



Original article

Life with a urostomy: A phenomenological study[☆]

Giulia Villa^{a,*,1}, Duilio F. Manara^a, Tommaso Brancato^b, Gennaro Rocco^c, Alessandro Stievano^c, Ercole Vellone^d, Rosaria Alvaro^d

^a School of Nursing, Vita-Salute San Raffaele University, 20132 Milan, Italy

^b Rome American Hospital, 00155 Rome, Italy

^c Centre of Excellence for Nursing Scholarship Ispasvi Rome, 00192 Rome, Italy

^d Department of Biomedicine and Prevention, University of Rome Tor Vergata, 00133 Rome, Italy

ARTICLE INFO

Keywords:

Experience

Phenomenology

Qualitative research

Self-care

Urostomy

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

[☆] Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conflict of interest

The authors have no conflicts of interest to disclose.

* Corresponding author at: School of Nursing, Vita-Salute San Raffaele University, via Olgettina 58, 20132 Milan, Italy.

E-mail addresses: villa.giulia@hsr.it (G. Villa), manara.duilio@hsr.it (D.F. Manara), tommaso.brancato@gmail.com (T. Brancato), genna.rocco@gmail.com (G. Rocco), alessandro.stievano@gmail.com (A. Stievano), ercole.vellone@uniroma2.it (E. Vellone), rosaria.alvaro@gmail.com (R. Alvaro).

¹ Present affiliation Giulia Villa: Unit of Urology, IRCCS San Raffaele Scientific Institute, 20132, Milan, Italy.

<http://dx.doi.org/10.1016/j.apnr.2017.10.005>

Received 16 August 2017; Received in revised form 22 September 2017; Accepted 15 October 2017

0897-1897/ © 2017 Elsevier Inc. All rights reserved.

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 ostomies 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? <i>Possible prompts: What happened? How did you feel?</i>
2	Can you describe the experience to have an urostomy in your life? <i>Possible prompts: What happened? How did you feel? How did you cope with it?</i>
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? <i>Possible prompts: Do you see yourself differently now than before? In what ways?</i>
7	How do you think other people see you? <i>Possible prompts: partner, family, friends, work colleagues?</i>
8	How do you see yourself in the future? <i>To go deeper: Why? How? Can you tell me more about that? Tell me: what were you thinking? How did you feel?</i>

Download English Version:

<https://daneshyari.com/en/article/8567582>

Download Persian Version:

<https://daneshyari.com/article/8567582>

[Daneshyari.com](https://daneshyari.com)