

Research Article

Patient's Experiences of Caring for their Colostomy at Home

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Introduction

Among cancers, the colorectal cancer is a second leading cause of cancer-related deaths [57]. The prevalence and death rate of colorectal cancer and inflammatory bowel diseases is more profound in low and middle-income countries. Likewise, in Pakistan, colorectal cancer includes in the top ten cancers [2]. The stoma formation is one of the treatment modalities to improve patients' quality of life by reducing the devastating effects of colon cancer. However, it has detrimental effects on patients' physical, psychological, social, and functional wellbeing [1,8,29,37]. All these effects make the stoma acceptance difficult and yield a feeble adaptation [4,6,35,37]. However, healthy self-care behaviors play a pivotal role in healthy adaptation [60]. Extensive literature is available on the stoma's adverse effects and the importance of self-care in adapting to the stoma [1,35-37]. Although the literature is available exploring colostomy pa-

Abstract

Background: Colostomy formation is an important but life changing modality for treating various colorectal morbidities which alter the patient's physical, psychological and social aspects of life. The management of colostomy is a simple yet technical task.

Aim: The purpose of current study was to explore the experiences of patients about performing the colostomy self-care at home.

Design and Methods: In this qualitative descriptive study ten participants were recruited through purposive sampling technique. Semi-structured interview guide was used to collect the data for theme and categories.

Results: The overall theme of Access, Affordability and Adaptation, with four subsequent categories including, Assistance for stoma care, Stoma care practices, Restricted activities of daily living, and Patient's needs and recommendations were revealed from data analysis.

The findings of the study revealed that lack of assistance, lack of teaching and training of colostomy self-care and as well as high cost and unavailability of stoma appliances at local pharmaceutical companies were triggering the patients' adaptation with colostomy.

Conclusion: The findings of study have highlighted the needs and challenges of colostomy patients while performing the colostomy self-care at home. The study has elaborated various factors that were contributing to the long-term dependency of colostomy patients, and impeding the patients' adaptation with colostomy. The findings informed the health care organizations about the need for development of educational programs and teaching guidelines for the colostomy patients to enable them to perform the colostomy self-care.

Keywords: Colostomy formation; Colostomy self-care; Patient's experiences adaptation

tients' experiences, there is a lack of such studies in Pakistan. The contribution of Pakistan in literature is limited to colostomy indications, complications, and stoma care services. To the best of the researcher's knowledge, no study had explored stoma self-management experiences in developing countries in order to identify the needs and challenges which the patient faces while managing their colostomy at home. Contrary to the western countries, there are no specialized colostomy education and training services in Pakistan to facilitate the patients in learning the practical stoma management skills. Furthermore, the technical skills of emptying and changing the bag are briefly explained to the family caregiver only at the time of discharge, which can be scanty for the adequate management of colostomy at home. Thus, the colostomy patients remain dependent on health care professionals for longer period of time and

repeatedly present to the hospitals for the colostomy-care and management. The study aims to investigate the needs and challenges of patients managing their colostomy at home.

Design and Methods

Study Design and Setting

A descriptive qualitative study was conducted at two tertiary care hospitals in Islamabad (the capital city of Pakistan) with capacity of 300 and 550 beds respectively. The selected health care facilities provide services to patients with the diverse ethnic and socio-cultural backgrounds.

Sampling and Participants

In this study, a total of twelve participants were recruited using the purposive sampling technique. However, two participants were excluded from the study because of the inability to approach them physically, and participants were unable to follow the instructions for online interviews. Thus, the final data was collected from ten participants with the achievement of data saturation. The selection criteria were: Adult individuals (aged 18 years and above) with temporary/ permanent colostomy, who were taking care of their colostomy for at least four months at home and able to speak either Urdu or English.

Interview Guide and Data Collection

The data was collected from the participants using the semi-structured interview guide (Appendix A). The interview guide was comprised of open-ended questions with the intent to explore the participants' experiences of colostomy self-care as well as their needs and challenges while performing their colostomy self-care at home. The interview guide was developed in both English and Urdu language and participants were provided with the choice to respond in a feasible language. However, all participants have recorded their responses in Urdu language. The spontaneous probing was done for further clarification of ambiguous concepts and field notes were also taken for recording non-verbal cues during the interviews. The interviews were audio recorded and were transcribed before the analysis.

Nine interviews were conducted face-to-face. One was audio recorded via phone call because of the infeasibility to physically approach the participant. Seven out of nine participants were interviewed at their home in a separate and quiet room. Moreover, the data from two participants were collected in the OPD of their respective hospitals when they come for routine follow-up with their physician. Each interview lasted between 35 to 45 minutes approximately.

Trustworthiness

The trustworthiness of the study was maintained through careful collection of the data with proper field notes and feedback from the research committee throughout the research

Appendix (A) English Interview Guide

S. No	Interview Question
1	How have you been caring for your colostomy at home?
2	How it affects your routine activities?
3	How having a colostomy influences your self-care and hygiene practices?
4	What challenges did you face while performing colostomy care at home?
5	How can you be helped to take care of yourself at home?

process [30]. A transparent record of the whole research process from the start of the study until reporting the finding was maintained. Moreover, the interview transcript was cross-checked with audio-taped data. The researcher also keeps the reflexive journal to assess the influence of the personal perception on the research process and detailed description of the study setting, methodology, process, and context was provided to ensure the study's transferability.

Ethical Considerations

Ethical approval was obtained from the IRB (institutional review board) of selected hospitals (Appendix E). Voluntary participation in the research study was ensured by taking informed consent from the participants. In this study, codes (P1, P2, P3) were assigned to each participant to maintain the participants' anonymity. The safety and confidentiality of information collected were guaranteed by keeping the hard data under lock and key and soft copy in a password protected computer.

Data Analysis

The data collection and analysis were done simultaneously to identify the prime concepts during data collection [30]. The data were manually analyzed following qualitative content analysis, provided by Elo & Kyngäs, [20]. Furthermore, the inductive content analysis approach was used to analyze the data for both manifest and latent meanings. Firstly, open coding was done. Codes then put into subcategories based on their linkages and then relevant subcategories combine to form categories. The clinical data and socio-demographic characteristics of study participants were manually analyzed with Microsoft excel.

Results

Characterises of Study Participants

A total of ten participants were selected in the study. 50% of the participants were male and half of them were female. Most of them were in their young adulthood stage. Five participants had colorectal cancer, three of them had inflammatory bowel disease and two of them had obstructive disorders. With regards to the cause of the disease, eight of the participants had permanent a stoma formation, while two had temporary stoma formation. The duration of the stoma formation ranged from 4months to 6 years (Table 1).

Table 1: Demographic Data of Study Participants.

Variables	Frequency (n)	Percentage (%)
Gender		
Male	5	50
Female	5	50
Age		
Young Adulthood (18- 35 years)	5	50
Middle adulthood (36-55 years)	3	30
Older adulthood (older than 55 years)	2	20
Marital Status		
Married	9	90
Unmarried	1	10
Education		
Middle Passed	3	30
Secondary	2	20
Higher secondary	3	30
Bachelor and Above	2	20
Occupation		
Own business (male)	4	40
Retired	1	10
Housewife (female)	5	50

The data analysis revealed an overarching theme that is Access, Affordability and Adaptation, corroborated by five categories with their sub-sequent sub-categories including, Assistance for stoma care, (formal and informal assistance, early independence), stoma care practices (use of stoma appliances, frequency of changing and emptying the bag and skin care) Restricted activities of daily Living (physical limitations, socialization, religious activities and sexual and reproductive life) and Patients needs and Recommendations (support system, competent nursing staff). The theme, categories and sub-categories are presented in Table 2.

Theme: Access, Affordability and Adaptation

The participants revealed the need for access to health care professionals, adequate guidance and training about stoma self-care and availability of stoma accessories to adapt with this life changing event. Nearly, all participants sought assistance of health care professionals for stoma care initially. Later, with the passage of time few of the participants started performing their stoma care independently, while other continued with the assistance of health care professionals for their stoma care. The participants share their experiences by stating that *"Initially, I daily had to go to the hospital for changing and emptying of this bag. But now I can empty the bag on my own. But yes, we still call the health care professional at our home for changing the bag"* (P9).

The participants recognized that the adequate guidance (pre-operative counseling, post-operative teaching and discharge training) and support (family, friends, social and financial support) is essential for adaptation with stoma. They posited that it not only decreases existential sufferings of patient, but also enable them to perform the stoma care independently. *"Nobody guided me initially regarding that [stoma management]. So even I wasn't aware of the stoma paste, due to that I was having cuts like blade at that place [stoma site]"* (P7).

The participants also expressed their suffering for not finding and purchasing of the suitable stoma appliances for self-care because of inadequate guidance by the health care professionals which were adding to their existential sufferings. *"I purchased 8 to 10 [colostomy] bags and then I returned it. If I was guided about which size of wafer and stoma pouch is suitable for me, so it become easy for me to get it"* (P3). Most of the participants highlighted the role of familial support in making the person independent to perform the stoma care. *"Initially, I was so feeble. I couldn't be able to do anything at that time. My daughter was doing it for me."* (P1).

Table 2: Theme, Categories and Sub-categories of Study Findings.

Theme	Categories	Sub-categories
	Assistance for stoma care	Formal and informal assistance Early independence
	Stoma care practices	Use of stoma appliances Frequency of emptying and changing the bag Skin care
Access, Affordability and Adaptation	Restricted activities of daily living	Physical limitation Socialization Religious activities Sexual and reproductive life
	Patients' needs and recommendations	Support system Competence of nursing staff

Category 1: Assistance for Stoma Care

Nearly all participants with stoma illustrated the need for assistance throughout their process of adaptation with a stoma. Most of the participants sought formal assistance from health care professionals. At the same time, some remain dependent on the family care givers for their stoma care. However, only a few of them were practicing their colostomy self-care at home.

Sub category 1:1: Formal and Informal Assistance. Initially, all participants required formal assistance of health care professionals for their stoma care by either visiting the hospital or calling the health care professionals at their home. The assistance level gradually shifted from formal to informal. Some family caregivers even started the stoma care soon after the participant got discharged from the hospital. At the same time, others took the time to learn the technical skills of stoma care. *Since my colostomy is being done, [name] company technician is changing the bag for me, while for emptying and cleaning of bag I get assistance of my wife* (P6).

The participants stated various reasons of dependence for their colostomy care. The physical limitations, fear of leakage, and lack of courage due to the scary appearance of stoma/ colostomy were the reasons for their dependence on the family caregiver. In contrast, the reluctance of family members, lack of knowledge/ training of colostomy management, and well socio-economic status were the reasons for seeking the assistance of health care professionals. Some participants shared that their physical limitations as a reason of getting assistance of family care giver. *"I lost approx. 7 to 8 kg of my weight after surgery. I wasn't been able to pick up myself. That's why one boy [medical technician] was doing it for me [changing and emptying of colostomy]"* (P3).

Moreover, lack of personal motivation and courage for doing self-care due to the scary appearance of the stoma was the reason for long-term dependence on health care providers. *"It's a novel kind of a thing, it's scary, even sometimes I close my eyes because, I did not have courage to see it"* (P6). Additionally, lack of technical skills was another reason for seeking professional assistance. As some participants reported that they need for assistance only in wafer cutting. *"I face difficulty in its cutting [wafer cutting]. If someone could teach me (the patient) regarding the cutting of wafer, so then 100% I could be able to manage it and start to tie my bag on my own"* (P5).

Sub category 1:2: Early Independence. Compared to the female participants, the young male participants gained early independence and started their colostomy care. The male participants revealed that, their role and responsibility toward their family make them motivated to come back to their life again. *"Initially, a boy changed it for 5 to 6 days for me, but then after 6 days I started changing it on my own. Definitely, I have to meet the requirements of the relationships too, I have a son of age 6 years. If a father himself would not going to do something for his children, for his family, so then who will be going to do it on his behalf?"* (P3). Contrarily, the female participants were less motivated toward colostomy self-care and exhibited long term dependence on formal and informal care givers. *"I myself do not feel the courage to do it by myself. So, I hired the technician for changing the bag."* (P8).

Furthermore, the participants who had good economic status preferred to continuously seek the formal assistance of health care professionals. *"I do not need to learn bag changing*

because my son said that, we would be going to hire somebody to do it for our mom" (P4). In contrast to the above, the participants who had some financial constraints were more inclined toward self care. "We don't have the money to even buy this bag than how can we afford to get it changed it from the hospital (P2).

Category 2: Stoma Care Practices

The study participants shared their routine practices of colostomy care which were related to the knowledge and usage of the stoma/ colostomy appliances, the practices of emptying, cleaning and changing of stoma/ colostomy pouch, the factors which determined the frequency of emptying and changing colostomy pouch, common skin problems due to having a colostomy and strategies to overcome these problems.

Sub category 2:1: Use of Stoma Appliances. Nearly, all participants were using stoma bag, wafer and stoma paste but most of the participants did not have a knowledge regarding advance stoma accessories whereas, who had the knowledge about these accessories, the financial constrain was the issue for not using them. "Except for the bag and wafer, I am using silus spray [stoma adhesive spray], stoma paste and stoma powder. One thing comes as a name of Diamond sachet [odor control sachet], it reduces the smell of stool, but I am no more using it because it is very costly (P5).

Sub category 2:2: Frequency of Emptying and Changing Stoma Pouch. The factors that determined the frequency of emptying and changing colostomy bag, includes the type and quantity of food, dragging sensation, discomfort and personal cleaning habits. "I use to empty it 6 to 7 times in a day...But it all depends on my diet, as much as I could eat on the daily basis (P5). "Just I use to clean it after every half an hour. Actually, when it fills and touches my abdomen, so I really feel a lot of burning here. It seems that somebody has sprinkled chilli powder or salt here (P1).

As for as the changing of stoma pouch is concerned most of the participants practiced changing the stoma bag after one week. However, the variation in temperature was a factor which affect the ware time of colostomy pouch. "The bag lasts up to 5 to 7 days in summer. In the same way the bag lasts up to 15 days in the winter season, maximum you can take it up to 20 days too. Because as soon as the summer starts and a person sweat more that reduce pouch ware time" (P7).

Sub category 2:3: Skin Care. The problems related to the skin around the stoma includes, itching due to leakage of fecal matter and frequent changing and cleaning of stoma pouch that damage the skin. Furthermore, sweating in the summer season aggravates skin problems. But the participants were not fully aware about stoma skin care practices. "My skin around stoma has turned blackish due to sweating. I use to clean with wipe and apply common lotion or powder on it but it doesn't put a lot of difference (P3). "In summer I encounter with redness and wound around my stoma. Then I wash it with Dettol water and apply a Vaseline on it" (P7). The participants also highlighted the practice of using ice cubes in colostomy bag to extend the wafer wear time and prevent skin damage due to sweat around stoma. "I used to put cold water or an ice cube in the bag so that's why Alhamdulillah I haven't faced any kind of problem and its good, because when I quit putting ice in my bag, so I had small kind of rashes been made on my side (around the stoma) (P8).

Category 3: Restricted Activities of Daily Living

The impact of having stoma on their routine life has not only limited their physical mobility but also affected their diet, sleep, hygiene and religious practices. While discussing the limitation, some participants also shared some strategies which they practice to cope effectively with the limitations.

Sub category 3:1: Physical Limitations. The participants were overwhelmed with the feeling of being physically restricted due to the presence of stoma. "I am not independent now; I am not free. Means I am restricted now. I couldn't do the work freely now! I couldn't be able to walk more. I couldn't run a lot" (P6). Some participants expressed their views regarding the change in nature of their job and clothing/ dressing style. They considered themselves unable to do some specific jobs and also faced some issues regarding the dress code of certain jobs. Like one study participant stated that, "I was doing service in the Army! So, then I left my job, because I wasn't able to do any kind of work at that time. Except that I am also a Tailor! But I couldn't be able to do the tailor work too, because a person couldn't be able to sit for so long because of it" (P10). Many participants were worried about their sleep difficulties due to the presence of stoma. They also shared some reasons which includes, difficulty in turning position, fear of leakage and frequent awakening to drain the bag. The insufficient sleep effects the health of many participants. "Initially I was adjusting the alarm, or somebody from my home was waking me up after 2 hours [so that I could empty the bag] and once I wake up after every 2 hours, so then really, I don't feel sleepy for the next 2 to 3. So then, the whole day I feel lazy and lethargic (P9). Additionally, some participants also explained the strategy to get enough sleep with stoma bag. "I used to eat the dinner at the time of Maghrib [with sunset] and even sometime I skip eating the dinner, so that turns better for me. Because then I could continuously take me sleep for straight 5 to 6 hours. Whereas if I eat dinner very late, I have to go to the washroom again and again" (P9).

The presence of stoma had adversely affected their self-hygiene practices, especially bathing routine and foot care. Eight participants reported inadequate bathing. They usually preferred to take bath on the day of changing the bag or they used to take sponge bath instead of put direct water on stoma and covering the bag with shopper before taking bath. "I have to put a light cloth on my stoma side, Since I have this bag, I couldn't be able to take bath completely" (P10). Contrary to above, one participant shared her practice of taking bathing with cold water. She claimed that by doing this she takes full shower without fear of any leakage. "Thank God I did not face any kind of leakage issue while putting water on it, because I take bath with the cold water (P8).

Sub category 3:2: Socialization. Most of the study participants remain confined to their home because of this colostomy bag. They perceived that it would look awkward, so they were reluctant to meet people. "I mostly try to avoid going in any gathering because my abdomen has turned big from one side. Even though I will wear any kind of cloth, it's been naturally visible and it looks bad! So, I am feeling embarrassed and hesitant in going anywhere" (P2). "It's really difficult to go outside, I had a habit of mingling a lot with the people, but now all is stopped. Before I was attending the gatherings, but now I couldn't be able to go there" (P9).

Moreover, the participant also shared his coping process and regains his socialization and shared her practice before going

anywhere. *"I go everywhere. But yes, what I do is that, as when I have to go to any function, so I use to call my technician and ask him to change my bag once, so that it will become a little strong, so that God forbidden any kind of mishap wouldn't occur there"* (P8).

Sub category 3:3: Religious Activities. The presence of stoma also affected the performance of routine religious practices of individuals. The participants considered it as the most adverse effects of stoma. They expressed that initially they had difficulty in performing religious activities but with proper guidance and support they started their practices again. *"I faced problem while offering the Namaz because initially, you don't know anything about it. Then I also talked with the Imam in the Masjid, he said that, "This is a Shariya freedom or helplessness. Before I was again and again coming back to home for ablution and was going back to Masjid for offering the Namaz"* (P7). Contrary to gained full normal routine, some participants were performing their rituals with some limitations. *"I couldn't be able to bend much, so I sit on the sofa for namaz. And as far as the reciting of Quran Paak is concern, So I keep the cushions in front of me, and can easily recite Quran while lying down"* (P8).

In contrast, some participants fail to do any rituals. *"No one couldn't be able to offer the Namaz with the colostomy. I have also discussed this problem with one of the Molvi, he said that, till this bag is with you, you couldn't be able to offer Namaz (P10). "Some people tell me that, "You couldn't offer Namaz now, Means the filth is stick with you so, that's why I did not offer any prayer for about one and half year, but now thank God I have started offering Namaz (P5).*

Sub category 3:4: Sexual and Reproductive Life. The direct and indirect impacts of stoma formation on participants' sexuality and reproductive life were Sexual dysfunction due to nerve damage, decrease intimacy, fear of spousal reaction and restricted sexual relationship. *"The feelings and desires remain at their place. But a person himself use to avoid something because of the disease, that maybe the other person would not get disturbed because of you"* (P3).

Furthermore, the female participant who was in child bearing age, highlighted her fear of being pregnant because of the hole in her abdomen. *"It happened one and a half years back, that I got pregnant, definitely I had a hole in my belly... right. So, when the delivery will come, and when the abdomen will turn more bigger day by day, so I told the doctors that, "Doctor my abdomen will get blown out". So, then I aborted that child. Then we didn't try for a baby again(P2).* Conversely, one participant expressed that he had no any difficulty or restriction on his sexual relationship. He stated that, *"I do not have any issue. I have an adequate relationship with my wife, even I also had a kid, who was born after my colostomy"* (P10).

Category 4: Patients' Needs and Recommendations

The participants revealed the various needs of colostomy patients and make some recommendations for helping them to adopt with new life. They emphasized the need for adequate counseling, teaching/ training, support system (family, social and financial support) and competence of nursing staff for eliminating the suffering of colostomy patients.

Sub category 4:1: Support System. Almost all participants emphasized the need for adequate support to adopt with colostomy. They required support not only in term of preoperative counseling, postoperative training and discharge teaching but

also, they exhibited the need for social and financial support system. Some study participants highlighted that before stoma formation they had not received adequate guidance or counseling from the hospital staff. *"When this colostomy was been created, I was very frightened, definitely this thing is very common for doctors. but I was really very worried because I don't know what will happen to me"* (P2).

They also asserted the lack of discharge teaching and because of this they have to face multiple issues of colostomy care at home. They stated that the hospital should equipped the stoma patients with all necessary information and resources to successfully manage their stoma at home. *"When a patient is been discharged from the hospital, so at least the hospital should send him back to home by making him independent enough, so that he wouldn't be helpless on anybody else. If I could say about myself, so we weren't aware of all these things in the initial 25 days to one month, as they haven't given us any kind of guidance regarding that (P3).*

Additionally, the participants also shared some recommendations for effective teaching. They highlighted the importance of discharge teaching by demonstration and audiovisual aid. *"I would be better if in the initial one and a half month, you learnt it from someone, but yes, the learning only takes place when you use to see the other person doing it (P3). I saw it on YouTube, as how the people are changing the bag, or whatever is there. But the issues were that, I do not know that, which type of stoma I have and what kind of accessories suit to my stoma, because a lot of things comes under this umbrella, and you couldn't even find those things in Pakistan"* (P3).

Furthermore, the participants emphasized the importance of social (family, friends and other colostomy patients) and financial support system, which help not only in decision making regarding stoma formation but also aid in the process of adoption and reintegration to their previous lifestyle. The participant verbalized that the decision for colostomy formation was very stressful for them but when they talked with other stoma patients, so they get courage and hope for a better outcome. *"We were not aware of this procedure, so everyone was worried, then we had a talk with one of a person [stoma patient] that given us a lot of satisfaction (P2).* Similarly, one female participant articulated that a good social and family support facilitates the recovery process after stoma. *"You won't even imagine how much my daughter cared for me during that [after colostomy formation] time. I am thankful to Allah for millions of times that I have such good family members (P1).*

As for as the financial support was concerned, only few participants having the facility of some kind of panel [medical insurance] but most were self-financing the expenses of colostomy appliances. The participants who have any medical insurance they were comfortable because they have a bulk of appliances in hand so that they may not face any difficulty. The participants who had no any medical insurance were depending on their family members for purchasing colostomy appliances. The high cost of stoma appliances was a major concern for them. The participant shared as, *"My brother and mother, they purchase all that for me. These things are turning more expensive now. My brother was saying that the cost of only this bag and wafer set is 1200 to 1250"* (P5). Additionally, he stated, *"My technician is charging 2000 for each time. Yeah, that's another expense really"* (P5). Contrary to the above, the participants who had no any kind of financial support system, they suffer physically and psychologically. *"I couldn't afford to buy in a bulk., sometime it*

happens that my bag gets a leak and I do not have the bag in my hand and even I cannot afford at that time so than I applied the tape on it and spend 2-3 more days with this. So, then the skin from there starts to peel out" (P10).

Sub category 4:2: Professional Competence. The participants expressed that well-prepared nursing/ medical staff is necessary for proper guidance of the stoma patients. They further explained that when the staff themselves do not know anything regarding stoma care and appliances, how can they guide the patients? Correspondently, the participant pointed out the incompetence and reluctance of hospital staff toward stoma care. The participant also suggested the need for training of nursing staff. *"I once faced a problem of bag leakage in the hospital, so I waited for so long. The hospital staff lingered it on from one person to another. So, I think this would be good, if the hospital management itself could first explain their nursing staff as how to change the bag so they can guide the patient regarding that" (P3).*

Discussion

The current study explored the process of adaptation and practices of stoma self-management at home. The findings revealed that stoma formation distorts the normal body functioning and social life of an individual that is consistent with the previous literature [15,16,45]. A person with new stoma formation needs assistance to re-establish his physical and social life. The initial effects of disease process and general health make the participants dependent on others for their stoma care and they felt the need for formal assistance to manage their stoma in the initial post-operative period as it takes approximately 2 to 4 weeks to adjust with stoma [38]. Unlike in Chinese culture where, the stoma patients were more inclined toward stoma self-management instead of exposing others from their filth of feces [60]. The participants of the current study demonstrated long term dependence on formal or informal care givers. The young male participants of the current study reported early adaptation and independence of stoma care as compare to the female participants. This finding contradict previous study that was conducted in Bharatpur Nepal that reported low acceptance and social engagement score in man [22].

The most prominent issue in stoma self-care was the lack of knowledge and skills about the use of stoma appliances. For effective stoma self-care at home, it is essential to educate the participants regarding the different types and proper usage of stoma appliances, the technical skills of changing, emptying and disposal of stoma pouch [11][48]. In the current study participants felt a need for detailed guidance from their health care team regarding the selection of stoma appliances which best meet their needs. Literature highlighted that it is the responsibility of nurses to make stoma patients independent in selection of suitable appliances and adequate stoma care [10].

Such as another concern that raised by the participants in current study was regarding the emptying of colostomy pouch. Berti Hearn (2019) suggested in guideline for stoma home care that it is recommended to empty the stoma pouch when it is 1/2 or 1/3 full but the type of stoma, size of pouch, use of antibiotics and any current bowel disease can influence the need for emptying of pouch [7] but the participants in current study felt the compulsion to empty the pouch more frequently due to the fear of leakage and to avoid dragging and burning sensation. As far as the changing of pouch was concerned, most of the study participants reported the practice of changing the

pouch after one week, whereas, one male participant was used to change the bag after 15 days or even some time for 20 -25 days and reported no any skin irritation. In contrast to these, the standard guidelines suggest to change the bag between three to seven days, as too frequently changing the bag, (less than three days) or too long (more than seven days) can cause skin irritation [7,10].

The study participants reported the most common skin problems were itching, skin irritation and skin breakdown around stoma. Their routine care practices included, washing and cleaning with hand wash, baby wipes, use of Dettol and tincture benzene and apply Vaseline, common lotion and powder to treat the damage skin. Whereas, the literature suggest that only warm water is sufficient for stoma skin care and avoid use of baby wipes, lotion, powder, any ointment around stoma as it can further damage the skin [13,48]. Most of the participants practice putting ice cubes in stoma pouch after draining and cleaning it and reported that it enhances the stickiness of wafer in summer season and keep the stoma healthy. Although there is no any scientific evidence of using ice cube in stoma pouch but this practice can be supported in a way that body temperature and hot weather also affect the wear time of stoma appliances [13,21].

The formation of stoma adversely influences the persons' activities of daily living and quality of life [9,45,46]. The participants felt restricted to continuous their routine activities including walking, running bending down, performing household chores, traveling and to continuous their job. Most of the participants of current study reported confined socialization due to the fear of leakage and overfilling of stoma pouch, all these finding were consistent with previous literature [5,16,25,38]. Only few participants of current study were using alternative strategies to overcome the issue of leakage which includes changing the stoma pouch before going outside, consuming less food intake and keeping extra supply in hand.

The participants also reported the stoma has also affected their personal hygiene. They felt difficulty in taking bath, due to the fear of pouch's wear off hence, the study of Burch, illustrated that bathing and showering is not a big challenge with stoma. There is only need to advise the stoma patients to take shower with old pouch and replace it with new appliance afterward [10]. The study participants highlighted the concerns related to performance of religious rituals.

Spirituality, plays an integral role in successful adaptation with stoma. The study finding of Li, C. C., Rew, L., & Hwang, S. L. (2012) reported, the guidance from the religious leaders not only assist the individuals in performing their religious rituals but also helps them to adapt successfully with their stoma [34,58]. But unfortunately, the few participants of current study were not received any religious guidance neither from the hospital nor from any religious leader that damage their spiritual life and adaptation process.

The participants of current study also reported the impact of stoma on their sexual and reproductive life including, sexual dysfunction due to nerve damage as a complication of surgery, and restricted sexual relationship due fear of spousal reaction [3,56]. In addition to this, one of female participant of reproductive age aborted her pregnancy because of fear that might her abdomen will burst out if she will carry a baby in womb. Providentially, the previous researches reported that the women with stoma can successfully manage pregnancies [39,55].

The study of Tao, H., Songwathana, P., Isaramalai, S. Arun, & Wang, Q. (2014) reported the use of high-waisted clothes and firm fitting under garments reassure female that pregnancy and child birth is safe with stoma [60].

Furthermore, the support of family and friends play a pivotal role in adaptation to life after stoma [43]. The participants of current study also acknowledged the support of family members in their recovery and management process. And affordability was another issue in the process of adaptation with stoma. The participants with well financial status were more inclined toward long term professional assistance instead of doing stoma self-care. As the study of Rachel Millard (2020) reported that the patients who are competent enough in selection of stoma appliances and perform stoma care effectively can maintain the skin barrier for longer period of time that eventually reduce the finance of supplies [64].

Eventually, the study participants mentioned that they did not receive adequate teaching and training about stoma management and found them insufficiently prepared for stoma care while getting discharged from hospital. Whereas, the study of Lim, et al (2015) suggested that the Lack of hands-on practice results in the difficulties in stoma self-care at home [38].

Conclusion

The current study employed a qualitative approach to learn participants' experiences of stoma self-care at home. The study findings highlighted multiple factors of long-term dependence for stoma care including insufficient preparation for stoma care, lack of acceptance and motivation of stoma care. The challenges faced by the participants were difficulty in activities of daily living, carrying out socialization, continuing the job and performing religious rituals. All these findings inform the health care professionals about the need for competent health care professionals, and development of educational programs and teaching guidelines for stoma patients to make them independent in stoma self-care at home.

Author Statements

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