Original article

The correlation between stigma and adjustment in patients with a permanent colostomy in the Midlands of China

ABSTRACT

Objective: To investigate the correlation between stigma and ostomy adjustment in patients with a permanent colostomy.

Methods: A total of 118 patients (male 81/female 37 with an average age 57.4±15.0) from six grade 3 hospitals of the Midlands of China with a permanent colostomy were recruited. Participants responded to a questionnaire to obtain sociodemographic data, Social Impact Scale (SIS) scores to ascertain stigma level and Ostomy Adjustment Inventory (OAI-20) scores to identify the level of psychosocial adjustment.

Results: The patients' average SIS score was (60.7±10.4). The QAI-20 total score was (41.3±10.8). The SIS total score and SIS subscores were negatively related to the total score and subscore of QAI-20 (r=-0.222~-0.537, all P<0.01). Multiple regression analysis revealed the level of self-stoma care performed, the degree of communication with medical staff, financial insecurity and social rejection when added into the regression equation had a significant negative impact on OAI-20.

Conclusion: In comparison to the average SIS score, the SIS score in this study sample is higher than midpoint, indicating stigma is closely related to ostomy adjustment. It is suggested that health professionals need to pay more attention to patients' expressed feelings of stigma to improve their ability to adjust to living with a colostomy.

Keywords Colostomy, stigma, ostomy adjustment.

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INTRODUCTION

Colostomy refers to the formation of a stoma within the large bowel whereby a piece of the colon (the stoma) is diverted through an artificial opening in the abdominal wall in order to bypass a damaged part of the colon. Colostomies are commonly formed to treat disorders of the digestive system such as colorectal cancer, inflammatory bowel disease and diverticulitis or to bypass a damaged part of the colon as the result of trauma.

Colorectal cancer is the leading reason for colostomy formation. The 2014 WHO World Cancer report shows that of all cancer cases in the past five years, colorectal cancer accounted for 10.9%, second only to breast cancer (19.2%) and thirdly prostate cancer (12.1%)[1]. The incidence of colorectal cancer ranked fifth in all cancers in China[2] and ranked fourth in the urban population in China[3].

Colostomy patients lose control of their bowel movements as the method of defecation has been changed. Further, they

need to wear a colostomy bag to collect excreta and, as a result, are always worried that the colostomy bag will leak, giving off an unpleasant smell and sound. The presence of a colostomy can adversely affect patients' daily life, sexual life and lifestyle in general as their body shape and function has changed [4-5]. Some patients see their colostomy as a taboo subject and are afraid of being discovered and having to reveal they have a stoma. Patients are often too frightened or embarrassed to talk about their colostomy in public. They feel stigmatised due to the presence of their colostomy[6].

Stigma is defined as a mark of perceived or actual disgrace or a feeling of being discredited that sets a person aside from others. It represents people who may be seen as unpopular due to a shortcoming or handicap. Stigma was introduced into the field of psychology by Goffman in 1963[7]. The stigma associated with a disease refers to patients' experience of a kind of inner shame arising from the illness. It is a feeling of being tagged or discriminated against and demeaned. It refers to alienation and avoidance by the individual by not being understood and accepted[8-9]. Goffman believes changes in the body, defects or deformities as well as having significant disease are characteristics of patients that make them more susceptible to feeling stigmatised. Many scholars have studied a variety of diseases that have an associated stigma, including mental illness, AIDS, cancer, incontinence, colon cancer and obesity[8,10-12]. MacDonald and Anderson in the United Kingdom surveyed 420 patients with rectal cancer, 256 of whom had a colostomy. Half the patients with a colostomy felt stigmatised, especially younger patients[13]. Smith studied 195 patients with a colostomy and found a negative correlation between the patient's disgust at having a stoma and how they adjusted to having a colostomy and life satisfaction in general[14]. Danielsen *et al.* in Denmark found a small cohort of 15 patients with colostomies had difficulty in disclosing they had a colostomy because this may impugn their reputation. As a result, they tried to limit the variety of daily outings, imposing self-isolation[6].

Disease-related stigma has become a strong predictor of disease adaptation and quality of life; however, in China research about stigma is focussed mainly on mental illness. There is almost no research on the stigma of patients with a colostomy.

Social adjustment refers to the individual's ability to adjust to or change the environment, in which case the individual's physical and mental state should be at an optimal state. Social adjustment is a proactive, dynamic self-adjustment process that is systemic in nature as it includes physiological, psychological, sociocultural elements and environmental aspects[14]. Colostomy patients face a variety of adaptation issues, including physiological, psychological and sociocultural aspects.

The level and characteristics of stigma associated with colostomy patients, as well as whether the patients' own feelings of stigmatisation and adaptation through social adjustment can influence each other, is worth exploring. Research on stigmatisation (perceived or actual) in relation to ostomies and people with colostomies, in particular, is currently lacking in China. Therefore, this study was designed to investigate the level of stigma and social adjustment in colostomy patients and to analyse the relationship between stigma and adaptation, and to provide an objective basis for clinical nursing interventions.

METHODS

Participants

Patients from the stoma therapy unit of six grade 3 hospitals in the Midlands of China from December 2016 to June 2017 were enrolled into this study by convenience sampling.

Inclusion and exclusion criteria

Patients were included if they:

1. were at least 18 years old;
2. had a permanent colostomy;
3. were in a rehabilitation period, having had a colostomy for one or more months;
4. were able to provide informed consent to participate in this research;
5. were able to read and understand Chinese.

Exclusion criteria

Patients with a cognitive disorder, metastatic cancer and other life-threatening serious diseases were excluded.

Survey procedure

The investigators in this study were enterostomal therapists and provincial enterostomal specialist nurses in each hospital. The authors trained the investigators how to conduct the survey. This included explaining in detail to the investigators how to convey the purpose of the survey, the methods of measurement and the details of the questionnaires used in the survey to potential study participants. Investigators followed uniform survey protocols when conducting the study. This included adopting a unified instructional language, timely feedback in response to participants' questions, and processes for entering and validating data to ensure the accuracy of the data. Participants' responses to the questionnaires issued were anonymous.

Measurement

Survey questionnaire

The survey questionnaire was developed by the authors. The questionnaire was comprised of 12 questions that included: age; gender; educational background; income level; house location; living state; average monthly income; length of time since surgery; types of medical payment; monthly cost of ostomy supplies; who performed the stoma care; stomal/peristomal complications; and, communication with medical staff.

Table 1: Characteristics of study participants

Characteristic	Numbers (%)
Age ≥ 60 years of age	55 (46.6)
Live with family or others	112 (94.9)
Lived in rural areas	61 (51.7)
Middle school graduates	47 (39.8)
Middle income range	46 (41.5)
Post surgery ≤ 6 months	45 (38.1)
Surgical procedure paid by medical insurance	85 (72)
Estimated cost of stoma products between 100 and 300 Yuan per month	57 (48.3)
Self-care of ostomy (without stoma nurse support)	46 (39)
No stoma or peristomal complications	86 (72.9)
Never communicated with medical staff	54 (43.4)

Social impact scale (SIS)

The SIS is widely used in cancer and other chronic diseases to measure the associated level of stigma. The authors and investigators used the SIS to measure the level of stigma in patients with colostomies in this study. The SIS was compiled by Fife and Wright in 2000 and was translated into Chinese by Pan *et al.* in 2007[15]. It consists of 24 items with four dimensions which are: social rejection; financial insecurity; internalised shame; and, social isolation. Each item scores from 1 (strongly disagree) to 4 (strongly agree). Higher scores indicate a higher level of stigma. Guan Xiao Meng *et al.,* who used the SIS in previous studies, obtained a Cronbach's α coefficient of 0.883[16]. The authors obtained Pan's consent to use the Chinese version of the SIS tool before the study commenced. The Cronbach's α coefficient set for this study was 0.915.

The Ostomy Adjustment Inventory (OAI-20)

The OAI-20 was developed by Simmons[17] *et al.* to assess psychological adjustment in patients with a stoma. The original scale comprised 23 items and four subfactors. Each item scored from 0 (strongly disagree) to 4 (strongly agree). Higher scores indicated better social adjustment. It was translated into a Chinese version by Gao Wen Jun *et al*. in 2011 to 20 items and three subfactors[18]. The Cronbach α coefficient in this study was 0.886.

Data analysis

Epidata 3.1 (Epidata Association Freeware) was used for data entry (QES file), developing archiving protocols (REC files) and for data verification/recovery (CHK files). IBM (2011) SPSS20.0 was used for statistical data analysis.

General information was described by simple frequencies and percentages. The SIS score and OAI-20 score were described by mean, averages and standard deviations. Comparisons between groups were tested by T-test or One-Way ANOVA analysis. Correlation between the SIS and OAI-20 scores was tested by Pearson correlation analysis.

Multiple regression analysis was used to explore the related factors affecting ostomy adjustment. $P<0.05$ was considered statistically significant.

RESULTS

Subject demographic characteristics and stoma-related information

A total of 118 patients were enrolled in the study. The mean age of participants was57.4±15.0 years. Eighty-one [68.6%] males agreed to participate the study. Additional characteristics of the study participants are identified in Table 1.

Social impact and ostomy adjustment findings

The average SIS scores were 60.7±10.4. The scoring rate was 63.2%. The social rejection, financial insecurity, internalised shame and the social isolation dimension scores were 21.8±4.3 (60.6%), 8.0±1.9, (66.7%), 12.7±2.5 (63.5%) and 18.2±3.6 (65%), respectively with response rates shown in brackets. Univariate analysis showed a significant difference with the SIS scores in the group regarding the different level of communication with medical staff; those who never communicated with the medical staff scored higher than other patients (Table 2).

The average OAI-20 scores were 41.3±10.8. The five lowest-scoring OAI-20 items identified by respondents are that because of my stoma I: limit my range of activities; am always conscious that my stoma may leak, smell, or be noisy; am always anxious about my stoma; feel that I will always be a patient; and, feel I am no longer in control of my life. Univariate analysis showed a significant difference with the OAI-20 scores in the group in relation to differences in average income, differing lengths of time post-surgery and differing levels of self-care. The SIS total score and subscores and OAI-20 total

Table 2: The general information and factor analysis of variance (n=118)

Item	Group	*n* (%)	SIS score (*x*±*s*)	*F*/t	*P*	OAI-20 score (*x*±*s*)	*F*/t	*P*
Gender	Male	81 (68.6)	60.9±10.9	0.06	0.808	42.4±11.1	0.018	0.895
	Female	37 (31.4)	60.3±9.7			42.1±11.2		
			60.5±8.8					
Age	18~44	22 (18.6)	61.4±11.6	0.16	0.845	42.6±8.2	0.141	0.869
	45~59	41 (34.7)	60.1±10.2			41.5±12.4		
	≥60	55 (46.6)	61.8±9.4			42.7±11.1		
Educational background	Primary school	43 (36.4)	60.2±10.3	0.71	0.589	42.1±10.3	0.083	0.988
	Middle school	47 (39.8)	58.3±13.3			42.8±11.6		
	Training school	19 (16.1)	67.0±14.8			41.8±10.8		
	Bachelor degree	5 (4.2)	57.3±4.6			40.2±18.3		
	Higher education	4 (3.4)	61.2±9.9			42.0±6.7		
House location	Rural area	61 (51.7)	59.9±11.2	0.39	0.533	41.2±10.2	1.234	0.269
	City	57 (48.3)	62.0±8.5			43.4±11.9		
Living state	Single	6 (5.1)	60.0±11.9	0.76	0.556	44.0±10.0	0.675	0.611
	With spouse	43 (36.4)	56.9±11.8			43.5±11.2		
	With spouse and children	54 (45.8)	62.0±13.9			40.5±11.2		
	With children	13 (11.0)	54.5±7.7			44.1±11.3		
	Other	2 (1.7)	62.2±10.8			46.5±0.7		
Average income	<500	20 (16.9)	60.9±9.3	0.79	0.531	40.5±7.9	4.034	**0.004**
	500~1000	9 (7.6)	61.3±10.5			35.2±11.9		
	1000~3000	49 (41.5)	60.2±11.3			41.6±10.7		
	3000~5000	30 (25.4)	54.3±6.3			42.9±9.7		
	>5000	10 (8.5)	59.9±9.6			53.4±14.4		
Postoperative time	≤6	45 (38.1)	62.4±9.9	0.88	0.454	40.0±10.2	3.085	**0.030**
	7~12	30 (25.4)	61.7±11.2			42.3±9.9		
	13~36	29 (24.6)	56.6±13.0			41.9±11.9		
	>37	14 (11.9)	58.8±4.8			50.0±11.8		
Types of medical payment	Socialised medicine	7 (5.9)	59.9±10.9	1.01	0.367	36.7±10.2	2.707	0.071
	Hospitalisation insurance	85 (72.0)	63.2±10.0			43.7±11.2		
	At one's own expense	26 (22.0)	63.2±9.0			39.1±9.7		

Table 2 (continued): The general information and factor analysis of variance (n=118)

Item	Group	*n* (%)	SIS score (*x±s*)	*F*/t	*P*	OAI-20 score (*x±s*)	*F*/t	*P*
Monthly cost of stoma product	<100	17 (14.4)	59.0±10.3	1.35	0.264	44.1±10.8	0.682	0.508
	100~300	57 (48.3)	61.9±10.9			42.9±10.4		
	>300	44 (37.3)				40.8±12.0		
Stoma care performed by	Self	40 (33.9)	61.1±12.4	1.24	0.301	45.9±10.2	2.711	**0.048**
	Self with little assistance	46 (39.0)	58.8±8.4			41.5±9.9		
	Self with much assistance	18 (15.3)	64.6±11.2			38.6±10.9		
	Someone else	14 (11.9)	60.8±10.3			39.1±14.5		
Stomal/ peristomal problem status	Yes	32 (27.1)	60.3±11.9	0.03	0.860	42.1±11.5	0.041	0.840
	No	86 (72.9)	60.8±10.0			42.6±9.9		
Communication with medical staff	Never	4 (3.4)	64.3±9.0	2.49	**0.048**	29.8±14.0	3.525	**0.009**
	Little	7 (5.9)	60.0±10.7			43.3±9.8		
	General	54 (45.8)	63.6±10.4			39.9±9.6		
	Often	47 (39.8)	57.2±10.1			44.9±11.4		
	Always	6 (5.1)	57.0±6.9			49.8±11.5		

score and the subscores were negatively correlated (r=-0.222~ -0.537, all P<0.01) (Table 3).

Multi-factor analysis shows that the level of stoma care performed by self, the degree of communication with medical staff, financial insecurity, and social rejection are risk factors of ostomy adjustment (Table 4).

DISCUSSION

The level and characteristics of stigma in patients with permanent colostomy.

The scoring rate of SIS score and subdimension score were higher than 50% in this study, which is similar to the findings of Wu Yan[19]. They surveyed 230 patients with a permanent colostomy; the average SIS scores were 56.07±12.57, the scoring rate of SIS score was 58.42%, the scoring rate of subdimension was higher than 50%. The highest score found in this study was the financial insecurity dimension, perhaps because men accounted for 65.3% of respondents, middle-aged respondents accounted for 58.4% of study participants. Males bear most of the responsibility for family income in China. The middle-aged population is the highest aged bracket in the working population in China. Study participants felt their family roles were being challenged and jobs were affected because of the stoma. As most stoma products are not included in insurance coverage in most parts of China, most colostomy patients felt some additional economic pressure. The second highest score was the social isolation dimension, which refers to loneliness, the feeling of being isolated from healthy people, being of unequal status in relationships and social interaction, which is similar to the findings of Danielsen[6]. Patients also described that as their body shape changed due to the colostomy, they had lost control of their bowel excretion and therefore they felt differently to other healthy people. Under the cultural atmosphere of China advocating collectivist values, people pay attention to an individual or a group's recognition of its social status and reputation. People with a stoma are eager to obtain social recognition[20], and are focussed on doing everything possible to "save face". Colostomy patients fear "losing face" and, therefore, feeling inferior[21]. This study showed that patients who communicated less frequently with medical staff scored lower than other patients. Those patients who communicated frequently with medical staff are better able to master the physical care of their stoma, keep abreast of the latest information on ostomy care and are better able to cope with various psychosocial situations.

Table 3: The correlation between SIS score and OAI-20 score

	SIS score	Social rejection	Financial insecurity	Internalised shame	Social isolation
OAI score	–0.537	–0.479	–0.466	–0.289	–0.535
Anxious preoccupation	–0.444	–0.395	–0.355	–0.222	–0.472
Acceptance	–0.419	–0.377	–0.358	–0.274	–0.383
Social engagement	–0.436	–0.389	–0.426	–0.223	–-0.416

All P<0.01

Table 4: The multivariate analysis of influential factors of ostomy adjustment (n=118)

Variable	Unstandardised coefficients				Standardised coefficients
	B	Std error	*t*	*P*	B
Constant	69.13	6.76	10.22	0.000	
The level of stoma care performed by self	–2.11	0.89	–2.38	0.019	–0.19
The level of communication with medical staff	3.39	1.06	2.25	0.027	0.18
Financial insecurity	–1.49	0.49	–2.99	0.003	–0.27
Social rejection	–1.07	0.27	–3.97	0.000	–0.36

The level of psychosocial adjustment and its correlated factors in patients with permanent colostomy

Social adjustment refers to the ability to adjust to the environment with the purpose of maintaining the best physical and mental state[15]. It is an active and dynamic self-adjustment process. It is also a systemic reaction, including physical, social, cultural and technical factors. Based on the score on the OAI, patients in this sample were at the medium level of adjustment, which is similar to the findings of Hu Ailing[22] and Xu Qin[23]. In this study, the main social adjustment problems of patients with a colostomy were social activity restrictions, anxiety, pessimism, loss of self-control, and fear of leakage of the colostomy bag. The study showed that the degree of stoma self-care is an important factor in the adjustment processes, which is consistent with many studies. Patients are transferred from the hospital to the community 5–7 days after surgery. The management of the stoma and replacement of colostomy bag are activities of daily living patients will have to do for the rest of their lives. Self-care is the foundation for patients to return to society. However, the current self-care status of patients with a colostomy is not optimal. In this study, only 30.7% of patients were fully self-caring in the management of their colostomy. At present, intervention studies have been carried out in China to improve the self-care level of patients with a colostomy through such methods as telephone interventions and the peer patient program[24].

This study shows that patients who are always communicating with medical professionals have higher OAI scores than other patients; this is similar to the results of Wang Miao[25]. The study pointed out that the health control of patients with colostomies tends to rely on health authorities and this is consistent with many related studies. It is believed that the guidance of professionals such as enterostomal therapists can improve the level of adjustment of patients with colostomies[26,27]. Those who are unable to communicate with health professionals are more likely to suffer from or exhibit symptoms of anxiety and depression. Therefore, enterostomal therapists should provide their hospital or outpatient contact details before the patient is discharged.

This study shows that patients' SIS total score and subscores are negatively related to OAI-20 (–0.222~-0.537) scores. The higher the patient's level of stigma, the lower the level of ostomy adjustment, which is similar to the finding of Dylan[8], who found a significant negative correlation between the stigma, adjustment and life satisfaction. In addition, this study shows that social isolation and economic insecurity have a negative predictive effect on ostomy adjustment. The sense of social isolation makes patients think they are isolated from healthy people and that they live in an unequal state in interpersonal relationships. They are also very sensitive and minimise social activities. Patients with poor economic conditions are under more pressure as well as trying to contend with their underlying diseases and a colostomy.

CONCLUSION

The normal defecation method of a patient who has a colostomy is interrupted as faeces are excreted through the stoma into a colostomy bag. Sometimes there is an associated noise and unpleasant smell. Leakage of the colostomy bag may occur for numerous reasons. As human excreta can trigger adverse reactions in people in general, colostomy patients may experience or at least imagine other people's adverse reactions. Any reaction indicative of disgust may contribute to the development of feelings of stigma. The main social adjustments to overcome were social activity restrictions, anxiety, pessimism, loss of self-control, and fear of the colostomy bag leaking. The underlying disease and resulting stoma exacerbated economic pressures on some patients.

During hospitalisation it is suggested that medical staff should teach patients the skills of ostomy care and psychological adjustment methods, as well as providing written instructions for colostomy patients. At the same time, health professionals should foster continuity of care of discharged patients through improved liaison and handover to community home nurses. By hosting fraternities and lectures regularly it is hoped that more regions in China will be able to incorporate ostomy products into medical insurance schemes as soon as possible, thereby reducing the economic pressure on ostomy patients. Overall, as much support and assistance should be given to colostomy patients to help them readjust to living with a colostomy.

As the sample size of this study was small, it is recommended that a larger, multi-regional survey and interventional study on preventing feelings of stigma in colostomy patients is conducted.

CONFLICTS OF INTEREST

No conflicts of interest have been declared by the authors.

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