Original Article

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Self-Care Strategies in Managing Physical Discomfort: Experience of Patient with an Intestinal Stoma

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ABSTRACT

Background: The physiological changes resulting from stoma formation necessitate that patients actively engage in self-care practices to manage their physical condition and maintain their well-being. In nursing, supporting and enhancing patients' self-care abilities forms a key aspect of postoperative education and continuity of care. However, research on stoma self-care practice in Malaysia remains limited. This study aims to explore the self-care strategies employed by patients with an intestinal stoma in managing physical discomfort. **Methods:** This exploratory qualitative study employed a case study approach, using semi-structured interviews conducted among 17 patients with an intestinal stoma in a public hospital in Malaysia over an eight-month period. The data were analyzed using a framework analysis approach. **Results:** Three key themes emerged from the analysis: managing pain, stoma care, and adjustment of daily routines. Participants identified these self-care practices as their experience managing their physical discomfort due to having an intestinal stoma. **Conclusion:** The findings underscore the complexity and multifaceted nature of self-care among stoma patients. These insights are essential for nurses in Malaysia, particularly in developing supportive frameworks and interventions to enhance patients' self-care abilities, which ultimately improve their quality of life (QOL) and healthcare outcomes.

Keywords: Ostomy; Physical Discomfort; Patient Experience; Self-Care

INTRODUCTION

An intestinal stoma, commonly involving either an ileostomy or colostomy, is created by exteriorizing the small or large bowel through the abdominal wall. It is typically necessary for conditions like colorectal cancer, inflammatory bowel disease, trauma, or congenital abnormalities (Wasserman & McGee, 2017) and can be temporary or permanent, depending on the patient's condition and treatment plan (Engida *et al*., 2016).

While stoma creation surgery can be a significant life-saving procedure, it also presents challenges to physical, mental, and other aspects of life, significantly impacting the patient's quality of life (Husaain & Dioso, 2025; Ssewanyana *et al*., 2021). Physical challenges include managing the stoma, coping with post-surgical discomfort or pain, and adjusting to changes in body function resulting from stoma formation (Stavropoulou *et al*., 2021). Routine tasks such as cleaning, preventing leaks, and appliance changes can be demanding, while dietary and hydration adjustments are essential to avoid complications like blockages or dehydration (Tsujinaka *et al*., 2022). These challenges demonstrate the need to implement self-care strategies to help manage the condition effectively and maintain the patient's QOL (Liu *et al*., 2025; Marcomini *et al*., 2024).

Self-care is conceptualized as the individual's ability to effectively manage symptoms, adhere to prescribed treatment regimens, and implement necessary lifestyle modifications required for living with chronic illnesses or conditions (Barlow *et al*., 2002). It is a dynamic process integrating health-promoting behaviors with illness management through maintenance, monitoring, and self-care management (Riegel *et al*., 2012). In stoma, it involves decision-making, maintaining stoma and skin stability, and recognizing or managing complications (Villa *et al*., 2019). This ability must be optimized by patients to manage their health and enhance their quality of

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life effectively (Aryani *et al*., 2025).

Within the healthcare setting, continuing care is often provided by stoma therapy nurses, who integrate various aspects of stoma management to support patients in regaining independence after discharge and achieving a smoother transition to daily life (Jin *et al.*, 2022). In this regard, nurses play an important role in tailoring their interventions to meet individual patient needs, particularly among those with chronic diseases who may have greater dependence in performing daily activities compared to patients without chronic conditions (Ertürk *et al*., 2025). Understanding patients' self-care strategies is therefore vital for nurses, as it provides insight into the challenges patients face in managing their stoma and the types of support they require. This understanding enables nurses to design more effective educational and follow-up interventions, strengthen patient autonomy, and enhance continuity of care after hospital discharge.

Numerous studies on stoma self-care have been conducted globally, particularly in Western countries (Collado-Boira *et al*., 2021; Giordano *et al*., 2020) and predominantly in China within Asia (Zheng *et al*., 2021; Wang *et al.*, 2022). While these studies highlight the challenges in managing physical changes, they are largely quantitative in nature and focus on individual self-management, offering limited insight into the contextual and culturally influenced aspects of self-care. Therefore, this study contributes new nursing knowledge by qualitatively exploring how Malaysian patients develop and apply self-care strategies to manage physical discomfort within their cultural context, providing insights to guide nursing practice and patient education.

METHODOLOGY

Study Design

This study employed an exploratory qualitative case study approach within the interpretive paradigm, which views reality as socially constructed and subjective. This design was appropriate for gaining more profound insight into the self-care strategies of Malaysian stoma patients, an underexplored area, and allowed for an in-depth examination of individuals within their real-life context (Yin, 2018).

Sampling

Purposive sampling was employed to recruit participants who were specifically knowledgeable and experienced with the study phenomenon. Eligibility criteria included patients aged 18 years or older with an intestinal stoma and the ability to communicate in Malay or English. Potential participants were identified from the appointment book of the Surgical Outpatient Department of a public hospital in Klang Valley, Malaysia, during their scheduled visits to the General, Colorectal, or Stoma Clinics. Concurrently, a maximum variation sampling strategy was adopted to capture a broad range of participants' experiences, encompassing differences in demographic background, stoma type, and duration of living with a stoma, thereby enhancing the depth and richness of understanding of the phenomenon. Data saturation was reached when interviews no longer produced new codes and categories, and the emerging patterns became repetitive across participants. The final two interviews confirmed redundancy in the themes and contributed to ensuring depth and consistency rather than adding new information. Therefore, the point of theoretical saturation was considered to have been achieved at 17 participants.

Data Collection

This study employed one-to-one semi-structured interviews guided by a topic framework, a common method in qualitative research (Creswell & Creswell, 2017). Key questions addressed sociodemographic background, stoma experiences, and daily care practices and were applied consistently across participants. Interviews were conducted privately, lasting 30–60 minutes, and took place over an 8-month period (August 2023–March 2024). All sessions were audio-recorded and transcribed verbatim.

Data Analysis

The data were analyzed using framework analysis, as recommended by Ritchie *et al*. (2003), comprising three phases: data management, descriptive account, and explanatory account. The data management phase began with a repeated reading of the interview transcripts to become fully familiar with their content. Initial themes were then developed and organized using a structured numbering system. For example, the theme "Stoma care" was coded as 2, with its subthemes "emptying/cleaning the stoma bag" and "changing the stoma appliance" coded as 2.1 and 2.2, respectively. Participant excerpts were subsequently indexed under the corresponding codes. For instance, the statement "I empty it myself… but if it needs changing, my sister helps me" was assigned to codes 2.1 and 2.2. A thematic chart (matrix) was then constructed to present each theme and its corresponding subthemes alongside the relevant participant excerpts. From this chart, the excerpts were summarized in the researcher's own words to capture the core meaning of the responses while preserving the original context and intent of participants' experiences.

In the descriptive account phase, the summarized data wAS reviewed to identify patterns, similarities, and differences across participants. Subthemes were refined, clarified, and grouped into broader categories that reflect shared experiences. This process enabled a clear organization of the data into coherent themes such as "Managing Pain," "Stoma Care," and "Adjustments to Daily Routines. Finally, an explanatory account was provided to explain the findings and make sense of the study results.

Quality Assurance in Qualitative Inquiry

The trustworthiness of the study was established in accordance with the four criteria proposed by Lincoln and Guba (1982), namely credibility, transferability, dependability, and confirmability. Dependability was ensured through team discussions, documentation, and an audit trail. Credibility was enhanced through one month of field engagement, which helped build rapport. Transferability was supported with clear sampling criteria and thick data descriptions. Confirmability was addressed through member checking with qualitative experts, peer debriefing, paraphrasing participants' responses, and reflective journaling to monitor biases.

Ethical Consideration

This study received ethical approval from ethical clearance from the National Medical Research Register, Malaysia, with reference number NMRR ID-23-01613-UFO on 10th July 2023.

RESULTS

Participant's Characteristics

Seventeen participants aged 21–65 were interviewed; most were middle-aged (n=7), followed by young adults (n=6) and elderly (n=4). Ten were male and seven were female, with Malays forming the majority (n=9). Most were married (n=9) and had completed secondary education (n=13). Nine had ileostomies, eight had colostomies, and 14 were temporary. The majority (n=12) had lived with a stoma for less than a year, with durations ranging from two weeks to six years. Participant characteristics are shown in Table 1.

Table 1: Participants' Characteristics

No	Age (years old)	Gender	Race	Marital Status	Stoma Status /Types	Period of Stoma Formation
P1	45	Male	Indian	Single	Temporary/ colostomy	2 weeks
P2	60	Male	Chinese	Married	Permanent/ colostomy	1 year
P3	46	Male	Malay	Married	Temporary/ ileostomy	4 years
P4	46	Female	Indian	Single	Temporary/ ileostomy	4 months
P5	37	Female	Malay	Married	Temporary/ ileostomy	1 year
P6	67	Male	Malay	Married	Permanent/ ileostomy	6 years
P7	20	Female	Malay	Single	Temporary/ colostomy	7 months
P8	47	Male	Malay	Married	Temporary/ colostomy	4 months
P9	51	Female	Malay	Widowed	Temporary/ ileostomy	2 years
P10	65	Male	Indian	Married	Temporary/ ileostomy	1 year
P11	26	Female	Chinese	Single	Temporary/ ileostomy	2 weeks
P12	47	Female	Malay	Married	Temporary/ ileostomy	2 weeks
P13	27	Male	Indian	Single	Temporary/ colostomy	10 months
P14	21	Male	Malay	Single	Temporary/ colostomy	1 year
P15	39	Male	Malay	Single	Permanent/colostomy	3 years
P16	65	Female	Chinese	Married	Temporary/colostomy	1 month
P17	59	Male	Indian	Married	Temporary/ ileostomy	18 months

Theme Identification

The analysis revealed three main themes related to self-care strategies in managing physical discomfort associated with stoma formation. These themes were further refined into subthemes to capture variations in self-care approaches, as illustrated in Figure 1.

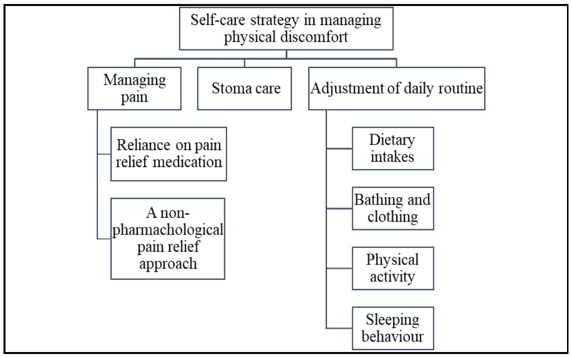

Figure 1: Themes and Subthemes Describing Self-Care Strategy in Managing Physical Discomfort

Theme 1: Managing Pain

Patients in this study highlighted pain management as a primary concern following stoma formation surgery. They utilized both pharmacological and non-pharmacological strategies to alleviate substantial pain at the surgical site, especially during the early postoperative phase.

Reliance on Pain Relief Medication

The patients perceived pain management during the early postoperative stage as primarily reliant on medication. Patients reported that their self-care strategies and daily life activities were closely tied to concerns about pain intensity. This concept was exemplified by P3 in the excerpt below.

…after the anesthesia wore off, I started to feel pain; even moving it hurt. While I was in the ward, I asked for pain relief medication, and they gave it to me on schedule.

The persistent pain often led patients to continue using prescribed analgesics at home, highlighting the importance of effective pain management for a smooth hospital-to-home transition. For instance, P3 described using pain medication selectively, taking it only when the pain became severe, to manage discomfort while avoiding excessive drowsiness.

When I got home, I was still in pain. The green and yellow pain medication helped and made me sleepy, so I only took it when needed.

A Non-Pharmacologic Pain Relief Approach

The patients also perceived non-pharmacological pain relief as a complementary strategy to enhance comfort following surgery. They recognized the critical role of rest in alleviating postoperative discomfort and prioritized recovery. P12 exemplified the previous point by embracing rest to manage the pain after stoma surgery.

I just rested and did not move much because the surgical wound hurts more with movement. It helped.

Some reported using splinting techniques to manage pain from intra-abdominal pressure during activities such as sneezing or coughing. For example, P7 described pressing a pillow against the surgical site to provide stability and relieve discomfort.

I often feel throbbing when I cough or clear my throat, so I hold my stomach with a pillow to ease the pain. Without it, the pain worsens.

Theme 2: Stoma Care

The stoma caused changes in bodily function, requiring regular cleaning and maintenance. Caring for a stoma, especially in the early postoperative period, was overwhelming due to pain, unfamiliarity, and the complexity of self-care routines. In this study, the patient was informed that emptying or cleaning the stoma appliance was manageable, but changing it proved more challenging and required assistance, as illustrated by P12.

I empty it. I needed to change the appliance, so my sister did it because I could not see the hole to adjust it.

While patients with newly created stomas often required more assistance initially, some with long-term stomas also remained dependent on others. This was shown by P17, who had a stoma for 18 months and relied on his wife to change it, as he recognized it was challenging.

I have not tried doing it myself yet (changing the appliance). My wife always helps because it is not easy to sit and do it alone...

In addition, some patients reported managing their stoma independently, demonstrating familiarity with self-care routines over time. P6, for instance, had a permanent colostomy for six years and was no longer dependent on his children for care after six months of stoma formation.

Around six months, I could do it myself; before this, I depended on my children to change the stoma appliance and clean it…

Theme 3: Adjustments to Daily Routines

Beyond pain and stoma care, physiological changes forced patients to modify daily routines. Adjustments in diet, hygiene, clothing, activity, and sleep became essential self-care strategies to manage discomfort and maintain well-being.

Dietary Intakes

The patient adjusted their dietary intake by considering food types, meal timing, portion size, and frequency to manage abdominal discomfort as digestion and waste elimination changed. They commonly opted for a soft diet, avoiding densely fibrous, gas-producing, and spicy foods while increasing fluid intake to regulate digestion. For example, P12 avoided spicy foods and nuts, opting for lighter, easily digestible meals like rice porridge with soup, like a postpartum confinement diet.

I am on a restricted diet right now because I don't feel brave enough to eat spicy food and nuts. I'm eating things like rice porridge with soup, like in confinement.

Other patients perceived a need to control their food intake and adjust meal timing to control stoma output. P1, for instance, with a temporary colostomy, described his strategy of reducing food intake to manage stoma output better.

I am eating very little food, worried that the feces will come out in a large amount.

P3 illustrated adjusting the meal schedule to regulate stoma output by skipping breakfast and refraining from eating in the afternoon.

I skipped breakfast. When I last ate at 3 PM, by 8 PM, a lot of stools came out. So, at night, not much stool came out.

However, overly restrictive dietary practices can lead to neglecting proper nutrition, which is crucial for healing and may result in severe complications and hospitalization. For example, P9 relied solely on a liquid diet for two weeks after discharge, resulting in nutrient deficiency with weakness, lack of energy, and a fainting episode at home and readmission to the hospital.

Two weeks after hospital discharge, I only consumed liquids or a soft diet, which left me utterly drained of energy. I ended up fainting at home and returning to the hospital.

Bathing and Clothing

The presence of stoma requires patients to adjust their bathing and clothing routines for comfort, hygiene, and stoma care while addressing body image concerns. The patients were cautious during bathing, using protective covers, selecting soap carefully, monitoring water temperature, and using specific wiping techniques. P13, for example, used a plastic cover to shield the stoma from water and prevent complications during bathing.

I was scared to shower because water touching the stoma area was a concern. I covered it with plastic to protect it.

Some patients were carefully selected and used soap to minimize exposure to harsh chemicals. The patient believed this self-care approach protected the stoma and peristomal skin from potential irritation, as illustrated by P17.

I removed the stoma appliance before showering and avoided using soap like Dettol.

Another patient stressed the need to check water temperature before bathing to avoid stoma-related discomfort. For instance, P6 routinely adjusted the shower temperature, especially in the morning, to prevent peristomal issues such as retraction and stiffness.

Before showering, I check the water temperature. If it's too cold, my stoma retracts, and the incision area stiffens.

Regarding clothing, the patients opted for loose-fitting garments for comfort and ease of pouch maintenance. For example, P10 preferred loose clothing and expandable pants over zippered ones to avoid compressing the surgical wound and to provide space for the stoma and its appliance.

I need larger clothes, like XXL tracksuits or expandable jogger pants, no zipped pants. It gives me flexibility and space for my stoma and wound.

Physical Activities

Patients reported selecting physical activities that were not strenuous, such as light exercises, to avoid stoma-related complications. Initially, the patient recognized the adverse effects of limited movement; they gradually sought ways to regain mobility within their comfort zones. P6 exemplified this, who initially struggled with restricted movement and discomfort, highlighting the importance of recognizing the body's signals, as prolonged immobility leads to stiffness and pain, a critical step in self-care.

At first, I couldn't move. Staying still hurt (points to back), so I lay down until I got stiff. Then I realized I needed to move, not just lie down.

As the condition improved, patients gradually resumed activities they once enjoyed, though with significant modifications. For example, P9 noted that tasks involving lifting or pushing heavy objects became risky, as doing so could potentially harm their stoma.

At home, I enjoy tidying up and rearranging, but now with the stoma, I can't lift heavy objects or push things anymore.

The potential risk of injury to the stoma site led some patients to avoid sports activities that could pose a threat. Like P17, opting not to participate in sports like tennis, fearing that a tennis ball impact could damage his stoma.

I cannot play games or be active in sports. I fear what might happen if it (a tennis ball) hits the stoma...

Sleeping Behavior

They also perceived the need to adjust their sleeping positions and inspect and empty the stoma bags during the night to avoid the risk of appliance compression and leakage, particularly during sleep. For instance, P3 shared that he had been sleeping upright for four years, believing that this position helped protect the appliance and prevent leakage.

I have slept upright for four years… Turning compresses the appliance and may cause leakage. I miss sleeping normally.

In addition, the unpredictable bowel output often forced patients to check and empty their stoma appliance at night. For example, P15 reported discomfort and fear from pressure caused by accumulated fecal output and gas, prompting frequent inspections.

… Sometimes during the night, I feel much pressure, like the appliance will burst, like a balloon. So, I turn to my side because I'm afraid it might break… Then get up to check and empty it.

DISCUSSION

The findings show that managing the physical discomfort of a stoma involves pain management, stoma care, and lifestyle adjustments. Patients prioritized pain relief as essential for recovery, recognizing the benefits of both pharmacological measures, such as analgesics, and non-pharmacological strategies, like rest and reduced physical activity. This aligns with a Chinese study reporting that stoma patients relied on prescribed medications to manage pain (Lo *et al*., 2021) and with a study in Pakistan demonstrating that rest reduced surgical pain and supported recovery (Naz *et al*., 2022).

However, this study advances current understanding by showing that Malaysian patients' pain management strategies are shaped not only by guidance from healthcare providers but also by personal interpretations of endurance and self-discipline. Participants viewed pain as a test of resilience and were cautious about overusing pain medication, demonstrating a balance between reliance on pharmacological support and the desire for self-control. This insight highlights the complex interplay between patients' perceptions of pain and their self-care decisions, extending beyond the predominantly biomedical framing reported in international studies.

When pain is perceived as a threat to quality of life, patients are more likely to seek medical treatment or adopt alternative self-care approaches (Brown & McCormick, 2006). However, concerns remain about medication misuse, as persistent opioid use after surgery has been well-documented (Griffiths *et al.*, 2023), and patients with opioid dependence often experience longer hospital stays and higher readmission rates (Gupta *et al.*, 2018). Findings from this study highlight the importance of nurses prioritizing comprehensive pain assessment and implementing multimodal pain management strategies following stoma surgery. This includes delivering structured pain education that emphasizes the appropriate use of analgesics while addressing potential risks of misuse, as well as encouraging non-pharmacological pain-relief strategies to promote comfort and independence. Ineffective pain management may hinder stoma self-care and increase patient dependency.

Previous studies have reported that patients with stomas often struggle and require assistance in managing their stoma care (Alwi *et al*., 2025; Jeppesen *et al*., 2022). Similarly, findings from the study conducted in Malaysia indicated that many patients continue to encounter difficulties in independently changing their stoma bags and frequently depend on others for help. This reliance is most commonly supported by spouses and children, reflecting strong family involvement in caregiving. Such a pattern is likely influenced by cultural and religious values, particularly the collectivist orientation that reinforces family caregiving responsibilities (Helnarska, 2024; Sumari *et al*., 2020).

However, patients who remained dependent on others tend to experience reduced autonomy and a lower quality of life compared to those who manage their own stoma care independently (Liu *et al*., 2021). This study's findings highlight the culturally embedded and family-co-managed nature of stoma self-care in Malaysia, which extends beyond individual-centric models commonly described in the literature. They underscore the need for family-inclusive interventions by healthcare providers, particularly nurses, that aim to enhance patient autonomy while maintaining family support. This can be achieved through structured coaching, supervised practice, and timely troubleshooting until independent competency is both attained and sustained. Evidence also suggests that continuing care programs are effective in improving self-care ability and overall health outcomes among patients with stomas compared to routine care (Jin *et al*., 2022). However, in the Malaysian clinical context, structured continuing care programs for stoma patients are still limited and inconsistently implemented, indicating a critical need to strengthen post-discharge follow-up and continuity of nursing support.

The findings of this study indicated that patients consistently reported difficulties in modifying their diet and sleep as part of daily routine adjustments. Cultural beliefs strongly shaped dietary practices, particularly among Malays, who adopted restrictive habits similar to post-birth confinement, that limited food variety. This aligns with prior studies among women during childbirth confinement in Malaysia, showing confinement diets restrict protein and fiber intake, leading to nutrient deficiencies (Shukri *et al*., 2018; Selau *et al*., 2019). Dietary avoidance was especially common among ileostomy patients, increasing the risks of malnutrition and dehydration (Michońska *et al*., 2023), the main causes of rehospitalization (Vogel *et al*., 2022). The findings suggest that stoma dietary practices among patients with an intestinal stoma in Malaysia are driven largely by culturally sanctioned risk-avoidance behaviors and further compounded by persistent knowledge gaps regarding safe dietary management. Accordingly, the use of culturally adapted, mechanism-based health education with clear monitoring thresholds is expected to improve nutritional adequacy and reduce the risk of complications.

Studies conducted in Turkey reported that frequent nighttime awakenings caused by discomfort from ostomy pouches, anxiety about leakage, and poor sleep habits contributed to poor rest quality and sleep deprivation (Kalayci & Duruk, 2022; Temiz *et al*., 2022). Sleep disturbance was further exacerbated as patients frequently adjusted their sleeping position or emptied their appliances at night to prevent leakage, resulting in persistent sleep disruption. The findings of this study suggest that such sleep disturbances are not merely physical consequences of stoma management but also reflect underlying psychological factors, particularly vigilance and fear of leakage, which persist long after the postoperative period.

This indicates that patients are not only managing their stoma but are also constantly monitoring their bodies, a pattern that may contribute to chronic stress and fatigue (Rud *et al.*, 2022). Therefore, patients living with a stoma require structured, mechanism-based guidance delivered early and reinforced throughout follow-up care. Such guidance should combine device optimization and leak-prevention strategies with brief behavioral sleep interventions. Early post-discharge reviews and simple monitoring targets can help reduce hypervigilance, interrupt the vigilance–fatigue cycle, and ultimately improve sleep quality.

Limitations

A limitation of this study is its focus on a single center, which may limit the diversity of perspectives captured and the transferability of the findings to other contexts. Nevertheless, the study provides valuable and in-depth insights into the phenomenon under investigation. Although religious factors were not explicitly mentioned by participants when discussing self-care and managing physical discomfort after stoma formation, they should not be overlooked in future research, particularly within Malaysia's multi-religious context, where faith-related beliefs and practices may influence patients' approaches to stoma self-care. Future qualitative studies could further explore these contextual influences and examine how tailored educational and support interventions may enhance patients' self-care ability and overall well-being.

CONCLUSION

This study makes a unique contribution by exploring self-care strategies among Malaysian stoma patients, emphasizing the influence of cultural factors, such as family involvement and dietary beliefs, on managing physical discomfort. The findings demonstrate that stoma care and daily routine adjustments are complex and ongoing processes that significantly influence patients' adaptation and quality of life. The study highlights the importance of healthcare providers, particularly nurses, adopting holistic approaches and developing personalized, culturally sensitive health education plans. Future multicenter research and tailored self-care interventions are recommended to further strengthen support and improve patient outcomes.

Conflict of Interest

The authors declare that they have no competing interests.

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