17.89). The loss of masculinity or femininity related to the patients' socially defined cultural conception is another statement that should be highlighted (ES = 5.26). They also must cope with their lack of preparation for self-care (ES = 11.57).

The patients felt that ostomy care is a family burden. Processes of confrontation, denial, stress, and isolation were present in the patients' speech (ES = 12.63¹). The denial of the stoma caused fear, resignation, and self-hatred and prevented self-care and increased their dependence (ES = 24.21¹). The change in body image was one of the most recurrent aspects in the discourse of the participants. The change was perceived to be worse by women, who experienced a decrease in their social activities and in their quality of life in general (ES = 24.21²). However, despite these negative experiences, it was also understood as an opportunity to continue living.

Patients perform self-reflection exercises and continuously fight against the sensation of loss. A significant finding of some studies is that a couple's relationship can be strengthened in certain cases (ES=25.26). A participant in the study of Silva, Siqueira, Bezerra, Paranaguá, and Barbosa (2010) expressed that

The support of my wife was fundamental. [She was] always understanding. I always felt that my life could return to normal, with friends [as well as] my emotional and sexual life. This adaptation was not easy, but you have to conform, and you have to learn to live with the ostomy.

Patients try to return to their routines as soon as possible (ES = 12.63²). However, when the stoma showed poor improvement, the assimilation and return to normal was delayed, causing discomfort (ES = 3.16). Difficulties with adapting to the new body reality produced limitations in daily living (ES = 14.73). However, despite these difficulties, patients stated that they lived better with the stoma bag than with the disease, that is, they perceived that the stoma bag distances or hides the presence of the disease, which they perceived as the greater threat (ES = 8.42).

Appreciating Other Aspects of Life After the Change

With the creation of the stoma, patients begin to value other aspects of life that they did not previously contemplate. Mechanisms were put into place to preserve personality, and a new identity was built (ES = 15.78). As the patient adapted to his or her new situation, the patient accepted the reality and changes in his or her own existence (ES = 18.95). Some of the participants commented, "Getting angry only makes it worse. But it's something to which we have to adapt; it's the only way out" (Backes, Backes, & Erdmann, 2012). In the study of Bulkley et al. (2013), another participant stated that "I feel like I had a second chance to live when I needed a colostomy surgery . . . I'm grateful that I'm a survivor of colon cancer . . . I find myself enjoying things more. I like myself better now."

Strategies Developed to Cope With the Situation

The habitual tendency of the patient is to achieve maximum autonomy; therefore, self-care is a major strategy. The initiation of self-care is complex. Nevertheless, patients ultimately established routines and understand stoma care well, including aspects related to nutrition, stoma bag change, devices, and hygiene (ES = 33.69). Sometimes, the help of a caregiver or a family member was needed to detect complications (ES = 18.95). Health

education and consultation with professionals was a key point for improving self-care and for coping with the stoma to prevent complications over the medium and long terms (ES = 17.89).

The strategies for maintaining self-esteem and safety as coping mechanisms for the change in body image were meaningful (ES = 26.32). The support of the partner and the social network was a key factor regarding the acceptance of the body image (ES = 12.63). The Internet was a useful resource for searching for information and connecting with other people in similar situations and with professionals who helped and provided advice (ES = 6.31). One of the participants in the study of Frohlich (2012) pointed out that

The Internet was a great place to begin my disclosure. I found [that] it provided a safe and relatively anonymous environment to meet others. The confidence I gained in this space allowed me to disclose my ostomy more comfortably to my family and friends.

Finally, spirituality emerged as a relevant intervention area. Starting from the cultural differences between the countries represented in the review, as explained by different studies, spirituality helped patients to interpret their health condition and overcome difficult times (ES = 20). One participant in the study of Carvalho, Budó, Silva, Alberti, and Simon (2015) stated,

What I do believe in is God [. . .]. I am a firm believer in God, that God helped me a lot through this. [. . .] Even the doctor told me, after I recovered, that God was with him during the surgery.

Social and Work Effect

The ostomy can produce a separation from or the partial or total loss of work, which leads to a decrease in socio-economic status and increases feelings of helplessness (ES = 25.26¹). In this regard, men perceived a loss of their masculinity when they no longer played an economic support role in the family because work was a frame of reference for the construction of the male identity (ES = 5.26). For patients, returning to work was welcome after recovering from surgery. Informing their colleagues beforehand of their clinical condition was considered beneficial because it enabled an understanding of their health status (ES = 3.16). Sharing experiences in mutual support groups was an effective strategy to improve coping (ES = 15.78).

To facilitate adaptation to the work environment, patients created habits to avoid performing many stoma bag changes or much stoma care during work hours (ES = 1.05). Despite efforts to adapt, some studies showed that people with intestinal stomas felt embarrassed at work

because of the noises and odors generated by the stoma and feces. They were also afraid of damaging the stoma or losing their job because of their condition (ES = 9.47¹). A participant in the research of Grant et al. (2011) reflected, "I was having accidents. And I was a teacher . . . I felt totally ashamed. You maybe do not think much about it, except when you're having an accident at work; that's really difficult."

The attitude of the patients regarding their social networks varied. Some people communicated their health situations to help maintain their social relationships (ES = 10.52). Others hid it based on fear or concerns about the reactions of those around them. Hiding can generate stressful and traumatic situations that favor isolation even more (ES = 9.47²). Social support was the key to effective coping. The patients experienced true mourning for the loss suffered; therefore, the support of family and friends mitigated their situation (ES = 25.26²).

Finances were another aspect that concerned the patients because the stoma and its care involve an economic outlay, and it was difficult for the patients and their families to absorb these costs. Moreover, sometimes it forced them to modify their way of life (ES = 7.36). One of the participants in Dabirian, Yaghmaei, Rassouli, and Tafreshi (2011) stated, "Each bag costs 13,000–14,000 rials, and we need at least one new bag daily. If we don't watch our diet, [then] we may need more than two bags per day. Most of us are just employees on a low salary, so how can we afford it?" Importantly, this issue shows variability because the situation in different countries likely depends on their system of health benefits.

Effect and Participation of the Family in the Process

The family was the primary source of social support. Generally, the caregivers included the parents, the daughters, and the partner. As the participants expressed, the partner played a key role as a support figure. They were instrumental in both care and emotional support after the surgery. This situation led to fear about the process of the partner adapting to the new condition (ES = 20.1). Some studies showed that patients felt impotent and rebellious when they did not receive the support of the family (ES = 8.42¹). Patients who had children showed concern for their well-being and for how their new situation would affect them (ES = 9.47).

The participants were also concerned about their relationships with their partners because they influenced coping and recovery. These concerns generated the need for fuller and more intense communication among the members of the family (ES = 11.57). Some studies also identified situations of overburden within the couple because a stoma disrupts sexual intimacy (ES = 18.95).

One of the central codes in this category was sexuality. Some studies indicated that this element was key to contributing to the success or failure of the relationship and well-being of the couple (ES = 3.16). The alteration in body image affected sexuality and produced a loss of libido, impotence, low self-esteem, and changes in ejaculation (ES = 8.42²).

Care Received and the Relationship With Health Professionals

Although these thematic statements worked as independent categories in the analysis, we considered it more appropriate to present their findings jointly, given the affinity among them.

Different studies highlighted the figure of the nurse as an advisor, consultant, and care manager within the therapeutic relationship (ES = 15.78). The information provided to patients becomes a fundamental pillar upon which the patient-professional relationship is articulated. When there was a relay of information, education, and preparation prior to the intervention, the care was highly valued (ES = 23.16¹). The information must be appropriate in quantity and presented in a clear, simple language adapted to the educational level of the patient.

Patients also valued being informed about the most negative aspects of the process (ES = 10.52). According to the studies reviewed, it was clear that the approach to patient care should be comprehensive, not only focusing on physical aspects but also addressing other areas (e.g., social and family life, sexuality, spirituality), and should account for factors such as the age of the patient. Therefore, the development of early, individualized, holistic pre- and postoperative care plans was important (ES = 11.57).

Another fundamental aspect to improve health care was to inform patients about stoma support groups because they enabled the sharing of similar experiences and helped patients to approach their new situation (ES = 3.16). Follow-up evaluations of patients after discharge through the continuity of care were positively valued (ES = 7.36). In fact, some studies showed that lack of time and professionals' lack of specific knowledge about performing the necessary care hindered recovery and coping (ES = 4.21).

The treatment received was another relevant issue. Some studies showed that patients perceived a lack of dialogue and communication with health care professionals and a lack of accessibility to them, which led patients to feel that they lost their rights (ES = 17.89). In contrast, the time that nurses dedicated to listening was considered fundamental to transmit the therapeutic options that can lead a patient to full autonomy. Furthermore, this process involved an emotional discharge (ES = 8.42).

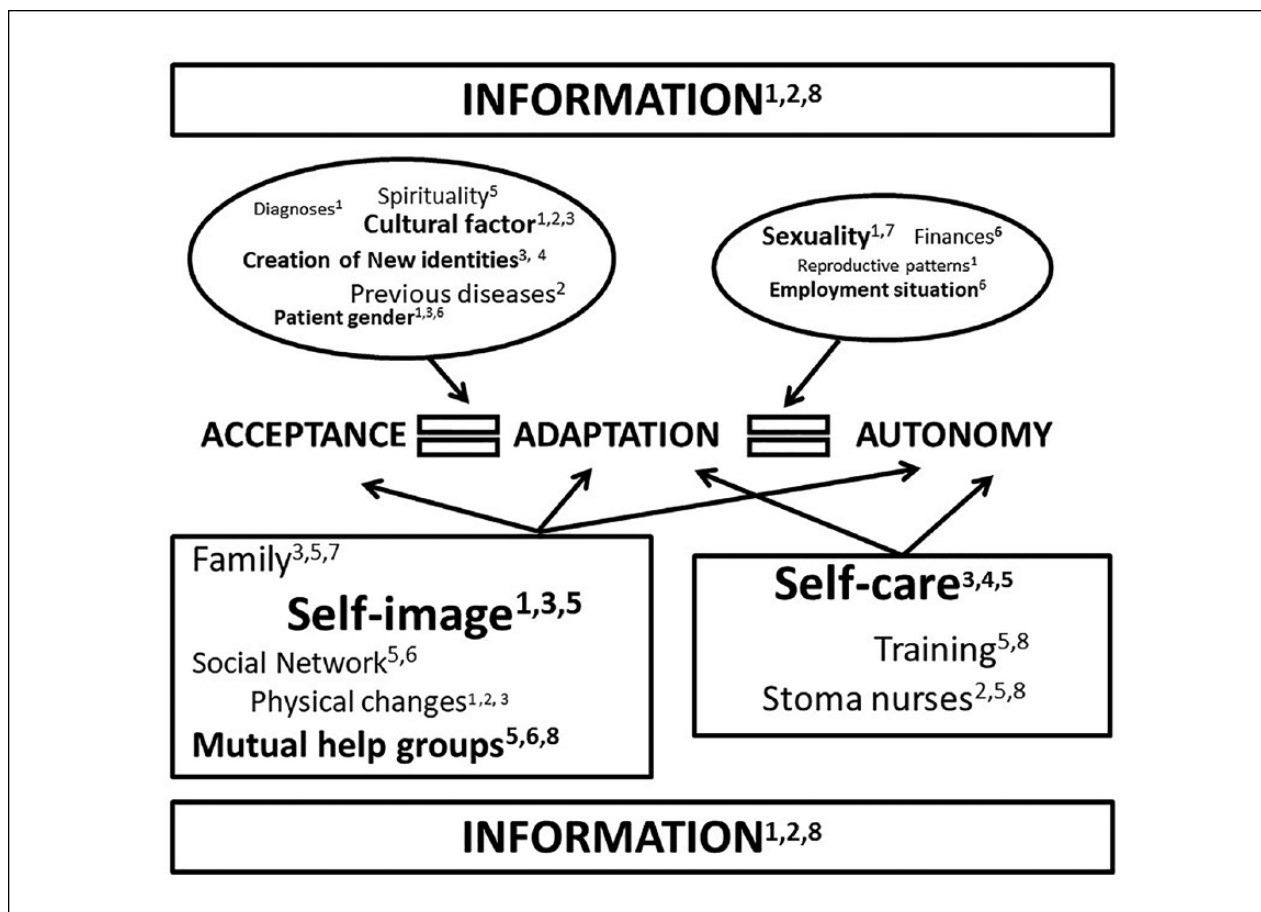


Figure 1. Modified Triple A Model^a (Bonill-de-las-Nieves, 2011).

Note. The most relevant thematic statements are expressed in the form of a code within the figure. This code indicates in what category each appears. In addition, the prevalence of the indicator is shown by the size and emphasis of the font. Analysis categories: 1. Description of the disease process; 2. Factors that determine coping with the news of the ostomy; 3. Significance and experience of the new body reality; 4. Appreciating other aspects of life after the change; 5. Strategies developed to cope with the situation; 6. Social and work effects; 7. Effect on and participation of the family in the process; 8. Care received and relationship with health professionals.

The participants of some studies indicated the positive aspects of being able to access a multidisciplinary team of nurses, doctors, and psychologists, and they attached great importance to the specialization of nurses as stoma-therapists (ES = 23.16²). A participant in Mota et al. (2016) stated,

I did not want to take care of myself. In the first months, I did not want to move until the scar healed. But then I went to the stomatherapy service, and I consulted with the nurse. I learned well, and I started doing it alone.

Discussion

According to the experiences of the participants of the reviewed studies, we found that once the first symptoms appear, people with intestinal stomas begin a process that will help them reach autonomy. This process is in line

with the theories of Lazarus regarding the management of stress and emotions, as well as their implications in disease management. Thus, this model describes the process as a set of cognitive and behavioral efforts that people living with stomas set in motion to respond to the specific demands of a situation perceived as problematic to restore balance (Lazarus, 2006). Thus, we identified strategies that focused on the problem (e.g., related to self-care of the stoma) and strategies that focused on emotions (e.g., being able to express how they feel in a family environment or in a peer group, which helps regulate the emotional consequences of living with the stoma).

In this sense, the previous study from which this review was developed (Bonill-de-las-Nieves, 2011) defined a conceptual model of the suffering of people with intestinal stomata. We called this the “Triple A Model: Acceptance, Adaptation, Autonomy” (Figure 1). The findings of the current review consolidate the main

postulates of the model; at the same time, they have enriched it by incorporating specific nuances for a better understanding.

The first step consists of accepting the disease diagnosis; relatedly, patients must accept that they are going to be ostomized. The acceptance of both the disease that results in the stoma and the body modification that occurs after surgery enables the person not only to begin the process of adaptation toward their new body reality but also to achieve a better adaptation than those who have not accepted the diagnosis or the presence of the stoma. It is remarkable how patients adjust their goals to changing circumstances and how they alter their goals to their illness. Moreover, illness variables can impact how their goals change (Janse, Ranchor, Smink, Sprangers, & Fleer, 2014). Throughout this process, multiple factors intervene, the influences of which either favor or delay the patient's ability to adapt to their new situation. The factors that favor this process include the support of family and friends, being able to rely on the stomatherapist nurse, their own beliefs, the possibility of reconstruction, the implementation of coping mechanisms (e.g., think positively, be optimistic, and so on), a group of equals, and the technical options for stoma management, always taking into consideration achieving autonomy as soon as possible. In some cases, spiritual well-being helps to empower that positive attitude (Bulkley et al., 2013). Likewise, Kenderian et al. (2014) described the psychological challenges that patients face when they become ostomized. Other factors that might hinder this process are the problems related to care management, therapeutic failure, and financial problems as well as the absence of the aforementioned favorable factors. As such, Danielsen, Burcharth, and Rosenberg (2013b) discussed the importance of including family members (in that case, wives) throughout the informative process regarding the creation and management of the stoma. In some other cases, stoma can affect work, not only if the stoma imposes extra cognitive or physical demands but also if work involves lifting and bending, which can be prohibitive (McGrath et al., 2017).

Throughout the acceptance–adaptation–autonomy process, the factor with the greatest weight is the information provided to the patient because it is directly linked to all of the other factors and contributes significantly to the progression of the patient. The nurse stomatherapist, who becomes a fundamental figure ensuring the effective coping of the patient, should also be highlighted because this specialist allows the patient to develop self-care strategies that lead him or her to achieve full autonomy with regard to the process. In this sense, Danielsen, Burcharth, and Rosenberg (2013a) review corroborates the importance of the educational programs aimed at patients with intestinal stomas. In addition, previous studies (Coca,

García-Llana, Larrinoa, & Serrano, 2015) have demonstrated the effectiveness of these professionals, highlighting that patients treated by specialist nurses require 70% less care time than patients not treated by specialist nurses. They also have fewer hospital admissions due to complications, incur half the average direct cost of treatment when a specialist nurse is not referred, and (most importantly) report much greater well-being and quality of life as well as suffer less pain.

Finally, it is important to consider the differences in subjects with a temporary stoma compared with those with a permanent stoma. Persons with a permanent stoma had significantly higher physical role function scores compared with persons with a temporary stoma (Boraii, 2017). In addition, people with a temporary stoma were prepared to accept a high incontinence rate and even willing to compromise on survival to avoid a stoma (Young et al., 2018)

About the Method

Systematic reviews of qualitative studies and metasynthesis provide a broad view of people's experiences in the face of health problems. Highlight recent studies about the adaptation following a new diagnosis of type 1 diabetes in adulthood (Due-Christensen, Zoffmann, Willaing, Hopkins, & Forbes, 2018) or how do people experience early intervention services for psychosis (Hansen, Stige, Davidson, Moltu, & Veseth, 2018). This article focused on understanding the experiences of people living with an ostomy based on an exhaustive review that included works from several countries, including the United States and Australia as well as those in Europe, Latin America, and Asia. This analysis enabled the identification of common elements present in the studies analyzed, which strengthens the international relevance of the work. Moreover, this review updates the findings of previous papers about similar characteristics, although the number of papers analyzed and the representativeness of the countries herein are more significant than in previous works (Tao, Songwathana, Isaramalai, & Wang, 2014; Thorpe et al., 2009). Although published systematic reviews within this field have recently proliferated (Danielsen et al., 2013a; Kenderian et al., 2014; Vonk-Klaassen, de Vocht, den Ouden, Eddes, & Schuurmans, 2016), they have not incorporated qualitative research or focused on specific aspects. Thus, our review proposes a holistic approach. Finally, we agree with Thorne (2017) when she describes the lack of rigor and interpretative capacity of many of qualitative metasynthesis that recently have proliferated. In our work, we have tried to develop a rigorous interpretation based on a previous theoretical framework, which grouped the diversity of human experience before the ostomy.

Weaknesses and Strengths

To contribute to the uniformity of qualitative synthesis publications, this work is in line with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research guide (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

In relation to the categories described, we opted to use a previous model that worked well in a previous study. As such, this review strengthened the coherence of the category scheme and consequently the model generated. However, some questions are yet to be answered. For example, the differences depending on the type of disease that results in the stoma constitute one line of research that must be explored to definitively clarify the model and the findings of this review.

Another point of discussion involves the critical evaluation of qualitative studies. The guidelines of Sandelowski et al. (2007) have been followed to include studies according to the quality of the findings. Recent studies suggest that opinions are divided concerning the evaluation of the quality of qualitative evidence (Noyes et al., 2018), which is why we have also chosen to test certain methodological aspects of the articles.

Practical Implications

The results of this study allow a better understanding of the experiences of people with an intestinal stoma and to identify conditioning factors. The initial reactions of the subjects in the presence of the stoma imply a resignification process to incorporate into their identity something new that is initially seen as alien. Autonomy is the primary objective for which strategies focused on the problem and emotion are put into effect, that are in turn conditioned by different elements: family, professionals, information, peer network, and so on. All of this is proposed under a theoretical model named the Triple A Model.

The Triple A Model can help health care systems and professionals design interventions aimed at improving the quality of life of people who live with an ostomy because it outlines a coherent itinerary of the treatment process as well as identifies and marks those factors that can facilitate or hinder this process. Thus, this model offers a theoretical framework of interest for the development of clinical practice guidelines, protocols, clinical pathways, and other research documents. In addition, it might be useful as a theoretical basis for the development of future research.

Author Contributions

César Hueso-Montoro, Rafael Montoya-Juárez and Candela Bonill-de-las-Nieves designed the study. All the authors contributed to the implementation of the research and writing of the

manuscript. Specific contribution related to systematic review and metasynthesis: the search and critical appraisal were conducted by Concepción Capilla-Díaz and Sandra Milena Hernández-Zambrano. Rafael Montoya-Juárez and César Hueso-Montoro resolved the discrepancies in critical appraisal. The analysis was conducted by Concepción Capilla-Díaz, under Rafael Montoya-Juárez and César Hueso-Montoro supervision. Candela Bonill-de-las-Nieves, M^a Nieves Pérez-Marfil and José Miguel Morales-Asencio assessed the partial reports of the results.

Acknowledgments

A group of experts in qualitative research has collaborated in this research. They advised the authors in the critical appraisal phase. We are also grateful to Liliana Marcela Reina-Leal for her contribution in the search. Thank you for your support.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the “Ministry of Health, Junta de Andalucía,” Spain [Grant Number PI-2011-0564].

Supplemental Material

Supplemental Material for this article is available online at journals.sagepub.com/home/qrh. Please enter the article’s DOI, located at the top right hand corner of this article in the search bar, and click on the file folder icon to view.

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