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Life with a urostomy: A phenomenological study☆

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ABSTRACT

Aim: To explore the experiences of self-care of patients with urostomy and to identify the influencing factors of self-care.

Background: The creation of a urostomy results in the loss of an important bodily function and an alteration of the body image and causes physical, psychological, and social changes in the lifestyle through the adjustment and management of the new condition. In literature, there are few studies that analyze the lifestyle of people with urostomy.

Methods: In this qualitative design, an interpretative phenomenological analysis was used. Eleven people living with urostomies took part in semi-structured interviews consisting of open-ended questions about their self-care experience. Data were collected between March and September 2016.

Results: Six themes and twelve subthemes emerged from the data analysis. The themes were: Surgery impact, body image, daily and social-life activities, stoma and sexuality, managing stoma education, family and friends' support.

Conclusions: This study highlights the impact a stoma has on people's lives. This impact should be absorbed with personalized education before the surgery with the eventual need of a continuous and planned educational course respecting the patients' needs. This study shows that a continuous and planned educational plan is crucial for patients living with urostomies. Therefore, nurses should provide patients an adequate support and a personalized education program to cope with ostomy.

1. Introduction

Bladder cancer (BC) is the seventh most commonly diagnosed cancer in the men population worldwide, in the European Union, the age-standardized incidence rate (per 100,000 person/years) is 19.1 for men and 4.0 for women (Ferlay et al., 2013; GLOBOCAN, 2016). In Italy, the prevalence of BC was 225,000 cases and the incidence was 115,000 new cases in 2010 (AIRTUM Working Group, 2014). Radical cystectomy is the standard treatment for localized muscle-invasive and metastatic bladder cancer (MIBC) in most countries (Hautmann et al., 2007; Mertens et al., 2014). There are different types of urinary diversions: continent and incontinent. One of the most common urinary diversions is an abdominal one, such as an ileal or colon incontinent conduit (urostomy) (Nieuwenhuijzen et al., 2008; Stenzl, 1999). Up to 48% of patients develop early complications including urinary tract infections, pyelonephritis, ureteroileal leakage and stenosis; the main complications in 5 years follow-up studies being stomal complications in up to 24% of cases and functional (Madersbacher et al., 2003; Nieuwenhuijzen et al., 2008). In Italy, according to the latest data, the total number of people with urostomy is over 20.000 (Federazione delle Associazioni Incontinenti e Stomizzati, 2017).

Men and women undergoing radical cystectomy with the

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construction of an urostomy face multiple physical and psychosocial challenges, including potential impairment of their health-related quality of life (HRQOL) (Gomez, Barbera, Lombraña, Izquierdo, & Baños, 2014; Recalla et al., 2013). The subjects perceive themselves as disfigured, express feelings of anxiety and depression, and have moments of helplessness and hopelessness. Some patients report difficulties in their work and social functions, sexuality, body image, and stoma function (Recalla et al., 2013). These individuals not only have to deal with the challenges associated with ostomy surgery, but also cope with the underlying urothelial cancer that led to their surgery (Gomez et al., 2014). A qualitative analysis of the biggest challenges reported by 178 long-term colorectal cancer survivors with ostomies, revealed six different themes that posed the greatest challenges to ostomates: dealing with the ostomy and its appliances, discomfort, comorbidities and complications, healthcare barriers, quality of service, negative psychosocial impacts, support and education, coping philosophies and adaptations (McMullen et al., 2008). The HRQOL score among community-based people with urostomies after surgery has been reported to be lower than that among persons with colostomies or ileostomies (Furukawa, Sasaki, Matsui, & Morioka, 2013). Since the average length of hospital stay following surgery is decreasing, many patients are discharged before they master all the knowledge and techniques needed to manage their ostomy (Furukawa et al., 2013). This can delay the learning process to cope with an ostomy and impair the recovery of the HRQOL (Furukawa et al., 2013).

One of the principal goals of nursing management following surgery is the development of an individualized care plan that incorporates attainable goals to ensure the best possible HRQOL and a smooth transition back into the community (Furukawa et al., 2013; Recalla et al., 2013). Previous authors noted that high quality nursing support before, during, and after surgery is a key component that contributes to positive outcomes in ostomy patients (Recalla et al., 2013). Promotion of effective self-care among individuals with urostomy is extremely important for the optimal ostomy adjustment and for the patient's outcomes (Recalla et al., 2013). Factors influencing self-care include experience, skill, motivation, culture, confidence, habits, functions, cognition, support from others, and access to care (Riegel, Jaarsma, & Stromberg, 2012). Self-care is considered essential for the maintenance of psychological stability and quality of life among individuals with urostomy, and most care activities associated with urostomy are performed at home by patients and their families or other informal caregivers.

The elements of self-care in patients with urostomy have not been studied so far. Therefore, the purpose of this study was to explore the experiences of self-care of patients with a urostomy and to identify the influencing factors of self-care. Since every person living with a urostomy requires unique care (Spiers, Smith, Simpson, & Nicholls, 2016), qualitative methods, which focus on the individual, seemed ideal to explore every patient's experience.

2. Material and methods

2.1. Study design

Qualitative methods are useful for researching experiential processes and filling the gaps in existing knowledge (Spiers et al., 2016). For this topic we adopted a phenomenological study design using Interpretative Phenomenological Analysis (IPA). Phenomenology is a qualitative research approach committed to the examination of how people make sense of their major life experiences, IPA takes a hermeneutic, idiographic, and phenomenological stance, allowing a nuanced explication of participants' experiences and is well suited for concepts that are complex and ambivalent, such as the topic under scrutiny (Smith, Flowers, & Larkin, 2009a). To collect data we chose face to face semi-structured interviews as a method to explore the patient's experience.

In this study, we adopted the definition of self-care described by Riegel et al. (2012), self-care is defined as a naturalistic decision-making process that influences actions that maintain physiological stability, facilitate the perception of symptoms, and direct the management of those symptoms.

2.2. Participants

Twenty-three people living with urostomy were selected on a voluntary basis after their visit to the Urology Day Service at the San Raffaele Hospital in Milan - Italy. The research team chose a purposive sample of eleven people out of a total of twenty-three people (Francis et al., 2010). Inclusion criteria incorporated: i) living with a urostomy, ii) Italian as the main spoken language of the person, iii) no major complication after surgery and no mental problem or cognitive deterioration diagnosed. We kept recruiting patients for the study until we reached a data saturation point (Smith et al., 2009a; Wray, Markovic, & Manderson, 2007). The construct of saturation in qualitative research is complex and questionable, however the research team thought that the understanding of the information retrieved could give sufficient depth to shed light on the topic under exploration (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

2.3. Data collection

Data were collected through eleven semi-structured interviews face to face held between March and September 2016. The semi-structured interviews consisted of open-ended questions about radical cystectomy surgery and life with a urostomy (Include Table 1). The interviews were done four to six months after the surgery so that the patient went back home from the hospital, where he/she used to be cared for by nurses and other healthcare professionals, and faced and adapted to his/her new life with a urostomy. These interviews were audio-recorded and transcribed verbatim. The interviews lasted between 25 and 55 min with a total recorded time of 438 min. The semi-structured interview technique was designed to encourage the participants to share stories or experiences in response to a broad data-generating question. The interviews were conducted by expert nurses who were not involved in patient's care.

The aim of a semi-structured interview is largely to facilitate an interaction letting participants tell their own stories, in their own words (Smith et al., 2009a). Open-ended questions were used to encourage participants to reflect on their own experiences. Data about age, gender, marital status, employment status, and caregiver were also retrieved. (Include Table 2).

Table 1
Semi-structured interview questions.

1	Can you tell me about the experiences of cystectomy and the urostomy creation? *Possible prompts: What happened? How did you feel?*
2	Can you describe the experience to have an urostomy in your life? *Possible prompts: What happened? How did you feel? How did you cope with it?*
3	Can you tell me what you think about the urostomy self-care and how you manage this new condition?
4	Can you tell me your difficulties about the urostomy self-care?
5	What would help you to improve your self-care in this new condition?
6	Has the urostomy changed the way you think or feel about yourself? *Possible prompts: Do you see yourself differently now than before? In what ways?*
7	How do you think other people see you? *Possible prompts: partner, family, friends, work colleagues?*
8	How do you see yourself in the future? *To go deeper: Why? How? Can you tell me more about that? Tell me: what were you thinking? How did you feel?*

Table 2
Demographic and health characteristics.

Age	Mean	69
	Range (minimum-maximum)	59–83
Gender	Male	9
	Female	2
Marital status	Married/In a relationship	10
	Widowed	1
	Single	0
Employment status	Employed	4
	Retired	7
Caregiver	Spouse	7
	Relative	1
	Other	3

2.4. Data analysis

Data were analyzed in accordance with the principles of the IPA (Smith et al., 2009a; Smith, Flowers, & Larkin, 2009b). Two researchers independently started the analysis, investigating in-depth one case after another. In case of disagreement, the two researchers returned to the original texts of the interviews and to the field notes and reformulated the shared themes. The first step of the IPA involves immersing oneself in the original data. At this stage, it is important to read and re-read the transcripts, make margin notes, create a summary list of the margin notes, develop the emergent themes, and look for connections among them. Once each interview is individually analyzed, the process is then extended to scan the entire set of transcripts for a full listing of theme summaries, grouping of theme summaries, recoding transcripts with overall themes, and finalizing the list of themes with extracts (Smith et al., 2009b).

2.5. Study rigor

Criteria to promote trustworthiness referred to credibility, transferability, dependability, and confirmability (Long & Johnson, 2000; Morse et al., 2002). Strategies have been adopted to ensure trustworthiness: prolong engagement of the researchers in the study, multiple interviews and notes, member checking and triangulation (Long & Johnson, 2000; Morse et al., 2002). The characteristics of the investigators were also important. They had to be responsive, adaptive to changing circumstances, showing professional immediacy, sensitivity, and proficiency in clarification and summarization (Morse et al., 2002). Verbatim quotes were included throughout the analysis to give the participants a voice, so that readers could trace back the research team's interpretations, demonstrating sensitivity toward the context (Spiers et al., 2016). A member of the research group who had not participated in the interviews read the original un-coded transcripts to validate the results.

Ethical approval

The work has been carried out in accordance with the code of ethics of the World Medical Association (Declaration of Helsinki). Ethical approval was obtained by the Institutional Review Hospital Board and by the Medical Director of the Urology Unit. The interviews were conducted while respecting the patients' privacy in a private and quiet space in the hospital. Confidentiality was assured and the participants were free to leave the study at any time. The investigators assigned each patient a number to hide their identities. The research team gave every participant an information sheet with detailed information of the study that was read carefully and explained by the investigators prior to the interview. The interviewers allowed patients to read the written consent, reflect and decide before giving their informed consent.

Table 3
Themes and subthemes. Summary of the analysis.

Themes	Subthemes
1. Surgery impact	Life expectancy and fear of relapse Physical repercussions of surgery Quality of life impact
2. Body image	
3. Daily and social life activities	Daily activities and hobbies Away from home management Job and stoma management
4. Stoma and sexuality	
5. Managing stoma education	Home stoma management and reference people Nurse's support Problem management strategies Lack of information
6. Family and friends' support	Emotional involvement and encouragement Feeling of pity

3. Findings

Eleven participants were involved in the study, two women and nine men with an average age from 59 to 83. Data about age, gender, marital status, employment status, and caregiver were also collected and showed in Table 2. (Include Table 2).

Six themes and twelve subthemes emerged from the data. (Include Table 3).

3.1. Surgery impact

The patients spoke of different and sometimes opposite surgical and life experiences and how they influenced their lives. They said they tried to live their lives as best as they could despite the problems they had to cope with in the management of the new conditions, the physical consequences of the surgery, uncertainty about life expectancy, and fear of relapse.

3.1.1. Life expectancy and fear of relapse

Many patients felt that surgery gave them a fresh survival opportunity, though with its "burden" of complications and getting along in a new situation.

> *"I serenely went to the operating theatre… otherwise there wouldn't have been any life expectancy at all." (Patient No. 8).*

However, many patients reported that they had been shaken by the idea of having cancer and felt uncertain about the future, fearing deterioration or developing another type of cancer.

> *"… [this] is the third tumor I have had… I'm afraid that sooner or later I'll get the right one which will fool me. Let's hope I can make it … I mean, to stay alive for the next ten years." (Patient No. 8).*

3.1.2. Physical repercussions of surgery

Patients had different and opposite opinions on physical repercussions of surgery. Some of them had no physical problem; others, on the contrary, had several from bleeding to constipation, to muscular pain, to temperature, and nausea.

> *"I've seen myself changed a lot… when I came back home [from the hospital] I told myself, at this exact moment I'm not my actual age, I am many more years older. […] Indeed, I had lost a lot of weight… which I now have regained. I had to catch the elevator to go up just one floor, which I wasn't used to." (Patient No. 3).*

3.1.3. Quality of life impact

The surgery did not just have physical repercussions; its major and most important consequence was the impact on the quality of life. The patients referred not only the impact of the urostomy on the body, but also, broadly speaking, on their new life conditions: sexual function, urinary continence, ostomy care, work and social life.

In fact, many patients reported the effect of urostomy on their lives, although some of them felt it more deeply than others.

> *“It's kind of a huge impact… in fact [the urostomy] is a little thing that does change one's life… You have to take into consideration a lot of factors that you didn't even consider before…” (Patient No. 3).*

3.2. Body image

The patients interviewed had different opinions on this subject. Some of them stated that the urostomy did not change the way they saw themselves, while others affirmed that, whenever they looked at themselves in the mirror, they felt disturbed both aesthetically and psychologically.

> *“I am the same person I was before, actually, I have to admit that I'm even more pampered [laughs]. This helps me. […] Fortunately, it's not a deficiency that can be seen… from the physical point of view they see me walking slowly, walking up the stairs with difficulty, they know I had to go through a surgery but not like that… It's not like the person who has to go around in a wheelchair. Unfortunately, there are a many things that are much worse than this.” (Patient No. 7).*

> *“The only thing is that when I look at myself in the mirror when I'm changing my clothes, [I feel] a bit of discomfort from the aesthetic point of view. I mean, even from the approaching point of view with my wife, it's not a nice thing, it's that what psychologically disturbs me, it's what disturbs me more than anything else… then all the rest is fine.” (Patient No. 8).*

> *“I can not wear my jeans because my body was changed.” (Patient No. 9).*

3.3. Daily and social life activities

The patients informed us how the new conditions sometimes clashed with the habits they had before the surgery. They explained they had to come to grips with different challenges in their daily life when it came to stoma management, resulting in adaptations to avoid possible problem that could crop up when they were far from home.

3.3.1. Daily activities and hobbies

Almost all the patients expressed their will and wish to do the things they used to do before the surgery, and, sometimes, they even managed to do them.

> *“Well, it's that I used to go for a walk every day but now I can't… I hope I can find more energy to do things I used to do before.” (Patient No. 4).*

As for the social sphere, some patients reported they did not feel any change since the urostomy could not be seen beneath the clothes. Moreover, it was not something they talked about when they met friends or colleagues.

> *“People, who don't know anything about it, see me as before, because whenever I have clothes on, it seems as if nothing has changed.” (Patient No. 8).*

3.3.2. Away from home management

Although some patients expressed their will to do things they did before the surgery, they also mentioned the complexity of managing the stoma away from home because of the fear of leakage and getting wet in social situations.

> *“I want to stay at home because I have all my comforts. Going to my daughter's, bringing the additional night bags to change, I'm afraid of wetting the bed… of disturbing.” (Patient No. 5).*

3.3.3. Job and stoma management

A few patients said they faced the same problem at work. Therefore, they affirmed that they were planning to organize everything at their working place so that they would be prepared in case problems arose.

> *“I still have to understand how to deal with stoma management at work, I have already thought that I could carry something to change at work; some changing bags I can keep in my closet.” (Patient No. 11).*

3.4. Stoma and sexuality

The surgery has an important impact on sexuality but not many patients faced this issue. The few patients who did, referred to it as an important and heartfelt problem. The surgery had a deep impact on both the physical and the psychological sides of sexuality. Cystectomy is associated with significant changes in sexual functions for both men and women (e.g. erectile dysfunction, altered vaginal anatomy). Physical alterations associated with urinary diversion and resulting changes in body image, emotional and psychological responses of both patients and their partners, may impair sexuality and sexual satisfaction, and strain intimate relationships.

Some patients contended that, whenever they looked at themselves in the mirror, they felt strange and did not feel attractive anymore. Moreover, the problem was not just psychological but, in many cases, it was a physical problem, and, even though, they tried to find help from doctors, they did not get treatment. Therefore, the majority of the patients were resigned to live with it.

> *“Since the surgery, I can no longer have sexual intercourse. It's not a nice thing, so I have to give it up, that's the conclusion… which demoralizes me. Now, I hope the physician will find me a solution. Otherwise, never mind… I'll try to forget even that.” (Patient No. 8).*

> *“If I have to be honest, the only problem I have is the one related to sex. It is something I am interested in. I have already talked about it with the doctors… and I have to resign myself to it, so that is not easy.” (Patient No. 10).*

3.5. Managing stoma education

3.5.1. Home stoma management and reference people

It emerged from the interviews that there were patients who felt they could independently handle stoma management, while others were not as confident because of physical difficulties or uncertainties.

> *“It was hard at the beginning. My wife helped me in changing two-three times, but then I started to do it on my own and now I'm getting faster and faster.” (Patient No. 8).*

Those who felt unsure looked for the support of others such as relatives, spouses, or nurses.

> *“Then I have to change the bag when it's almost full and the plate every two days. I can do it on my own but I prefer if we are two when doing it… my wife helps me.” (Patient No. 2).*

3.5.2. Nurses' support

Patients referred to nurses as an important source of support both on the practical and on the psychological sides. Many patients told us how they valued nurses' support before and after the surgery, because they taught them to manage the stoma and helped them to cope with it.

> *“In my opinion, the nurse has been an important psychological support. I wasn't left all by myself… she told me, ‘You're going to learn, as everyone*

> *else has done before you, you will learn'. She has really been… to me, she has been important, from the psychological point of view." (Patient No. 8).*

The patients also reported that, if complications or other problems stopped arising after some time, stoma management got easier.

> *"I didn't have any difficulty… after the nurse came by the first time to show me how to do it, she never came back, I did it by myself and I still do it now." (Patient No. 5).*

One patient told about his negative experience. He reported that, when complications appeared, a nurse did not recognize the problem.

> *"When I had a problem, she didn't recognize it. She underestimated it." (Patient No. 1).*

3.5.3. Problem management strategies

Sometimes, the information received was not enough. Some of them explained how scanty the information received was and how this had implications on their life after the surgery. Thus, many of them had to look for and learn new strategies to solve problems, such as leakage and stents obstruction.

> *"I have to check more frequently, in these weeks, I'm trying and it seems better, but I'm afraid of going because I'm afraid of getting wet, so I'm always near my house." (Patient No. 3).*

There are, however, factors that can improve stoma management, such as the learning of the right technique and having a relative with a stoma.

> *"I've learned from the experience of a relative dealing with a bowel-related stoma, and he managed to do it pretty well. So, seeing the experience of a relative helped me in some way… how he managed everything… [I had] an idea of how it would be… I could see that his life didn't change." (Patient No. 11).*

3.5.4. Lack of information

Three patients experienced lack of information in their hospital stay. Lack of information and very little time dedicated to the patients by the nurses lead to negative consequences in stoma management.

> *"The method I had been taught before didn't work anymore, it wasn't good… but here they gave me another type of plate that perfectly fitted the stoma. Fortunately, thanks to this new method, everything's fine." (Patient No. 7).*

3.6. Family and friends' support

All the interviewees highlighted the importance of family and friends' support during the time of their adaptation to the new state of health.

3.6.1. Emotional involvement and encouragement

Relatives, friends and colleagues can offer encouragement to help patients to overcome problems.

> *"I wanted to act like a heroine, I wanted to pretend it was nothing, I wanted to pretend to be a woman who wasn't afraid of anything, to encourage myself. But I was terribly scared. But, since I knew that upstairs there were my children waiting for me, this encouraged me." (Patient No. 5).*

3.6.2. Feeling of pity

It may sometimes happen that relatives, instead of being a source of help and relief, make patients believe they pity them because of their illness.

> *"I hope they don't pity me but that they accept me… although, it depends on each person's mentality… I have friends who don't even notice it… friends who look at me and say "poor man". (Patient No. 11).*

4. Discussion

Patients living with urostomies have to confront a physical change that determines the consequences in every aspect of their lives with important psychological and relational aftereffects. This paper tried to explore the self-care performed by urostomy patients to identify the main factors that influence it.

4.1. Surgery impact

Before the surgery, the quantity and quality of information played an important role in shaping the patient's expectations. Lack of preparation and psychological support resulted in a dearth of knowledge with negative consequences; on the contrary, a satisfactory preparation and adequate information resulted in less fear and the capacity to cope with the surgery and its consequences. It emerged that information and psychological support were key elements in the management of a urostomy patient and his/her quality of life (Wright, 2009). Lack of information and too little time dedicated by physicians and nurses created stoma management problems. This aspect has already been highlighted in other manuscripts, which revealed that, at the time of diagnosis, the information regarding daily life was not sufficient (especially regarding sexual, social, and work life), while patients were provided with information about the surgery and stoma management (Danielsen, Burcharth, & Rosenberg, 2013; Mohamed et al., 2014).

Some of the patients underlined the importance of a multidisciplinary team; in fact, the imparting of education by a multidisciplinary team resulted in a more effective adaptation, greater self-care, and a higher quality of life (Wright, 2009). A patient's preparation for the surgery, psychological support, adequate information, and the presence of a multidisciplinary team are essential for adaptation to new conditions (Wright, 2009).

The patients reported different expectations after their surgeries. Some of them saw it as an opportunity to survive, whilst others affirmed they were afraid of having a relapse or another form of cancer. Some studies have shown that the quality of life in people with urostomies is lower than in those with ileostomies or colostomies. This seems to be linked to a radical cystectomy irreversibility, and a short hospital stay after the surgery (Furukawa et al., 2013; Nichols & Riemer, 2008; Recalla et al., 2013).

This study clearly corroborates how difficult it is to accept the stoma in one's life, especially because of the crucial first impact, which tends to be negative in most cases, a finding that is also confirmed in the literature (Claessens et al., 2015; Davis et al., 2011; Recalla et al., 2013). Many articles highlight how, as time passes after surgery, the patients show better management and adaptation (Claessens et al., 2015; Davis et al., 2011; Furukawa et al., 2013; Liu et al., 2016). Our findings show that the stoma conditions, the quality of life, daily life activities, social life, body image perception and sexuality correspond to similar results present in the literature (Davis et al., 2011; Furukawa et al., 2013; Lim, Chan, & He, 2015; Richbourg, Thorpe, & Gene, 2007).

The stoma's influence on the quality of life is strictly dependent on the information that patients receive before and after the surgery and the presence of important figures such as nurses, doctors and other healthcare professionals. Patients who had received little information before the surgery suffered a severe impact on their quality of life, while patients who had received enough information suffered a minor impact. Therefore, it is pivotal to stress the importance of a pre-surgery education aimed at giving essential information to the patients. This need is underlined in many researches, since nurses should explain to patients the nature of a stoma, its consequences, and practical management aspects (Wright, 2009). Many patients, in our research, reported that the most significant changes were fatigue, loss of weight, pain, temperature and infections, while others did not mention any particular problem after the surgery.

4.2. Body image and sexuality

The interviewees referred not only physical consequences but also psychological ones. The worst were those that influenced their psychological sphere since, as highlighted in the literature, urostomy impacts various areas, such as body image perception and sexuality (Davis et al., 2011; Furukawa et al., 2013; Lim et al., 2015; Richbourg et al., 2007).

Regarding body image perception, the research showed opposite results: some patients affirmed that the stoma did not change the way they saw or thought of themselves, while others asserted that it was both aesthetically and visually disturbing. In the literature, many papers underline how a stoma can lead to a loss of self-esteem (Mohamed et al., 2014) and pose difficulties in adapting to the new condition, as it represents a change in body image (Mohamed et al., 2014; Recalla et al., 2013).

Speaking of sexuality, the patients who decided to share their personal experience referred of having physical and psychological difficulties, as a result of a body image alteration. The results in the literature substantiate these outcomes (Danielsen et al., 2013; Modh, Mulhall, & Gilbert, 2014; Mohamed et al., 2014; Recalla et al., 2013).

4.3. Daily and social life activities

Not only does urostomy influence the most private spheres of a person's life; it also poses new challenges in everyday life. The literature highlights how living with a urostomy influences many spheres, such as daily life activities, thereby requiring the ability to cope with and adapt to a new state of health (Davis et al., 2011; Furukawa et al., 2013; Lim et al., 2015; Richbourg et al., 2007). The same findings have been found in our research: patients affirmed that the stoma clashed with their previous customs, leading to a difficult adaptation process to manage the stoma the best they could.

However, despite the impact the stoma had on their lives, all the patients asserted that they intended to do the things they were accustomed to doing before the surgery. Some patients contended that they did not feel any negative effects on their own social life because they could do the things they used to do earlier, such as dine with friends, because the stoma, under the clothes, could not be detected. This emerged as a positive factor, because a reduced social activity after the surgery negatively affects the quality of life (Davis et al., 2011; Furukawa et al., 2013; Liu et al., 2016).

Patients had different and opposite opinions about outside-home stoma management: some of them affirmed that they did not have to substantially change their habits, while others said they had problems and had adopted strategies to avoid eventual inconveniences. This difference between the two types of experiences can be explained by an individual patient's needs, experiences, and way of life.

4.4. Managing stoma education and family and friend's support

The stoma not only determines challenges in social life, but also in-home management, even though a patient can count on the support of his/her relatives. Relatives, friends, and colleagues seemed to help the patient, thanks to their participation and encouragement. In fact, support from other people is one of the predictors of a good level of self-care (Riegel et al., 2012). However, this dependency, in some patients, led to a feeling of being pitied. These results can also be found in other papers, where the authors underline that people living with stomas may confront feelings of stigma and low self-esteem because of a social and psychological maladjustment (Davis et al., 2011; Recalla et al., 2013; Richbourg et al., 2007). In the interviews, some patients reported being independent in stoma management and daily life activities, while others said they needed someone—a relative, the spouse or a nurse—to help them out.

Adaptation strategies are derived not only from a patient's own understanding, but also from the support provided by the healthcare staff. Every interviewed patient underlined the importance of the nurses' role, especially before the surgery. Many patients also referred that, although the time they spent with the stoma nurses was precious and helpful, it was not enough. Hence, some of the patients emphasized the importance and essentiality of nurses, but as part of a continuous education program starting before the surgery and continuing after it and until the patient had gained confidence enough to perform independently. Nursing support is one of the key factors for positive results among ostomy patients (Lim et al., 2015; Recalla et al., 2013; Wright, 2009). Many authors stress the efficacy of planning the educational participation of patients as a means to promote self-care among those living with stomas and highlight that this planning should continue after their discharge from the hospital (Haugen, Bliss, & Savik, 2006; Mohamed et al., 2014; Recalla et al., 2013; Richbourg et al., 2007; Tal et al., 2012; Wright, 2009). Literature suggests that nurses are supposed to intervene both before and after the surgery to prepare the patient for stoma adaptation, complication identification, and the comprehension of stoma device supplies (Haugen et al., 2006).

When patients learn new strategies, independently or from other sources, the direct consequence is better adaptation to the new state of health. All these strategies proved themselves useful to solve common problems such as leakage and ureteral stent obstruction. Despite the occurrence of management problems, it is possible to use proper strategies that can let a patient live his/her social life without the fear of unpleasant situations (Davis et al., 2011; Recalla et al., 2013; Richbourg et al., 2007). Another element surfaced with intensity from the interviews, showing that a good level of self-care in stoma management represents a positive factor. In the literature, one of the positive factors in stoma management is a high level of self-care at the time of discharge and for one month after the discharge (Haugen et al., 2006; Tal et al., 2012). Two of the interviewees luckily, affirmed that they had some earlier understanding of stoma management because one of their relatives had a stoma. This seemed to be helpful because it gave the patients an idea of what living with a stoma could mean, thereby making them aware that they could lead the same life they had lived before the surgery.

4.5. Limitations

This study does have some limitations. The data analysis has been done on just eleven ostomy patients' interviews, this highlights how difficult it was to find patients with stomas who were willing to take part in such a research. This was probably caused by the embarrassment and reticence when it came to talking about private topics like body image and sexuality. One of the main reasons that could have caused such uncommunicativeness could be the semi-structured nature of the interview. In fact, the participants had to talk about their most private feelings and experiences face to face with a nurse. Another limitation was the time of the interviews: these were performed four to six months after the surgery to give the patient time to return home from the hospital and adapt to his/her new life with a urostomy. In fact, it is important to consider if the time between the surgery and the interview was enough for the adaptation, and, in this logic, it could have been interesting to conduct another interview, six months after the first one, to analyze the different themes and contents that could emerge during the time between the first and the second interview. In this sense, the scrutinized literature does not provide clear indications.

5. Conclusion

The results show that life can be complex for urostomy patients, since a urostomy brings changes in all possible aspects of their life, resulting in the need for a psychological and practical support system. For instance, not only are the patient's adaptation skills important, but also his/her reactive skills, the care of his/her family, and an adequate level of self-care, all of which can play an important role in letting him/her return to pre-surgery work and social activities.

Considered this, we think it is important to provide urostomy patients support and continuing education to foster a high level of self-care, better quality of life, and respect for their needs. We are also convinced that there should be further research in future to help urostomy patients to have the best possible level of self-care and help nurses deal with them through a personalized education program.

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