

REVIEW ARTICLE

The Self-Care Engagement of Patients with An Intestinal Stoma: A Narrative Review

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ABSTRACT

An intestinal stoma is an emerging issue among chronic gastrointestinal conditions. It imposes a significant burden on patients' lives and makes it imperative for them to engage in self-care activities to manage their condition and improve their quality of life effectively. However, engaging in self-care is complex and demanding. This review aims to gain a clear understanding of the issue of self-care among patients who are living with an intestinal stoma. From the review, the self-care issues of patients living with intestinal stomas were less comprehensive, and the evidence that is produced by those studies seems difficult to transfer to the Malaysian context due to the vast differences in terms of cultural practice. The result of the study suggests an in-depth exploration of this phenomenon, encompassing the viewpoints of both patients and healthcare providers. It could be advantageous in the development of a comprehensive framework for supporting self-care engagement among patients who are living with an intestinal stoma in a healthcare context, which could improve the patient's quality of life.

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INTRODUCTION

An intestinal stoma is a growing concern among patients with chronic conditions, particularly for those with digestive tract disorders. It is a life-saving operation in which the bowel tract is circumvented through an incision in the anterior abdominal wall (1). It can be referred to as colostomy and ileostomy for diversion of the faecal stream. It is known as temporary or permanent based on its indication and the patient's comorbidities (2). Globally, benign and malignant gastrointestinal conditions have been identified as the major reason for the construction of intestinal stomas compared to other gastrointestinal conditions (1,3).

The condition of having an intestinal stoma is complex, and dealing with this condition presents a unique

challenge. The creation of an intestinal stoma results in the loss of sphincter regulation and sensation, resulting in involuntary bowel elimination, including unintended faeces and flatus outputs, as well as spillage that produces an offensive smell and commotion (4,5). This condition necessitates that intestinal stoma patients continually wear stoma appliances and be able to manage them (6,7). In addition, patients with an intestinal stoma have to alter their diet and avoid foods that generate gas, colour, and odour, as well as those that increase faecal output, constipation, and leakage (8).

The presence of an intestinal stoma imposes a significant burden on the lives of patients, making it imperative for them to engage in self-care activities to manage their condition and improve their quality of life effectively. Self-care is a widely recognised concept that pertains to the provision of assistance to patients with chronic illnesses and is aimed at enhancing their health and overall well-being, as well as facilitating their ability to cope with the challenging life circumstances that may arise as a result of their illness (9,10).

Nevertheless, engaging in self-care is complex and demanding, and patients have frequently expressed difficulties in engaging with self-care when they have returned home (11,12). They lack the autonomy to incorporate self-care behaviours into their daily routines at home, such as maintaining personal hygiene, managing stoma appliances, identifying and managing issues that are associated with stomas, engaging in physical activity, and complying with follow-up visits (13–16). Besides, there is also the inability to adapt to life changes and embrace the challenge of having a stoma while maintaining their daily routine and function within their life system (17–19).

It seems that to engage in self-care, patients require a strong and effective support system, especially from family members, peers, society and healthcare providers (6,20,21). Several works of literature have suggested that self-care support for patients with an intestinal stoma is required by the patients as early as when patients prepare themselves to accept the decision on the need for the construction of a stoma and should be continued until the patient can live with the stoma independently and comfortably (11,22). The support provision that is primarily from the healthcare providers is important to empower patients in self-care (23–25).

This study aims to clearly understand the issue of self-care among patients who are living with an intestinal stoma. The findings aided the researcher in comprehending the phenomenon, and new research areas that can be recommended.

MATERIAL AND METHODS

The narrative review methodologies utilised in this study adhered to the narrative review framework that was proposed by Ferrari (26). Six databases, including PubMed, Scopus, Springer Link, Cochrane, Web of Science (WOS), and ProQuest, were utilised to conduct a literature review with a restricted time frame of publication spanning from 2012 to 2022. Medical Subject Headings (MeSH) terms of “self-care” and “intestinal stoma,” and employing Boolean operators such as “AND” and “OR” were used to search for relevant studies.

Inclusion and exclusion criteria

Self-care of individuals with intestinal stomas (e.g., ileostomies or colostomies) and the age of study participants (at least 18 years) were the criteria for inclusion in the articles. For reasons of time and translation expenses, studies reported in languages other than English were excluded.

Literature search strategy

The literature search consists of three distinct stages:

identification, screening, and eligibility, as visualised in the PRISMA flow diagram 2020 in Figure 1. A total of 3,872 records have been identified. Subsequently, 211 duplicate articles were removed. During an examination of the titles and abstracts, a total of 3,240 publications were eliminated from consideration due to their lack of relevance to patients with an intestinal stoma. A total of 276 articles were discovered, with an additional seven papers that were uncovered through the referencing of a list of connected articles. 36 publications were omitted from the total of 241 due to their unavailability. The remaining 385 reports were reviewed for eligibility, and 364 were rejected owing to irrelevant outcomes, commentary papers or opinion articles and unmet inclusion criteria. Only 21 articles were selected for the study.

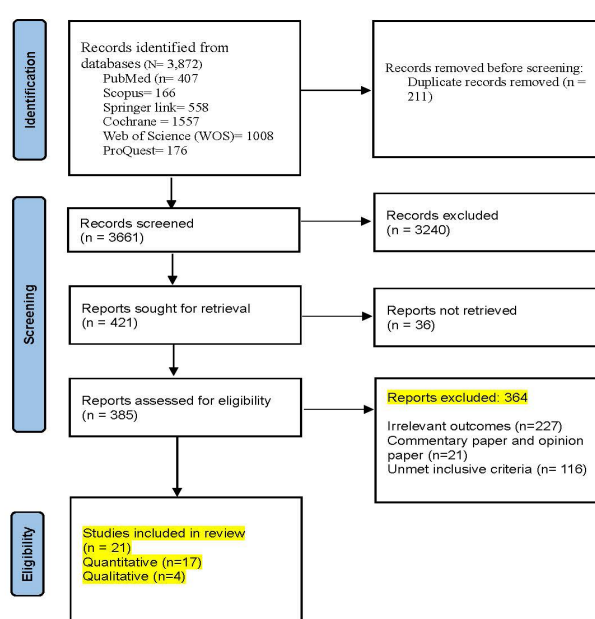


Figure 1: Process of Literature Search

FINDINGS

From the literature search, a total of 21 articles were included in this study. In general, most of the selected articles were quality enough to be included in the study. The authors clearly described the study’s methodology, objective, and interpretation of the results. 17 of them were quantitative studies and four were qualitative. The majority of the studies were conducted in Asian countries, with 12 studies being carried out in China (13,15,27–36), one in India (14), and two in Singapore (12,37). Three studies were conducted in Europe, including one in Spain (38), Poland (39) and in Brazil (40). Two studies were found in Middle Eastern countries, i.e., Jordan (41) and Egypt (16). One study was conducted in the United States (42).

Across the selected studies, 13 of them were related to the self-care of patients with intestinal stomas from the patient’s perspective (12–16,30–33,38–41) and

Table I: Characteristics of selected studies

No	Authors/ year	Country	Design	Aim	Sample	Data collection method/ tool	Findings
1.	Tao et al. (2014)	China	Qualitative	To explore the self-care behaviour among persons with a permanent colostomy in a Chinese cultural context of emphasising the role of family caregiving	Seven adults with permanent colostomy	In-depth interview	All informants intended to take care of their colostomies with a proper degree of independence. In some cases, the patient still relies on their family members to apply skin barriers due to the worry of leakage
2.	He et al. (2021)	China	Qualitative	To explore the immediate postoperative experiences before discharge among patients with rectal cancer and a permanent colostomy in China	18 patients newly living with colostomy in China,	Semi-structured interview	Most participants were too weak or not motivated to participate in their stoma care during their hospitalisation. The worry of unhealing surgical wounds, physical symptoms, stoma complications, and initial unproficiency in stoma self-care would decrease their actual confidence in stoma self-care.
3.	Autocuidado et al. (2013)	Brazil	Qualitative	To identify the conditioning factors to self-care practice of ostomy patients, and verify knowledge and practices on stoma care	30 patients with a stoma who registered Cear6 Ostomy Association	Semi-structured interview	Learning to take care of the stoma: education-support system; Stoma Care: knowledge and practices; and difficulties found in the practice of self-care.
4.	Lim et al. (2015)	Singapore	Qualitative	To investigate patients' experiences of performing self-care of stomas in the initial postoperative period.	12 patients 1 month post-operatively in a colorectal ward in a hospital in Singapore	Semi-structured interviews	Some patients considered that the problems and concerns about their stoma started only after they were discharged from the hospital. Patients were not ready to engage in their self-care when they returned home because they did not receive sufficient information preoperatively.
5.	Thomas and Nirmal (2019)	India	Quantitative	To assess the self-efficacy of stoma care among patients with a stoma	23 colostomy or ileostomy patients	Becker's stoma self-efficacy assessment tool	The majority of the participants with a stoma had a moderate level of self-efficacy about stoma care.
6.	Elshatarat et al., (2020)	Jordan	Quantitative	To identify Jordanian ostomates' health problems and their self-care ability to manage their ostomies.	168 Jordanian patients with intestinal ostomies	Self-care ability scale	The majority of the patients were dependent (partially or dependent) in taking care of all steps when managing their ostomies.
7.	Cheng et al., (2013)	China	Quantitative	The purpose of this prospective, descriptive study was to assess ostomy knowledge, self-care ability, and psychosocial adjustment in Chinese patients with a permanent colostomy and to investigate the correlation among these three characteristics	54 Permanent colostomy patients	Self-care ability scale	Of the 54 respondents, 20 managed the stoma on their own, 30 patients managed with some help, and four received care from someone else.
8.	Mohamed (2019)	Egypt	Quantitative	To assess the level of knowledge and self-care practice for patients with permanent stoma and its effect on their QOL and self-care efficacy	70 permanent stoma patients	Becker's stoma self-efficacy assessment tool	Unsatisfactory level of knowledge and self-care practice among patients with permanent stoma.
9.	Collado-Boira et al. (2021)	Spain	Quantitative	To examine stoma self-care and health-related quality of life in patients with drainage enterostomy, describe clinical and sociodemographic variables and analyse the relationship between all of them. Trained	176 permanent and temporary stomas	Specific questionnaire for Ostomized Patients (CAESPO)	The level of SC of the stoma across the patients was high.

CONTINUE

Table I: Characteristics of selected studies (CONT.)

No	Authors/ year	Country	Design	Aim	Sample	Data collection method/ tool	Findings
10.	Wang et al. (2022)	China	Quantitative	To evaluate the level of stigma and self-management ability of Chinese patients with IBD-related stoma using an online questionnaire.	70 permanent stoma	Becker's stoma self-efficacy assessment tool	The average score on the self-efficacy scale was 75.79 ± 23.91 , which reflected a moderate level of self-efficacy, and 69 (39.2%) respondents had low level of self-efficacy. Additionally, this survey revealed that financial burden may have a direct effect on the quality of stoma care. Therefore, the patient's economic status influences self-care.
11.	Su et al. (2016)	China	Quantitative	To examine stoma self-efficacy (SE) and its association with health-related quality of life (HRQOL) and social support in patients with temporary ostomies	150 temporary ostomies	Stoma Self-efficacy Scale (C-SSES)	85.6% of respondents showed low or moderate self-efficacy related to ostomy care.
12.	Bazaliński et al. (2014)	Poland	Quantitative	To evaluate satisfaction with life and management of difficult situations in people with the stoma	198 patients with stoma	Generalized Self-Efficacy Scale (GSES)	Nearly half of the respondents (47.0%) represented a high sense of self-efficacy, while 30.0% - low and 23.0% - medium. Patients with intestinal stomas caused by colorectal cancer demonstrated lower levels of self-efficacy compared to those with other clinical conditions.
13.	Jin, Ma and Jiménez-Herrera (2020)	China	Quantitative	Exploring the relationship between stoma acceptance and stoma care self-efficacy in patients with colostomy and whether self-disgust and stigma play mediating roles in this relationship	476 patients with a stoma	Becker's stoma self-efficacy assessment tool	Regression-based mediation modelling showed that personal disgust and stigma had significant mediating effects on stoma acceptance and stoma care self-efficacy. The two factors were strong negative predictors of stoma care self-efficacy in turn.
14.	Crawford et al. (2012)	US	Randomized controlled trial	To compare 2 methods of ostomy care instruction to determine their effect on patients' knowledge, skills, and confidence related to postoperative ostomy care	64 patient with stoma	Direct observation on skill Visual Analog Scale (VAS),	No significant difference was found when the mean confidence with self-care was compared.
15.	Zhang et al. (2013)	China	Randomized controlled trial	The purpose of this study was to evaluate the effect of enterostomal nurse telephone follow-up on the adjustment levels of discharged colostomy patient	103 patients with colostomy	Becker's stoma self-efficacy assessment tool	Results of this study indicated that participants in the study group had higher stoma self-efficacy compared with those in the control group.
16.	Wang et al. (2018)	China	Randomized controlled trial	To explore the effects of a home care mobile app on the outcomes of stoma patients who discharged from hospital.	203 patients with a permanent stoma	Becker's stoma self-efficacy assessment tool	The stoma self-efficacy scores of the intervention group were significantly higher than those of the control group respectively at 1, 3 and 6-month follow-up.
17.	Wen et al. (2019)	China	Randomized controlled trial	Determine the effect of a transtheoretical model (TTM)-based intervention on patients with an ostomy and provide patient-centred, accessible assistance, and dynamic education to improve patient self-management.	92 patients with stoma	Self-management of Ostomy	A significant improvement in self-management ability in the process of change, the decisional balance, and self-efficacy in the intervention group compared with those in the control group after four intervention sessions and up to 6 months of follow-up.

CONTINUE

Table I: Characteristics of selected studies (CONT.)

No	Authors/ year	Country	Design	Aim	Sample	Data collection method/ tool	Findings
18.	Lim et al. (2019)	Singapore	Randomized controlled trial	To evaluate the preliminary effects of a newly developed STOMA psychosocial intervention programme that was delivered via a multi-modal and multi-dimensional approach on the improvement of outcomes of colorectal cancer patients with stoma	Eighty-four patients with newly formed stomas	Becker's stoma self-efficacy assessment tool	Participants in both groups had increasing self-efficacy scores, but the findings showed no significant differences in the levels of stoma care self-efficacy at each time point
19.	Su et al. (2019)	China	Randomized controlled trial	The aim of this study was to investigate the effects of an evidence-based continuing care bundle on selected health outcomes in patients with temporary stomas after anterior resection for rectal cancer	144 CRC patients with temporary stomas	Becker's stoma self-efficacy assessment tool	The intervention group had significantly improved self-efficacy after the intervention
20.	X. Zhang et al. (2020)	China	Randomized controlled trial	To explore the effects of the hospital-family holistic care model based on 'Timing It Right' on the health outcome of patients with permanent colostomy. Background:	119 patients with permanent enterostomy	Self-care Agency Scale (ESCA)	The self-care ability of the intervention group was significantly better than that in the control group at discharge, 3 months and 6 months after discharge.
21.	(Xu et al., 2018)	China	Randomized controlled trial	To explore the effect of a self-efficacy intervention on the quality of life of patients with a permanent colostomy.	Forty-eight patients in treatment for permanent colostomy	Becker's stoma self-efficacy assessment tool	Self-efficacy between two groups of patients after 10 days of intervention is significantly not different. It is significantly different after 1 and 3 months of intervention.

eight pieces of evidence on the healthcare provider support provision for self-care (27–29,34–37,42). This information is illustrated in Table I.

The issue of self-care engagement of patients with intestinal stoma from the patient's perspective.

Out of the 13 studies regarding self-care of patients who are living with a stoma, this study has found that the majority of the studies have reported the issue of self-care engagement of patients with intestinal stoma (12,14–16,30–32,40–42). It can be observed that self-efficacy in the self-care of patients with an intestinal stoma was low to a moderate level in numerous studies (13–15). For instance, two different studies in China involving patients with temporary stoma (13) and Inflammatory Bowel Disease-Related Stoma (15) show low or moderate levels of self-efficacy. In India, (14) claim that the level of self-efficacy in stoma care among the majority of patients with gastrointestinal stomas was moderate. These studies indicated that patients with an intestinal stoma were less confident in managing their stoma and personal performance regarding social functions associated with having a stoma. The Bekker's self-efficacy scale was the main instrument that was used in most studies, measuring the level of self-efficacy of patients with a stoma, which comprised two dimensions, i.e., stoma care self-efficacy and social self-efficacy (13–15).

In other surveys, they examined the ability of patients with an intestinal stoma to manage their stoma, and they found that the patients demonstrated a lack of ability to manage themselves (30,41). The inability to change the stoma appliance or clean the stoma bag independently was the major concern of patients in managing their stoma (30,41). In China, most patients with permanent colostomy managed their stoma with some help (30). In addition, more than half of Jordanians with ostomies had some assistance from relatives to take care of their ostomies (41). A self-care ability scale is used to evaluate the patient's self-care ability and practice in changing and irrigating the ostomy pouch, taking care of the peristomal skin, and wearing clothes over the ostomy (30,41).

This phenomenon was further described in a few qualitative studies (12,31,40). The majority of patients with rectal cancer and permanent colostomies in China were too weak or unmotivated to participate in their stoma care during their hospital stay, despite their strong willingness to practise stoma self-care during their immediate postoperative experiences before they were discharged (31). Moreover, concerns about an unhealed surgical wound, physical symptoms, stoma problems, and initial incompetence would lower their actual confidence in performing stoma self-care (31). A descriptive study exploring patients' experiences of performing self-care for stomas in the initial

postoperative period in Singapore indicated that the patients were unprepared to engage in stoma self-care after they were discharged from the hospital (12). In this study, the patients believed that their stoma issues and concerns began only after they were discharged from the hospital, since nurses were always ready to provide immediate support when they were in the hospital. From the interviewing of patients with stoma in Brazil, the patients highlighted difficulties in caring for the ostomy bag, including placement and adaptation of appropriate appliances (40).

Concerning the aforementioned issues, this study has discovered that the self-care engagement of a patient with an intestinal stoma is influenced by both internal and external factors. Self-disgust, stigma, finances, and clinical condition constitute the patient's internal factors (15,32,39). In contrast to individuals with non-cancerous stomas, patients with intestinal stomas caused by colorectal cancer demonstrated lower levels of self-efficacy (39). In addition, the patients who experienced internal disgust and perceived external stigma due to the stoma reported lower levels of stoma care self-efficacy (32). (15) added that the quality of stoma care may be directly impacted by the financial strain on the patient.

The external factor pertaining to the issues of self-care engagement was a lack of information from healthcare providers (12). A descriptive study exploring patients' experiences of performing self-care for stomas in the initial postoperative period in Singapore indicated that patients with intestinal stomas were not ready to engage in their self-care when they returned home because they did not receive sufficient support during preoperative (12).

Healthcare provider support for self-care

Strategies of HCPs support for the self-care of the patient with an intestinal stoma.

The majority of healthcare providers preferred a conventional method of communication in providing self-care information to the patients such as verbal and written communication, i.e., face-to-face and or through phone calls (27,35–37), compared to the combination of other communication technologies such as digital video disc, mobile applications, and online teaching (28,42). In two studies in China, (36) utilised face-to-face or phone calls to conduct self-efficacy intervention among patients with a permanent stoma, and (35) carried out face-to-face and take-home manuals in educating stoma management to patients with a permanent stoma. The same approach was also applied to newly formed stomas in a tertiary hospital in Singapore (37).

The information provided by the HCP to the patients was not limited only to stoma management, such as the method to clean the stoma, changing the stoma bag,

identifying, and handling stoma-related complications. Other components of self-care that help patients with a stoma to live better include maintaining physical, psychological, and social aspects are also emphasised (28,29,34,35,42). For instance, in an early study by (42), the teaching focused on stoma management, including pouch emptying, ostomy sizing, and product application techniques and information about recommended diet, possible medical complications, and practical information related to living with an ostomy. Similar educational content was emphasised in a continuing care bundle (29) and a home care mobile application educational program (34). All the aforementioned information, however, was typically provided to the patient following stoma placement (27,29,34,36,42).

Among the healthcare providers, nurses appear to be more involved in providing support to enhance patient self-care engagement of a patient compared to other healthcare professionals (27,29,34–37,42). Accordingly, wound ostomy continence nurses are responsible for providing instruction for teaching ostomy care in the US (42). Furthermore, in China, the majority of the instructions were delivered by enterostomal nurses (29,34,35).

The effectiveness of HCPs' support for the self-care of patients with stoma

Out of eight studies, numerous studies demonstrated a positive improvement in patients' self-care in managing their condition after stoma formation (27–29,34–36). By using a different evaluation of self-care on the effect of HCP's support provision, the majority of studies demonstrated a positive improvement in patients' self-efficacy in caring for their stoma (27,29,34,36). The rest of the studies revealed that the self-care ability of patients with stoma had improved after the intervention (28) and self-management ability (35).

CONCLUSION

This study concluded that self-care engagement across patients with an intestinal stoma is a not straightforward task. The issues related to self-care of intestinal stoma should be examined not only from the perspective of the patient but also from the perspective of healthcare providers and the healthcare system. To the best of the author's knowledge, there are no studies that address self-care of intestinal stomas from both the perspectives of patients and healthcare providers in the healthcare system. Moreover, the evidence that is produced by those studies seems difficult to transfer to the Malaysian context due to the vast differences in terms of cultural practice. Therefore, an in-depth exploration of the issue of self-care of a patient living with a stoma, from both the perspective of the patient and HCPs in the healthcare system in Malaysia, needs to be carried out in future studies. The outcome may assist in developing

a framework for supporting the self-care of patients with an intestinal stoma.

STRENGTH AND LIMITATION OF STUDY

The review yielded useful insights in the existing literature on the self-care engagement of patients with stomas, which can be applied to establish the groundwork for future research. Nevertheless, a more extensive method of evaluation might be required. Narrative reviews lack an evidence-based synthesis for specific inquiries and do not provide unambiguous guideline recommendations.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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