

# ปัจจัยที่มีความสัมพันธ์กับคุณภาพชีวิตด้านสุขภาพของผู้ป่วยมะเร็งลำไส้ใหญ่ที่มีทวารเทียมในปักกิ่ง ประเทศจีน

## Factors Associated with Health-related Quality of Life among Patients with Colorectal Cancer and Stoma in Beijing, China

นิพนธ์ฉบับ

Original Article

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### บทคัดย่อ

**วัตถุประสงค์:** เพื่อศึกษาปัจจัยที่เกี่ยวข้องกับคุณภาพชีวิตด้านสุขภาพของผู้ป่วยมะเร็งลำไส้ใหญ่และมีทวารเทียมในกรุงปักกิ่ง ประเทศจีน **วิธีการศึกษา:** การศึกษาแบบภาคตัดขวางนี้คัดเลือกผู้ป่วย 207 คน ที่มีทวารเทียม รักษาที่โรงพยาบาลมิตรภาพปักกิ่ง มหาวิทยาลัยแพทยศาสตร์ สาธารณรัฐประชาชนจีน ใช้แบบสอบถามที่ผู้ตอบด้วยตนเองประเมินคุณภาพชีวิตด้านสุขภาพ แบบประเมินเพศ/ภาพลักษณ์ การทำหน้าที่ของทวารเทียม การสนับสนุนทางสังคมและความสามารถในการดูแลตนเอง วิเคราะห์ข้อมูลด้วยการทดสอบค่าที่การวิเคราะห์ความแปรปรวนทางเดียว และการวิเคราะห์ค่าสหสัมพันธ์เพียร์สัน **ผลการศึกษา:** คะแนนเฉลี่ยระดับคุณภาพชีวิตด้านสุขภาพเท่ากับ  $126.61 \pm 33.74$  คะแนน (ช่วง 56 - 230 คะแนน) พบว่าคุณภาพชีวิตด้านสุขภาพสัมพันธ์เชิงลบกับการทำหน้าที่ของทวารเทียม ( $r = -0.601$ ) และสัมพันธ์เชิงบวกกับปัจจัยด้านเพศ/ภาพลักษณ์ การสนับสนุนทางสังคม และความสามารถในการดูแลตนเอง ( $r = 0.195, 0.396, 0.511$ , ตามลำดับ) ( $P$ -value < 0.01 ทั้งหมด) **สรุป:** ที่ศนคติทางเพศ/ภาพลักษณ์ การสนับสนุนทางสังคม และความสามารถในการดูแลตนเองเป็นปัจจัยสำคัญที่เพิ่มคุณภาพชีวิตด้านสุขภาพ พยาบาลสามารถส่งเสริมคุณภาพชีวิตของผู้ป่วยที่มีทวารเทียมด้วยการปรับปัจจัยเหล่านี้

**คำสำคัญ:** มะเร็งลำไส้ใหญ่; ทวารเทียม; คุณภาพชีวิตด้านสุขภาพ; การสนับสนุนทางสังคม; ความสามารถในการดูแลตนเอง; เพศ/ภาพลักษณ์

### Abstract

**Objectives:** To examine factors associated with health-related quality of life (HRQoL) among patients with colorectal cancer and stoma in Beijing, China. **Method:** This cross-sectional study recruited 207 patients with stoma at Beijing Friendship Hospital, Capital Medical University, China. Self-report questionnaires of HRQoL, sexuality/body image, stoma function, social support and self-care ability were administered. Independent sample t test, one-way analysis of variance and Pearson product moment correlations were used for data analysis. **Results:** The mean score of HRQoL was  $126.61 \pm 33.74$  points (range: 56 - 230). HRQoL was significantly negatively correlated with stoma function ( $r = -0.601$ ) and positively correlated with sexuality/body image, social support and self-care ability ( $r = 0.195, 0.396$ , and  $0.511$ , respectively) ( $P$ -value < 0.01 for all). **Conclusion:** Positive sexuality/body image, stoma function, social support, and self-care ability of patients were important factors that affect HRQoL. Clinical nurses can help patients with stomas improve their HRQoL by intervening in these aspects of their lives.

**Keywords:** colorectal cancer; stoma; health-related quality of life; social support; self-care ability; sexuality/body image

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## Introduction

With the rapid development of China's economy and changes in the living environment and diet of Chinese residents, the incidence of colorectal cancer has continued to increase.<sup>1</sup> China is the country with the largest number of new cases and deaths from colorectal cancer each year.<sup>2</sup> Colorectal cancer has severely affected and threatened the health of the Chinese people.<sup>3</sup> Surgery combined with radiotherapy and chemotherapy is currently the standard treatment for colorectal cancer. At present, the number of patients with stoma in China has exceeded 1 million.<sup>4</sup> With

the increase in the number of patients with stoma, the psychology, physiology, and quality of life of these patients have garnered the attention of the Chinese government.<sup>1</sup>

After enterostomy surgery, the integrity of the patient's body is destroyed. Many patients are afraid of the odour produced by stoma excretion of faeces, which seriously hurts their self-esteem. They may develop an avoidant personality and refuse to socialize. Some men have sexual dysfunction such as erection and ejaculation problems due to enterostomy. Some women have dyspareunia caused by

painful intercourse, which leads to tension in the relationship between husband and wife.<sup>5</sup> Colorectal cancer patients with stomas have a sense of shame and low self-esteem about their body image, which can reduce their quality of life.<sup>6</sup>

Stoma affects the patient's quality of life, leading to psychological and sexual problems, dissatisfaction with changes in body image, changes in daily life, travel difficulties and fatigue.<sup>7</sup> The existence of stoma not only affects the patient's body image but also the patient's physiological function, which first causes a decline in physiological activity function and then social function, emotional function and quality of life. After ostomy surgery, patients experience different degrees of fatigue, insomnia, loss of appetite and other physical discomforts, which also leave them unable to carry out activities of daily living, work and social activities.<sup>8</sup> Preserving stoma after colorectal cancer surgery causes personal image disorder (80.1%), anxiety (36.2%), depression (30.1%) and pain (58.5%).<sup>9-11</sup>

Sexuality/body image refers to the image an individual has of his or her body and sexual activity. It is the perception of patients with stoma towards their image of sexuality and body. Sexuality/body image may have effect on the patient's health-related quality of life (HRQoL). Stoma function refers to the defecation function used to replace the original perineal anus, which is actually a diversion of the faecal outlet. Stoma function may have effect on HRQoL. Social support is defined as the perception of receiving support from significant others such as family members, friends, colleagues and the medical staff. Social support includes three components namely objective support, subjective support and utilization of support. Social support has effect on the HRQoL of patients with stoma. Self-care ability refers to the ability to perform stoma care to maintain life, health, and comfort. self-care ability will have effect on HRQoL among patients with stoma.

This research used Ferrans' Revised Wilson and Cleary model for the HRQoL model for guidance. The model mainly focuses on the relationship between environmental, functional status, general health perception, and overall HRQoL. Their combined effect has been found to improve the patient's HRQoL.<sup>12</sup>

For this study, four factors were considered in explaining the health-related quality of life (HRQoL) of patients with stoma, which could singularly or together affect HRQoL. These factors were social support, self-care ability, sexuality/body image and stoma function. All the factors and

their association with HRQoL are provided in detail as follows. Social support is an environmental feature that directly affects the patient's HRQoL. Stoma function and sexuality/body image are functional state they are component of Ferrans' Revised Wilson and Cleary model for HRQoL. Self-care ability belongs to general health perceptions that is a component of Ferrans' Revised Wilson and Cleary model for HRQoL.

Clinical research on HRQoL in patients with colorectal cancer is limited. The purpose of this study was to examine the factors associated with HRQoL in patients with colorectal cancer and stoma. The research hypothesis was that sexuality/body image, stoma function, self-care ability, and social support were associated with HRQoL among patients with colorectal cancer and stoma. The results could be useful as information for evolving interventions to improve the HRQoL of patients with stoma.

## Methods

In this cross-sectional study, the sample consisted of male and female patients with colorectal cancer who had temporary or permanent stoma and were receiving treatments at the hospital under the jurisdiction of the Beijing Hospital Administration in China. Patients were recruited according to the following inclusion criteria. They had to be 18 years old or older, one month after the end of the full cycle of chemoradiotherapy, have the Activity of Daily Living (ADL) score of 60 - 100 points, be able to write and read in Chinese language and cooperate with the investigation, have no history of chronic pain and long-term use of analgesics, and have no colorectal cancer recurrence or metastasis. The participants were recruited while visiting the stoma clinic of Beijing Friendship Hospital affiliated with Capital Medical University on Wednesdays at 8:00 am - 12:00 pm.

The sample size for this study was calculated using G\*Power 3.1 software.<sup>13</sup> Using a conventional power estimate of 90%, with the alpha level set at .05, the effect size was 0.3,<sup>14</sup> requiring a total sample size of at least 194 subjects. Considering a 10% invalid questionnaire rate, the total sample for this study was 216 subjects. Therefore, this study sample included 216 patients. Of these, 207 patients completed the study for a response rate of 95.83%.

## Research instruments

A demographic record form and four self-report questionnaires were used in this study. Content validity was tested in this present study by three experts who were wound and ostomy continence specialist nurses with senior professional titles. The internal consistency reliability was tested in this study using 20 individuals with characteristics comparable with the participants.

Social support refers to perceived support from significant others such as family members, friends, colleagues and the medical staff. Social support includes three components: objective support, subjective support and utilization of support. It was measured by the Social Support Rating Scale (SSRS). The Social Support Rating Scale (SSRS)<sup>15</sup> was used to measure social support. It has 3 dimensions with 10 items. The possible total score was 11 – 66 points. A higher value indicated a higher level of social support. Internal consistency reliability was acceptable with a Cronbach's alpha coefficient of 0.69. The questionnaire had a good content validity with a content validity index (CVI) of 0.779.<sup>15</sup> and 0.817 in this study.

Self-care ability refers to the ability to perform stoma care to maintain life, health, and comfort. It was measured by the Stoma Self-Care Scale-early-stage version (SSCS-early stage version). The Stoma Self-Care Scale-early stage version (SSCS-early stage version)<sup>16</sup> was used to measure the patient's ability to care for his or her stoma after surgery. The response was a 5-point Likert-type scale ranging from 1- very unskilled, to 2- unskilled, 3-average, 4-skilled, and 5- very skilled. The scale has 10 items in total with a possible score of 10 to 50 points, where higher scores indicate higher ability to care for the stoma. The content validity was good in a previous study (CVI of 0.9424)<sup>16</sup> and in this study (CVI of 0.942). The internal consistency reliability was high with a Cronbach's alpha coefficient of 0.942 in this study.

Sexuality/Body image refers to the perception of patients with stoma towards their image of sexuality and body. Stoma function refers to the defecation function used to replace the original perineal anus, which is actually a diversion of the fecal outlet. They were measured by the items of sexuality/body image and stoma function in the self-reported Stoma Quality of Life Scale (SQOLS).<sup>17</sup> The scale consisted of 21 questions. With a response of a 5-point Likert-type rating scale, 6 questions measured work/social function, 5 questions measured sexuality/body image, and 6 questions measured stoma function. With a different scale, one, one and two

questions measured financial impact, skin irritation, and two overall satisfaction, respectively. With a possible total score of 0 – 100 points, higher scores indicated better sexuality/body image; while higher scores indicated poorer stoma function. Internal consistency reliability of sexuality/body image and stoma function were acceptable in the past study (Cronbach's alpha coefficients of 0.79 and 0.76, respectively)<sup>17</sup>, and high in this study (0.84 and 0.89, respectively).

Health-related quality of life (HRQoL) refers to the aspects of patients experience and cognition of their own status in their culture and value system that are affected by diseases. This was measured by the Chinese Version of Colorectal Cancer-Specific Quality of Life Questionnaire-C59 (QLQ-CR59).<sup>18,19</sup> QLQ-CR59 is composed of two parts, the core module QLQ-C30 (V3.0) and the specific module QLQ-CR29 specially used for colorectal cancer. The QLQ-C30 consists of 5 functional domains, 3 symptom domains, 1 overall health subscale and 6 specific items reflecting symptoms. The QLQ-CR29 incorporates 4 multi-item scales and 19 single items assessing a range of symptoms and problems common among patients with colorectal cancer. The total score on this scale ranges from 56 to 230 points. A higher score indicates better HRQoL. Internal consistency reliability of parts of QLQ-C30 ranged from low to high in the past study (Cronbach's alpha coefficients of 0.54 - 0.86).<sup>18</sup> Similarly, Internal consistency reliability of parts of QLQ-CR29 ranged from low to high in the past study (Cronbach's alpha coefficients of 0.54 - 0.82)<sup>19</sup>, and high in this present study (0.981).

## Participant ethical protection

The study was approved by the Institutional Review Board, Burapha University, Thailand (approval number: G-HS037/2565; approval date: June 25, 2022) and the Research Ethics Committee of Beijing Friendship Hospital affiliated with Capital Medical University (approval number: 2022-P2-128-01; approval date: May 6, 2022). The investigators explained to all participants the purpose, process, benefits, and voluntary nature of the study. Participants were advised that they could withdraw at any time without affecting their treatment. Data were anonymous and confidential.

## Data collection procedures

The questionnaire was distributed and collected on the Star online platform on Wednesdays 8:00 am - 12:00 pm,

while the patient was waiting in the ostomy clinic. The patient used his or her mobile phone to scan a QR code to complete the questionnaire. Patients who could not use a mobile phone to access the questionnaire or for other reasons were unable to complete the questionnaire online, were provided with paper questionnaires. Online questionnaires took 30 minutes to complete.

### Data analysis

Differences of HRQoL scores according to age group, sex, and stoma complications were compared using analysis of variance (ANOVA) and independent t test, as appropriate. Relationships of HRQoL with sexuality/body image, stoma function, social support, and self-care ability were tested using Pearson's product moment correlation analysis. Statistical significance was at a type I error of 5%. All statistical analyses were done using the software program SPSS 25.0.

## Results

Of the 207 patients with stoma, majority of them were men (52.66%) (Table 1). HRQoL scores of men and women were comparable 126.06 and 127.25 points, respectively, ( $P$ -value = 0.064). With an age range of 20 to 88 years, they were  $57.88 \pm 15.22$  years old by average and the majority were in their 60 - 79 age range (43.96%). The majority suffered from ostomy complications (54.11%). Participants aged 20 - 39 years had the highest HRQoL (137.581 points); however, no difference was found where compared to those in other age groups. Time after diagnosis, patients with stoma diagnosed at 61 - 84 months had the highest HRQoL scores ( $166.20 \pm 45.30$  points). A total of 45.89% of patients with stoma never suffered from stoma complications, and they had HRQoL of 146.42 points which was significantly higher than that in those with complications (109.82 points) ( $P$ -value < 0.001) (Table 1).

HRQoL was significantly, negatively correlated with stoma function ( $r = -0.601$ ,  $P$ -value < 0.01), and significantly, positively correlated with sexuality/body image, social support and self-care ability ( $r = 0.195$ , 0.396 and 0.511, respectively,  $P$ -value < 0.01 for all).

## Discussions and Conclusion

This cross-sectional survey aimed to investigate the status of HRQoL and its influencing factors in patients with ostomy in Beijing, China. Relatively moderate levels of HRQoL based

**Table 1** Health-related quality of life scores by demographics (N = 207).

Variables	N (%)	Mean $\pm$ SD	Test statistics	P-value
Age (year), range = 20 - 88, Mean = $57.88 \pm 15.22$				
20 - 39	31 (14.98)	$137.58 \pm 39.51$	1.821*	0.144
40 - 59	70 (33.82)	$122.77 \pm 29.60$		
60 - 79	91 (43.96)	$127.20 \pm 35.32$		
$\geq 80$	15 (7.25)	$117.20 \pm 25.02$		
Sex				
Women	98 (47.34)	$127.25 \pm 33.76$	0.064 <sup>†</sup>	0.801
Men	109 (52.66)	$126.06 \pm 33.86$		
Time since diagnosis (month), range = 8 - 324, mean = $37.99 \pm 48.77$				
$\leq 12$	84 (40.58)	$112.65 \pm 23.84$	9.283*	< 0.001
13 - 36	68 (32.85)	$128.32 \pm 35.10$		
37 - 60	17 (8.21)	$136.06 \pm 27.75$		
61 - 84	10 (4.83)	$166.20 \pm 45.30$		
85 - 108	11 (5.31)	$136.09 \pm 37.39$		
> 108	17 (8.21)	$126.62 \pm 33.74$		
Stoma complications				
Yes	112 (54.11)	$109.82 \pm 26.61$	85.210 <sup>†</sup>	< 0.001
No	95 (45.89)	$146.42 \pm 30.44$		

\* ANOVA.

<sup>†</sup> independent t test

on Ferrans' Revised Wilson and Cleary model were reported by the participants. It helped the researchers design an appropriate conceptual framework for investigating factors affecting HRQoL in patients with stoma.

Self-care ability belongs to general health perceptions that is a component of Ferrans' Revised Wilson and Cleary model for HRQoL.<sup>12</sup> This study found that patients with stoma who have low self-care ability were more dependent on caregivers and were unwilling to learn nursing knowledge and practice.<sup>20</sup> Similar to a previous study, patients with enterostomy were often unwilling to face the "new bowel passage," which made them more dependent on family members for care.<sup>21</sup> Young patients with stomas were more capable of self-care. Elderly patients with stomas in China often relied more on their children or spouses to take care of the stoma.<sup>22</sup> In traditional Chinese culture, there is a proverb that means that the parents give everything in the body and that there must be no damage to it. This means that loving the body is similar to loving one's parents. Patients aged 20 to 39 years had the highest stoma acceptance. Young patients are more likely to accept stoma-related knowledge and find relevant groups to obtain social support, such as groups on the WeChat or QQ platforms. There are more channels for obtaining information. However, older patients, especially those over 60 years old, had less access to health-related information. Due to their physical condition, it is more difficult for them to take care of their stoma by themselves than for younger patients.<sup>6</sup>

Sexuality/body image is a functional state that is a component of Ferrans' Revised Wilson and Cleary model for HRQoL.<sup>12</sup> After receiving ostomy surgery, men could have erections and ejaculation difficulties, and women could have sexual intercourse pain and other symptoms. Patients with stoma cannot trust their bodies as much as before, which leads to a sense of uncertainty and discomfort. The presence of a stoma changes their attitude towards life, which directly affects their HRQoL.<sup>23</sup> Patients with stoma cannot accept changes in their body image in the early stages of the disease. They think the stoma is a physical disability, but over time, they gradually accept their stoma and find that it is not so difficult to care for it. As time passes after surgery, many patients with ostomy can participate in more social activities and gradually resume their usual lives. Our result agrees with some other studies. The HRQoL of cancer survivors depends on the time of cancer diagnosis and cancer type.<sup>24</sup> Cancer survivors have complex HRQoL variability, and these populations may benefit from additional resources and interventions.

Stoma function is also a functional state that is a component of Ferrans' Revised Wilson and Cleary model for HRQoL.<sup>12</sup> After the implementation of enterostomy, the normal physiological defecation pattern of the patients will change. The patients have no consciousness of defecation control and irregular defecation, which inconveniences them and tests them physically and mentally. Complications often occur after enterostomy surgery, which seriously affects patients' quality of life.<sup>25</sup> Many studies have findings similar to this study, and problems with stoma function, such as changes in stoma shape or complications, reduce the quality of life of patients.<sup>25-27</sup> When patients with ostomy excrete more faeces or discharge more gas, the patient's ostomy bag will swell, and the patient's body will have a bad smell, which will directly reduce their HRQoL.<sup>28,29</sup>

Social support is an environmental feature that directly affects the patient's QoL. This is confirmed by the theory of Ferrans' Revised Wilson and Cleary model for HRQoL model.<sup>12</sup> Patients in these studies reported that they had no one to talk to when they encountered ostomy problems, and their spouses or caregivers also lacked knowledge about ostomy. Many caregivers of patients with stoma said "I'm scared, I can't even look."<sup>30</sup> This creates psychological hints for patients with stoma that aggravates their sense of stigma and reduces their quality of life. The results of such studies

are consistent with the theoretical framework used in this study.<sup>31</sup> Social support affects functioning, symptoms and perceptions of social support in patients with stomas. Ultimately, it directly affects the health-related quality of life of patients with stoma.

Sexuality/body image, stoma function, social support, self-care ability and HRQoL were significantly positively correlated. Many studies confirm that the sexuality/body image of patients with stoma is related to HRQoL.<sup>32,33</sup> After receiving ostomy surgery, men could have erection and ejaculation difficulties, and women could have sexual intercourse pain and other symptoms. In addition, many patients have an aversion to seeing their own stoma. These factors directly reduce patients' HRQoL.<sup>34</sup> Similar to a previous study, patients with enterostomy are often unwilling to face the "new bowel passage," which makes them more dependent on family members for care.<sup>21</sup> Due to the concept of filial piety in China, most middle-aged and elderly people live with their children in China. An ostomy further contributes to their dependence on young people to care for them when they are sick.<sup>35</sup> When the self-care ability of patients with stoma is improved, they can go out socially, no longer worry about stoma leakage and resolve any problems by themselves.<sup>30</sup> When patients with ostomy excrete faeces or discharge gas, the ostomy bag will swell, and the patient's body will have a bad smell, which will directly reduce HRQoL.<sup>28,29</sup>

The results could be used as a baseline for the HRQoL of patients with stoma in Beijing. In addition, the results could guide future research on the HRQoL of patients with stoma. This research collected data from one hospital in the Beijing area, which limited the generalization of the results to Chinese patients with stoma. Future research should be conducted with multicentre studies to explore countermeasures to improve the HRQoL of patients with stomas. Further intervention studies are needed to improve social support, self-care ability, sexuality/body image and stoma function and then improve HRQoL in patients with stoma.

According to the results of this study, clinical nurses can provide prospective interventions to patients with stomas. In clinical work, nurses can carry out different forms of health education, answer questions raised by patients in a timely manner, improve the knowledge and skills of patients with stoma in self-care, provide consultation to improve stoma function and sexuality/body image, and provide social support for patients.

In conclusion, findings can be used to provide a theoretical basis for nursing interventions to improve the HRQoL of patients with stoma. Based on valuable feedback from ostomy patients about their HRQoL and its influencing factors, nurses can use this knowledge to intervene, improve the HRQoL and reduce the suffering of these patients. To contribute to the HRQoL of ostomy patients and their families' well-being, further nursing intervention studies should be conducted with ostomy patients reporting a lower quality of life.

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