European Journal of Oncology Nursing 28 (2017) 107–113

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

The preoperative reaction and decision-making process regarding colostomy surgery among Chinese rectal cancer patients

Jun-e Zhang, PhD, RN [a], Frances Kam Yuet Wong, PhD, RN [b, *], Mei-chun Zheng, BN, RN [c]

[a] School of Nursing, Sun Yat-sen University, Guangzhou, China
[b] School of Nursing, The Hong Kong Polytechnic University, Hong Kong SAR, China
[c] Department of Colorectal Surgery, Cancer Center, Sun Yat-sen University, Guangzhou, China

ARTICLE INFO

Article history:
Received 20 January 2017
Received in revised form
26 March 2017
Accepted 29 March 2017

Keywords:
Preoperative reaction
Decision-making
Colostomy
Rectal cancer
Chinese
Qualitative research

ABSTRACT

Purpose: Patients with rectal cancer have issues in adjusting to their permanent colostomy after surgery, and support is required to help them resume normal life. However, few studies have explored the experience and factors that affect a patient's decision-making and maladjustment prior to colostomy surgery. The aim of this study was to explore the experience of rectal cancer patients who have to undergo colostomy surgery.

Method: A descriptive, qualitative design was used. We studied a purposive sample of 18 patients who had received a diagnosis of primary rectal cancer and were expecting permanent colostomy surgery. The thematic analysis approach was used to analyze the data collected using semi-structured, open-ended questions.

Results: The overriding theme that emerged was 'stoma dilemma: a hard decision-making process'. From this main theme, three themes were derived: the resistance stage, the hesitation stage, and the acquiescence stage.

Conclusion: It is hard for preoperative rectal patients to choose to undergo stoma surgery or a sphincter-saving operation. From the initial stage of definitive diagnosis to the final consent to stoma surgery, most patients experience the resistance and hesitation stages before reaching the acquiescence stage. Arriving at a decision is a process that nurses can facilitate by eliminating unnecessary misunderstanding surrounding colostomy surgery and by fully respecting patients' right to choose at the various stages.

1. Introduction

Colorectal cancer (CRC) is one of the most commonly diagnosed cancers worldwide. Compared with sphincter-saving operations, abdominoperineal resection with colostomy continues to be a primary and radical surgical approach for many patients with rectal cancer, resulting in the loss of defecation control function (Krouse et al., 2007; Sun et al., 2013). If possible, a sphincter-saving operation to avoid a permanent stoma is always the option that patients prefer (Wu et al., 2016). Around 100,000 individuals undergo stoma surgery each year in the United States (United Ostomy Associations of America, 2010) and China shares a similar statistic (Yu, 2005). Compounded by a cancer diagnosis, stoma surgery inevitably elicits psychological and social consequences that can be complex and lifelong (Simmons et al., 2007; Sun et al., 2013; Worster and Holmes, 2008).

Waiting for major surgery is a vulnerable period in a person's life, and patients may experience a variety of obvious or hidden feelings before their operation (Moene et al., 2006). Prior to surgery for a malignant condition, fear of the unknown may weigh heavily on patients' minds, including concerns about the outcome of the operation and altered life after surgery, and about losing their independence and integrity (Moene et al., 2006). Negative preoperative psychological reactions to surgery, such as uncertainty, feeling passive, and a helpless/hopeless response are consistently associated with poor outcomes, such as increased length of hospital stay, higher postoperative analgesic consumption, prolonged recovery time, and trouble cooperating with self-care activities (Waller et al., 2015).

Many patients with cancer experience psychological distress, such as anxiety and depression, at diagnosis, during treatment, or over a long period of time after treatment, as part of adjusting to this life change (Sivesind and Baile, 2001). Patients who undergo

---

* Corresponding author.
E-mail address: frances.wong@polyu.edu.hk (F.K.Y. Wong).

http://dx.doi.org/10.1016/j.ejon.2017.03.006
1462-3889/© 2017 Published by Elsevier Ltd.

permanent colostomy formation experience additional consequences such as altered body image; uncertainty about living with the stoma; the effect on their sex life; social handicap due to the odor, noise, and frequency of cleaning; dietary restrictions; stoma irritation; difficulty finding supplies; and limited ability to travel, participate in leisure activities, and find employment (Ang et al., 2013; Sun et al., 2013).

Losing one's rectum is negative and embarrassing where cultural sensitivity to the presence of a stoma is high (Simmons, 2014). Chinese people's self-identification is influenced to some extent by a famous Confucian saying that ‘The body, hair, and skin, given by the parents, must not be ruined; this is the beginning of filial piety’. Colostomy surgery involves the loss of important organs and impaired bodily integrity, and is thus detrimental to Chinese people's sacred sense of life. For the Chinese, life with no disability, beginning and ending well, is widely believed to be a minimum requirement for happiness. Unlike colon or upper rectal cancer patients, whose operations more or less only involve intestine removal, lower rectal cancer patients are often confronted with the decision to remove an important organ, the anus. This will in turn result in losing the important and fundamental physiological function of natural defecation, thereby negatively affecting patients' physical, psychological, social, and sexual health (Ang et al., 2013).

Since the effects of colostomy formation on patients may be significant, their decision-making experience is important in determining their quality of life and adjustment to life with a stoma. Preoperative “talking”, making the decision regarding colostomy surgery, may reduce the intrusive thoughts and psychological distress and facilitate the adaptation to stoma after operation (Leydon et al., 2000). Shared decision-making between clinicians and patients might be of value for patients with low-lying rectal cancer, to allow them to choose or at least reconsider the surgical style that will best fit the individual patient (Zolciak et al., 2006). A systematic review showed that from the limited evidence available, rectal cancer patients are prepared to trade significant reductions in life expectancy and overall survival to avoid certain colorectal surgeries, particularly stoma formation (Currie et al., 2014). Therefore, the decision to undergo colostomy surgery, based on feeling under pressure to do what is ‘right’, is complex and involves a considerable trade-off between perceived benefits and disadvantages (Currie et al., 2014; Worster and Holmes, 2008).

Previous studies have focused largely on health-related quality of life and psychosocial morbidity following stoma-forming surgery, such as stoma maladjustment, poor body image, uncertainty, depression, and social isolation. The measures have tended to be based on quantitative data. Listening to and understanding patients' experience in their struggles with stoma surgery, from receiving their diagnosis to their preoperative experience and the difficult process of deciding to undergo colostomy surgery, is of great significance to the integrity of the whole experience (Leydon et al., 2000). There is a lack of studies exploring the experience and factors that affect the decision-making and maladjustment before stoma surgery. The aim of this study was to explore patients’ experience in the preoperative phase, after rectal cancer diagnosis and prior to undergoing colostomy surgery. There were two research questions: (1) what was the real experience and reaction regarding colostomy surgery among rectal cancer patients? (2) What was the decision-making process before colostomy surgery among rectal cancer patients?

2. Methods

2.1. Design

A descriptive, qualitative design was employed to collect and analyze the data.

2.2. Sample and setting

The study was undertaken in a university-affiliated cancer center located in Guangzhou, southern China during the period from May to November 2014. The criteria for inclusion were having a diagnosis of primary rectal cancer, expecting a permanent colostomy after surgery, and the ability to speak Mandarin or Cantonese. Criteria for exclusion were confusion or mental disability. Inclusion or exclusion were confirmed by the first author after subjects had been recruited by the ward nurses. Finally, 18 patients were purposively selected to ensure that the sample included both men and women from a broad age range, with different educational backgrounds and occupations. All spoke Mandarin, except 2 who were Cantonese speaking.

2.3. Data collection

Participants about to undergo colostomy formation surgery in a colorectal surgical unit were invited to participate in the study 1–2 days before their colostomy surgery. The interviews were conducted in the stoma education room and carried out by the first author, an experienced qualitative researcher. A semi-structured, open-ended interview guide (See Table 1) was used for interviews with the preoperative patients. During the process of interview, the interviewer often probed further to invite elaboration on what has been expressed by the patients, including statements such as ‘could you elaborate more on the concerns in interacting with others’, ‘what does it mean when you say the stoma affect your daily life, could you provide some concrete examples?’ The interviews lasted from 30 to 45 min. The sample size was decided based on the concept of ‘saturation’, or the point at which no new information or themes are observed in the data.

2.4. Data analysis

Each recorded interview was transcribed verbatim by the principal investigator within 48 h of interviews. Mandarin and Cantonese shared the same written Chinese and all of the investigators were proficient in both Mandarin and Cantonese. In order to preserve the original meanings of the participants’ statements, all of the data analyses were conducted using the original Chinese transcripts. Thematic analysis was used to treat the data following the six phases outlined by Braun and Clarke (2006). The six phases were: (1) data familiarization, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. All the interviews were tape-recorded and transcribed verbatim into Chinese by the first author, leaving large margins for notes to be made. The audio recordings were listened to several times, checking against transcriptions to ensure their accuracy. The transcribed interviews were then read and re-read to facilitate data familiarization. The first two authors analyzed the data independently. We identified meaning units from the text that were related to the aim of the study. Coding of the data was then completed and similar codes were grouped into sub-themes, which ultimately formed the themes and an overarching theme. Throughout the analysis, themes were reviewed, defined and finally named to reflect the essence of the content. The data that were coded discordantly were discussed by the research group until consensus was reached. Finally, only the sub-themes, themes and significant statements were translated into English and verified by the first two authors.