

Experiences and coping strategies of colostomy patients in Ghana: A Phenomenological study

Adwoa Bemah Boamah Mensah (✉ adwoabemab@gmail.com)

Department of Nursing, College of Health Sciences, Kwame Nkrumah University of Science and Technology, Private Mail bag, University Post Office, Ghana

Vida Yeboah

Department of Nursing, College of Health Sciences, Kwame Nkrumah University of Science and Technology, Private Mail bag, University Post Office, Ghana

Er-Menan Amaniampong

Department of Sociology and Social Work, Faculty of Social Sciences, College of Humanities and Social Sciences, Kwame Nkrumah University of Science and Technology, Ghana

Kofi Boamah Mensah

Department of Pharmacy Practice, Faculty of Pharmacy and Pharmaceutical Sciences, College of Health Sciences, Kwame Nkrumah University of Science and Technology, Ghana

Grace Kusi

Department of Nursing, College of Health Sciences, Kwame Nkrumah University of Science and Technology, Private Mail bag, University Post Office, Ghana

Felix Apiribu

Department of Nursing, College of Health Sciences, Kwame Nkrumah University of Science and Technology, Private Mail bag, University Post Office, Ghana

Veronica Millicent Dzomeku

Department of Nursing, College of Health Sciences, Kwame Nkrumah University of Science and Technology, Private Mail bag, University Post Office, Ghana

Joseph Attakorah

Department of Pharmacy Practice, Faculty of Pharmacy and Pharmaceutical Sciences, College of Health Sciences, Kwame Nkrumah University of Science and Technology, Ghana

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Abstract

Background: Available empirical evidence shows increasing rates of stoma surgeries (i.e., colostomy) among persons in sub-Saharan Africa, particularly Ghana. Compared to developed countries, the management of colostomy is considered more stressful due to the absence of a homecare management model after discharge from the hospital. Yet, there exist a paucity of evidence on the experiences, challenges and coping strategies of persons living with colostomy after being discharged, within a resource constrained setting such as Ghana.

Aims: The experiences and challenges as well as coping strategies of colostomy patients were explored and described in this study.

Methods: Using a descriptive phenomenological design, semi-structured face-to-face interviews were conducted with a purposive sample of 15 patients with colostomy. Colaizzi's analytical framework and a deductive process was employed to thematically analyse the data.

Results: Themes that characterised participants' experiences and challenges with colostomy comprised: social stigmatisation, social isolation/withdrawal, sex-related challenges, psychological experiences and challenges, suicidal ideation, physiological experiences and challenges, dietary/eating challenges, difficulties caring for colostomy, skin disorders, cost of colostomy accessories, and work restrictions. Amidst these experiences and challenges, participants were shown to promote their resilience in the face of adversity through assets and resources: social support, spirituality and religion, lifestyle modifications, nutritional and pharmacological strategies, and improvised stoma accessories.

Conclusion: Persons living with colostomy experience numerous challenges that threatens their health and wellbeing. Yet, they rely on assets and resources to remain resilient in the face of these challenges. Findings have implications for policy interventions on public education, expansion of health insurance scheme, stoma nurse recruitment and training, and patients' resilience healthcare strategies of colostomy in Ghana.

Introduction

Colostomy is one of the most life-saving surgeries performed across the world, with the goal of either decompressing a blocked colon or diverting bowel content [1]. Available statistics across the world show that persons living with colostomy are on the rise. For instance, in the United States, evidence indicate that about 100,000 persons are operated on yearly, resulting in the creation of colostomy because of the increase in diverticular disease or colorectal cancer incidences [2, 3]. In the UK, available data suggests that approximately 200,000 persons are living with a stoma, with about 21,000 individuals undergoing stoma surgeries each year [4].

Similar evidence have been shown in most African countries [5–7]. For instance, colostomy is marked as the leading operation performed in sub-Saharan Africa [8]. In Eastern Africa, Calisti et al. [5] found that colostomy was the most frequent surgery performed. Like most SSA countries, Ghana lacks a national colostomy registry, however, institutional-based data indicate increasing incidence for colostomy due to recent increases in colorectal cancers and diverticular diseases [9]. For instance, recent data points to the fact that about 33 percent new cases of colorectal cancer out of every 100,000 persons are recorded yearly [10, 11]. These statistical evidences indicate that the problem of colorectal cancers is no longer uncommon among the indigenous people of Ghana. Further records from the Komfo Anokye Teaching Hospital (KATH) reveals that more than 100 colorectal cancer-related colostomies are done annually (KATH Ostomy Records, 2019). This infers that there is a significant number of people living with colostomy in Ghana. This situation is expected to worsen as the global burden of colorectal cancers and other inflammatory bowel diseases continue to rise [12]. Yet there is limited evidence on the experiences of persons living with colostomy.

Colostomy is used to prevent faeces from contaminating the distal large intestine segment, and it has helped to reduce the number of deaths associated with abdominal injuries [1]. Notwithstanding the benefits associated with colostomy surgeries, there are negative experiences and challenges of living with a colostomy. Previous studies have described common experiences of ostomates to include dermatitis, pain, leakages, odour, altered body image, social isolation, feeling of inferiority complex, suicidal intention, and stigmatisation [13–17]. Most of these studies however reflect the experiences of persons living with colostomy in developed countries. The differences in terms of sociocultural contexts and health systems within these countries may not support the transferability of the findings to colostomates within developing countries, particularly Ghana.

Further, there is evidence highlighting numerous challenges and lifestyle changes faced by persons who undergo colostomy surgeries after being discharged from the hospital [18], necessitating the need to understand the experiences and coping strategies of persons living with either permanent or temporal colostomies in the context of a developing country. To address this gap, this study explores the experiences of persons living with colostomy within the context of a developing country characterised with limited resource and an absence of a well-established speciality and homecare model for managing colostomy.

Methods

Theories and concept:

Colostomates can have their health, social relationships, and quality of life adversely affected by their colostomy conditions [18–20]. It is, therefore, necessary to explore the experiences and strategies they adopt in coping with these experiences. For such a phenomenon, the theory of resilience is considered appropriate as an analytical framework. Scholars have conceptualized resilience as one's ability to adapt successfully when faced with hardship and stress [21, 22]. Other studies explain that a resilient person portrays traits that include a variety of beliefs, feelings, and behaviours including optimistic attitude, hopefulness, perseverance, capacity to mobilise social and economic resources, and spirituality [23, 24].

While these definitions emphasise behaviours, [24] posit that resilience is an adaptive process that could vary in response to various situations, making it alterable. Implicit within these definitions are two major conditions: (1) a person's exposure to significant adversity; (2) the realisation of positive adaptive strategies irrespective of the adversity faced. Accordingly, both risk factors and protective factors determine how resilient a person becomes in the face of hardships [25]. Risk factors comprise those factors that threaten the wellbeing of individuals living with a colostomy. These could include stigma, isolation, difficult experiences, and lack of social support. On the contrary, protective factors are those factors that facilitate a reduction or elimination of the influence of the risk factors on Colostomates. That is, these protective factors strengthen the response of Colostomates to their negative experiences. Individual and context-based protective factors exist [26].

Protective (promotive) factors according to Zimmerman [27] can be grouped into two: assets and resources. Assets entail those positive factors and attitudes that reside within Colostomates such as self-esteem, spirituality, competence, and perceptions of self-efficacy. The resource aspect suggests factors external to the individual and could include support from family and other forms of social support. Scholars introduced the compensating model of resilience which posits that resilience operates as a factor that mitigates risk exposure. It is further argued that the outcome is shaped by both the risk factors and protective factors. In other words, the negative effect of risk factors experienced by an individual could be offset by protective factors (i.e., resources and assets) [28, 29]

Despite the usefulness of the theory of resilience in this study, it is not without flaws. A major problem encountered using resilience theory is how key concepts have been defined in various ways by resilient scholars [30, 31]. This contributes to the inherent difficulty in comparing results of studies that rely on the resilience theory due to the substantial variations in the operationalisation and measurement of the concepts [32]. Questions concerning whether resilience should be considered as an outcome, process, or trait remain [31]. Most importantly, others [25, 30] have alluded to the importance of contexts in understanding resilience. The implication of such an argument is that there is an absence of a contextual and culturally sensitive knowledge of resilience that is different from that of the overriding notions of resilience from the Western perspective [31]. This study contributes to addressing this limitation by exploring the forms and sources of resilience among persons living with colostomy in a sub-Saharan African context, with different sociocultural settings compared to Western countries.

Study design and setting

A descriptive phenomenological approach was adopted to explore and describe the experiences of persons living with a colostomy. Relying on phenomenology enriched the study's uncovering of the genuine lived experiences and coping strategies of individuals living with colostomy while enabling the authors to provide meanings to the experiences of these individuals without the influence of their perceptions [33, 34]. Consequently, the lived experiences of Colostomates were described and understood based on their accounts and perspectives. Additionally, owing to the sparse research on the experience and coping strategies of persons with colostomy from developing countries, using the phenomenological approach offered an opportunity for hitherto unavailable insights to be discovered and documented [34].

The study was conducted in Kumasi, particularly, the Komfo Anokye Teaching Hospital (KATH), popularly known as "Gee". The hospital serves as a tertiary referral point to about 12 administrative areas in Ghana including Western North, North East, the Ashanti, Bono East, Bono, Ahafo, Savannah, Upper East, Northern, Upper West, and other areas of the Eastern and Central regions of the country. Indigenous of other west African nations such as Burkina Faso and Ivory Coast also receive treatment from KATH [35]. Available data suggests that over 100 cases relating to colostomy are recorded at the KATH Surgical unit annually (KATH Ostomy Records, 2019). This justifies the suitability of Komfo Anokye Teaching Hospital for this study.

Study population, sampling technique, and sample size

This study is part of a larger research exploring the experiences of persons living with colostomy in Ghana. Data were collected from individuals receiving care on colostomy from the KATH Colostomy Clinic. This involved persons who had undergone colostomy surgeries and reports to the Clinic for review. Given the focus of this research, eligible participants who satisfied the following predefined inclusion criteria were recruited: (i) participants should be at least 18 years of age; (ii) should either be living with a permanent or temporal colostomy for more than three months, preventing the inclusion of persons who could only provide immediate post-operative experiences; (iii) could either speak English or 'Twi', the native languages of the researchers; and (iv) received or still receiving care from the colostomy clinic at KATH. Hence, individuals who do not satisfy these criteria were excluded from the study. The use of the above inclusion criteria ensured that the findings were contextually specific and accurate, and reduced selection bias, thus improving the usefulness of the findings [36]. Purposive sampling technique was used in identifying and recruiting participants for this study, aiding the researchers to include participants with knowledge of the phenomenon under study. All participants who were contacted were willing to participate in this study and therefore consented to their inclusion verbally and written. The sampling procedure was guided by both data and theoretical saturation [37], resulting in the final inclusion of 15 participants in the study. The inclusion of 15 participants in this study supports the recommendation that a sample of 5 to 25 participants is suitable for phenomenological studies [38].

Recruitment of participants

The Colostomy Clinic of KATH was used as the main recruitment outlet. Formal permission was granted by the head of the Surgical Unit at KATH, after reviewing the ethics approval provided by the Institutional Review Board (IRB) of the hospital, and an introductory letter detailing the purpose of the study. A pre-data collection interaction session with the staff was organised by the head to discuss the study and all related concerns. In recruiting participants who satisfied the inclusion criteria, the researchers relied on the assistance of these staff (i.e., nurses) who served as "recruitment links". To facilitate this process, another meeting was held to familiarise the staff with the inclusion criteria and were provided copies of the inclusion criteria sheet, details

concerning the study, and the contact details of the researchers. Potential participants who could not read and understand had recruitment nurses reading and translating the details of the sheets to them.

The second author (interviewer) was contacted when prospective participants were identified and their contact details were compiled by the recruitment nurses. Afterward, the researcher contacted each of the potential participants confidentially through the phone to assess and confirm their eligibility based on the inclusion criteria. Also, the researcher directly recruited participants during scheduled colostomy clinic days until data saturation was reached [39]. After participants had agreed to their inclusion in the study, they were informed of their rights to withdraw from the study at any point without any repercussions. Codes comprising the letters 'CP', and four digits were uniquely generated as an anonymised identity for each participant (for example, 'CP006'). Recruitment processes ended after the 15th participant since no new information was emanating from a further selection of participants.

Data collection

The study collected data through semi-structured face-to-face qualitative interviews with study participants. Interviews were aided by an interview guide (supplementary file) developed by the researchers based on study objectives. The development of the interview guide was informed by the research objectives and existing literature, and reviewed by a colostomy consultant as well as the first author, a nurse who is a qualitative researcher with extensive clinical experience. The structure of the interview guide was in two sections. Section A included questions on participants' characteristics such as sex, age, marital status, number of children, religion, and educational level. In section B, participants were asked about their psychological experiences; the social experiences they have encountered; challenges they have faced because of the colostomy, and how they coped after the colostomy was performed. Two language experts were consulted to translate (back-back translation) the interview guide into Twi (local language) independently. The second author (V.Y) conducted all interviews after receiving training from the first author (A.B.B.M).

The interview guide was piloted with four patients living with colostomy at the Kumasi South Hospital. This hospital was chosen for the pre-testing process because its structure and features are similar to that of KATH. Pre-testing the interview guide offered the researchers an opportunity to practically correct the initial design and wording of the interview guide. The first author (A.B.B.M), with a clinical experience subsequently reviewed the order of the questions for sociocultural suitability based on the pre-test interview outcome. Data obtained from these interviews were not included in the main findings reported in this study. Participants were allowed to choose their preferred locations for the interviews. Seven (7) of the interviews were conducted in participants' homes and eight (8) in an office assigned to the researcher at the Surgical Unit. This ensured that participants were comfortable and minimised intrusion from others. Interview language was Twi (local language).

At the beginning of each interview, participants were reminded of their rights to withdraw and their consents were verbally sought. The researcher at the beginning of each interview established an informal rapport with study participants to ensure they are comfortable and relaxed. During the interviews, echo probes and paraphrasing [40] where necessary, were 'thoughtfully' used to elicit and understand Colostomates' experiences and coping strategies. All the interviews were audio-tape recorded with the approval of participants. At the end of each interview, the researchers listened and transcribed interview audio, and new areas emerging were explored in subsequent interviews. These interviews lasted between 40 to 60 minutes, averaging 50 minutes. Transcribed interviews were provided to 3 randomly selected participants to read through their responses for validation. During interviews, responses were also reflectively paraphrased by the researcher as a way of clarifying if interpretations were in line with participants' intended message. All these participants endorsed their responses without any additions or omissions.

Data analysis

Data collection and analysis were done concurrently. All interviews were audio recorded to ensure that all of the information provided by the participants were captured and to make transcriptions easier for independent analysts to review. A.B.B.M and V.Y reviewed the audiotape recordings at the end of each interview and saved them on a password-protected laptop. Interviews were transcribed verbatim, then, translated into English language using the back-back translation process. A.B.B.M, who is fluent in both Twi and English, double-checked a random sample of the recordings and transcripts to confirm that the interviews, transcriptions, and translations were accurately done. NVivo 12, a computer-based program, was utilised to manage the data. Colaizzi's phenomenological approach, with a deductive analytic process, was used to rigorously analyse the data to find, understand, describe and depict [34] the experiences and coping strategies of colostomates. As a widely used approach in health research, it helped the authors to analyse specific aspects of colostomates' experience via the identification of 'essential themes' and a clear description of the fundamental structure of their experiences [41]. The transcripts were coded independently by two analysts (E.A and V.Y), and three transcripts were coded for validation by A.B.B.M. The findings were discussed and finalised by K.B.M, G.K, F.A, V.M.D and J.A. Data analytical processes based on Colaizzi's approach are elucidated as follows:

Step 1: The interview audios were transcribed ad-verbatim. After transcription, transcripts were translated to English language using back-back translation process by two independent translators who are fluent in both English and Twi languages. Main research objectives were used as a basis to re-organise the transcripts. Hence, under each objective, all responses reflecting that objective were re-organised under such objectives while maintaining participants' identity. Subsequently, the second and third authors repeatedly conducted a more in-depth reading of the data to familiarise themselves with the experiences and coping strategies of colostomates.

Step 2: In this phase, significant statements in the data that directly related to colostomates' experiences and their coping strategies were extracted from the transcripts as codes. These coding processes were guided by initial codes ('start list') based on the theory of resilience. The researchers explored the data to identify concepts embedded in the theoretical framework.

Step 3: Meanings were formulated from significant statements or phrases identified in step 2, relevant to the experiences and coping strategies of participants. In this stage, the meanings concealed in the various contexts of the phenomenon under study were described and illuminated by the authors. Both authors re-reviewed the data to identify emerging codes that were not included in the framework. Codes were discussed, discrepancies were clarified, definitions were revised and new codes were created by the authors. Afterward, various statements that conveyed comparable meanings were used in generating themes.

Step 4: A repetition of step 1 to step 3 was done for all 15 participants. In this stage, meaning relating to participants' experiences and coping strategies that were present in the accounts of all the participants were identified by the authors and clustered into essential themes based on their similarities and relationships.

Step 5: An exhaustive description was developed by the authors. The researchers produced a full and inclusive description of participants' experiences and coping strategies including themes generated in the previous steps (step 1 to step 4).

Step 6: The findings were then condensed and incorporated into a rich and detailed statement that captures all aspects the researchers found to be important in understanding participants' experiences and coping strategies.

Step 7: The authors sought verification from 3 participants by returning their transcripts to them for them to affirm whether their experiences were truly captured. This process did not yield any pertinent and new data from participants, ensuring that the findings were credible.

Trustworthiness and credibility

The principles of credibility, dependability, confirmability, and transferability [42] were used in various ways by the authors to enhance the trustworthiness of the study. First, the researchers deliberately enrolled members who met the inclusive criteria and could give in-depth descriptions of their experiences with colostomy and their coping mechanisms. Also, at the end of each interview, member checks were carried out by summarising key responses for participants to validate if they accurately reflected participants' true experiences living with a colostomy. Additionally, credibility was ensured by conducting an independent analysis of the data. An exhaustive description of the research methodology comprising the study design, recruitment procedure, data analysis, etc., were delineated for researchers to replicate and to ensure dependability [43]. The authors ensured the transferability of the findings by offering thorough descriptions of the study context, and participants' characteristics. This makes it possible for other researchers to transfer the findings to their contexts and settings. For confirmability, field notes, which included the participants' verbal and nonverbal clues, were used to substantiate interview transcripts [43]. Besides, all the back-to-back translations done by the two translators from 'Twi' to English were reviewed and verified by the authors. These processes enhanced the rigorousness and credibility of the study [44].

Results

4.1 Characteristics of Participants

Fifteen persons living with colostomy interviewed in this study were mostly females and between the ages of 18–65 years. The minimum educational level attained was primary education and the maximum was senior high education, suggesting a relatively low educational attainment. Most of the participants were Christians, with only one Muslim. Most of them had temporal colostomy conditions, and three participants reported permanent colostomy conditions, with a minimum and maximum stoma duration of 3 months and 19 months (1 year and 7 months) respectively. Participants had at least one child and a maximum number of four children. Nine participants were married, three were divorced, two of them were single and cohabiting respectively, while one was a widow. All participants were self-employed in the informal sector. Table 1 describes participants' demographic information.

4.2 Findings

The findings are presented narratively under two main objectives that informed this study: a) to explore and describe the experiences and challenges of colostomy patients; b) to describe colostomy patients' coping mechanisms (source of resilience) to their experiences. Under each of these objectives, sub-themes are developed to enhance the presentation of findings as illustrated in Table 2:

4.2.1 Experiences and challenges (risk factors) of colostomy patients

This theme describes various risk factors that characterise the experiences of individuals living with a colostomy. Numerous sub-themes underlying this major theme identified were: (1) social stigmatisation; (2) social isolation/withdrawal; (3) sex-related challenges; (4) psychological experiences and challenges; (5) suicidal ideation; (6) physiological experiences and challenges; (7) dietary/eating challenges; (8) difficulties caring for colostomy; (9) skin disorders; (10) cost of colostomy accessories; and (11) work restrictions.

Perceived and actual social stigmatisation:

Most participants revealed that their experiences living with a colostomy are characterised by perceived and actual stigma from social networks (immediate family members) and generalised others (friends and other members of society). For some participants, there were perceptions that others in the communities they reside in and at their various workplaces will stigmatise them upon knowing their condition. For instance, the account of CP007 revealed how reluctant she was to go out of her home and subsequently stopped her apprenticeship because of how uncertain she is concerning the reactions from others since they talk too much: "I cannot even go out because of the colostomy... I stopped because I don't want any to know that I have a colostomy. People talk a lot and I don't know what they will say if they see me with a colostomy." CP007 explains how the distended nature of the

colostomy bag could lead to her being stigmatised by others when in public: "The colostomy bag sometimes bulges in the dress I wear people may see it and they may start to point their hands at me when I am in public" (CP007). This was supported by an explanation offered by CP003. To her, she has decided not to inform anyone because of how they will be pointing fingers at and gossiping about her when they get to know of her condition. She explained citing an instance where she refused to provide actual information about her condition to a friend of hers:

"I could remember I went out once and a friend of mine's hand hit it. She asked me what it was but... I had to lie and say I am wearing a corset... I have not informed anybody. I am afraid when I inform people, they will end up telling everybody.... I am afraid people will end up pointing their hands at me when I am in gatherings. Some of my colleagues sometimes ask what has bulged up in my dress especially when I wear a certain dress but I still do not tell them it is a colostomy. They may start pointing their hands and gossiping about me." (CP003)

Another recounted: "...I am scared of what people will say if they see me in this situation. Most people do not know I have a colostomy." (CP011)

The above accounts however suggest that stigma expressed towards individuals with colostomy may not be straightforward. But rather dependent on people's knowledge and awareness of their conditions, implying that enacted or actual stigmatisation does not occur when their significant and generalised others lack such information about them. Therefore, others' knowledge and awareness of one's colostomy condition, as discussed above, facilitates stigmatisation from other members of the public. For CP008 for instance, his condition resulted in various negative reactions from others to the extent that his wife's family linked his condition to one who has been cursed. This is exemplified in his elucidations of his experiences:

"...But recently when people heard of my condition, they stopped collecting my funeral donations (contributions) because they said I'm sick. Some even see it as a curse that might have resulted from me wronging someone. For some too, it is very strange to them for a normal person to be having his faeces on his abdomen... Mmmmm... is not easy. ...my wife's family even attributed it to some spiritual thing..." (CP008)

The above was corroborated by CP006 and CP005, who narrated how their friends who are aware of their condition, sometimes pass derogatory comments, using their condition to tease them:

"...Few of my friends know I have a colostomy....., sometimes they make teasing comments which are unfavourable and act as if I cannot be involved in any activity due to my situation ..." (CP006)

"...Sometimes my friends..... hmmm, we used to eat and play together but following my surgery, eating with me has stopped. Their teasing comments and attitudes towards me now is just unacceptable! ." (CP005)

While nuclear and extended family members are considered to be primary sources of support to an individual in times of difficulties, especially in healthcare navigation [45, 46] such as colostomates, findings from this study proved otherwise. This is because some participants shared on how their family members stigmatised them. However, this was mainly gendered in nature. The Ghanaian cultural and traditional orientation assign domestic roles including cooking to the female gender, and women with colostomy in performing such roles experience greater challenges with stigma from other family members. Some female participants shared their experiences regarding how their family members refused to eat foods cooked by them, arguing that they could not eat food cooked from the same hands these colostomates use in cleaning their faeces. They shared their stories:

"...Please, it is only my mother that when I cook, she eats. Nobody in the house eats food cooked by me. This is because they said the same hand I used to pour my faeces is the same hands I used to cook." (CP004)

"The most painful aspect is when I cook, nobody wants to eat the food, not even my mother. They said I am dirty. My faeces are on my abdomen and I can't use the same hands I use for cleaning my colostomy to be cooking. I feel like an outcast in my home. They said I may have wronged someone for the person to have cast a spell on me..." (CP003)

One participant was observed to have internalised stereotypes held by others towards persons with a colostomy. This resulted in her engaging in self-stigmatising, considering herself as not being a human since he could no longer pass faecal matters through his anus: "...With the colostomy with me, I do not see myself as normal. No, I am not normal at all... Mmmmm... As a human being, you have to pass faeces through your anus. For as long as this colostomy is there, I feel less of human..." (CP002)

Social isolation/withdrawal:

Social isolation and withdrawal are other risk factors identified from the narratives of participants. Social withdrawal and isolation arise when an individual is disconnected from opportunities for interaction with others, i.e. when restraining behaviours are triggered by a person due to anxiety or fear evoked by the anticipation of others in a social situation [47, 48]. It is gleaned from most definitions that social withdrawal or isolation is initiated by a person. However, there is evidence that the actions of others could trigger social withdrawal and isolation. For example, stigmatisation and the absence of support from family [49] and the public. Participants described that the absence of the required support coupled with enacted stigma from those who otherwise should have offered them support causes them to feel socially isolated and withdrawn from all forms of opportunities to interact with others. This is caused by the unbearable odour and shyness because of the stoma. CP004 stated how he has isolated and withdrawn himself from his children because of his colostomy condition: "For my older child, she is staying with my mother. Because of the colostomy, I do not stay with any of my children" (CP004). One participant contended that leakages and offensive odour characterising her colostomy has constrained their ability to interact with others, causing her not to attend church. This is what she had to say: "...When the colostomy bag becomes heavy, the plaster tries to detach which causes leakages on me. I do not attend church now; I used to but have stopped..." (CP006). She added that those who may not know she has colostomy might touch the colostomy

which could cause problems for her: "...but those who do not know about my condition may touch the colostomy site, which may create a problem for me. Therefore, I do not attend church services. I do not attend any gathering because of the colostomy..." (CP006). Another argued how the colostomy has altered his way of interacting with others and limited his ability to attend programmes he is invited to:

"...Also, I always smell offensive because of the odour, even when I cover myself with a cloth while sleeping. So, I can't go out... I am a very sociable person, liked by people. I am scared that someone unknowingly may hug me and smell the odour. Therefore, when I am being invited for a programme I do not attend..." (CP010)

Besides, participants who were married recounted that the creation of their colostomy has resulted in challenges in their marriage. CP004 and CP005 for example indicated that their relationships with their partners have been unstable since their colostomies were created:

"...Since the creation of this colostomy, my fiancée, took care of me until I was discharged from KATH. After my discharge, he broke up with and has stopped taking care of me... he said I have made him spend too much money on the creation of the colostomy..." (CP004)

"...I used to go there [his wife's place]. Even last week, I went there two times. For more than one year now, we have not been together... We have not been together since the colostomy was created." (CP005).

Unlike other participants who withdrew and isolated themselves, for CP006, his withdrawal from his nuclear family was initiated by his wife's family. He narrated his experience saying: "...The family of my wife has prevented refused the lady bringing the child to me because of my condition... They said there are some rituals for me to do before they can allow the lady to bring the child to my house. Even when I call my wife, she tells me they will be coming to my house but they never come..." (CP006). He further cited an instance where he was exploited economically using his child's health which might not have happened in the absence of the colostomy, and he was close to his nuclear family: "...One day she called me that the child was sick, not knowing it was a lie. She had planned with the mother to take my money. I sent her the money not knowing the child was not sick" (CP006). Similar to CP006's situation, CP0015 who was initially socially active and the outgoing type changed when his colostomy was created. According to him, he has withdrawn himself from such types of interactions even with his family members due to the possibility of disgracing himself (colostomy leaking) during public gatherings. His situation is even worsened by the fact that the performance of his fatherly roles towards his children have been altered:

"Since the colostomy was created, I do not go for gatherings anymore. I was the outgoing type that goes out with friends and my family. But now, I am always at home because if I am not careful with it, I disgrace myself among gathering... I used to send my children out for outings a lot. However, since the creation of the colostomy, I am not able to do that again. My children always ask when I am taking them out. I have to forge excuses for them..." (CP009)

These findings depict situations where individuals with colostomy could not engage in social interactions publicly and even with their families. Garnered from this study is the fact that colostomy presents individuals with challenges in terms of social connectedness and social functioning. This could have implications for the mental health [50] of those living with either temporary or permanent colostomies.

Sex-related challenges:

The sexual functioning of individuals with colostomy was affected. This was mainly due to an altered sexual desire. For instance, CP010 explained how his normal pattern of intimate sexual life with his partner was affected since his wife is scared of the stoma: "My wife says she is afraid of the colostomy. I do not want to force her to have an affair with her. Therefore, since the creation of the colostomy I have never had an affair with my wife..." (CP010). This was supported by a female participant, CP011, who revealed that her feeling for sex has been altered, and she sees herself to be sexually unattractive because of the faeces she has on her:

"As for sex, I do not have any feelings for it. Looking at myself, I am always having faeces on me. How can I enjoy sex? My husband even understands. For more than a year now I have not had any sexual intimacy" (CP011).

From the above, such impairments could have numerous implications for couples. Health wise, not having sexual intimacy could affect Colostomates and their partners since it could trigger distress. Female Colostomates for example, who could not offer sexual satisfaction to their partners might feel insecure since their partners are likely to seek such services elsewhere. This could contribute to heightened sorrow for such persons. Sociologically, sexual intimacy between married couples is seen to facilitate procreation and lineage continuity for men, especially in the Ghanaian traditional society. Such impairment in this regard implies that the primary role of the family as an institution of procreation and family continuity becomes impossible in a way.

Psychological experiences and challenges:

This sub-theme comprises psychological risk factors experienced by individuals living with a colostomy. Almost all but two participants show that the colostomy has serious psychological and behavioural implications as suggested by [50]. Participants bemoaned that they are worried and depressed because of the leakages and odour associated with the colostomy. This was described by some participants as follows: "I have a very bad feeling about the colostomy... Everything about the colostomy is bad, leakages, odour..... am worried and depressed." (CP005). The reasons informing such worries and psychological disturbances were advanced by some participants, CP005 and CP009, who emphasised the leakages and inability to nurture their children respectively:

"...Sometimes when I am walking and faeces leak out of the colostomy bag, it disturbs me a lot... Because of this leakage I sometimes feel so ashamed of myself. I am not happy at all. It is not easy at all to live with this condition... it really disturbs me and get me depressed." (CP005)

"...Sometimes I feel very sorrowful. The way I used to cater and nurture my children but I cannot do that anymore. It is worrying ooo..." (CP009)

Anxiety was also observed among some participants. These apprehensions characterising the emotional and psychological wellbeing of individuals with colostomy emanate from the notion that there is the prospect that doctors might not be able to reverse the stoma created, as espoused by CP010:

"I think a lot about this colostomy. It has given me sleepless nights. Sometimes I say in case they decide not to reverse it, what will I do? I will think a lot about this colostomy. I am not happy with the colostomy at all..." (CP010)

Here, the findings portray how negatively the psychological and mental health of individuals living with colostomy were threatened by their challenges and experiences.

Suicidal ideation:

In addition to the psychological impact participants faced, a few of them expressed how least resilient they could be. They indicated that because of how depressed, worried and, how anxious they were concerning the future made them physiologically vulnerable to suicidal intentions. According to them: "...I have a lot of bad feelings with the colostomy. Sometimes I even feel like ending my life because of this thing..." (CP008). This was affirmed by another participant: "I think a lot sometimes... Sometimes I feel like taking medicine to kill myself..." (CP011). Suicidal intentions of persons living colostomy as documented in this study is not startling. As emphasised in the literature on resilience, mental health, and suicide, when persons living with colostomy have low psychological resilience it increases their poor mental health (depression, anxiety, and negative emotions), and predisposes them to suicidal intentions [51, 52]. Thus, positive emotions are important in the resilient ability of Colostomates to rebound from their stressors.

Physiological experiences and challenges

Aside from earlier experiences and challenges highlighted above, physiological risks were emphasised by participants to threaten their wellbeing. One sub-theme evident in the accounts of participants related to their experience of pain. As explained by CP002 for instance, she experienced a bloated abdomen and pains at the stoma site: "...The problem occurs when my abdomen gets distended... I am also experiencing pains at the incision site as a result of the colostomy." (CP002). The experience of physical pain reverberated in the comments of CP010 when he was recounting his lived experiences with a colostomy. He had this to say: "...Sometimes too my abdomen could pain me a lot." (CP010)

Another health problem encountered by persons living with colostomy was the absence of physical strength. One of the participants described how unhealthy she is after the stoma was created: "...the colostomy has made me unhealthy. I am always shivering when I am trying to walk..." (CP002). When asked if it was because of the stoma created, she confidently answered: "Yes... I was well until the colostomy was created." (CP002). CP010 reiterated while explicating her condition because she could not eat as required: "...I'm not strong anymore. How can I be strong if I do not eat as I used to? If I eat hard food, I get constipated faeces. Because of that, my energy level is down. Most of the times I am very weak. (CP010). She further showed how her physical appearance has been "The colostomy has also changed me a lot physically. Even my appearance has changed..." (CP010)

Dietary/eating challenges:

The absence of physical strength and ensuing poor health expressed by participants was found to be due to decisions made concerning their diets. For instance, participants highlighted that they stopped eating high fibre diets, green leafy vegetables as well as gas producing foods such as beans, egg, and milk. This was a self-initiated approach to control flatulence, bowel movement and leakages. Consequently, the nutritional status and physical strengths of these Colostomates was compromised. This is illustrated in the quotes below:

"Mmm... now, the food I eat has even changed. The moment I eat corn foods or 'kontomire'¹, the colostomy gets filled up and the faeces will just start to leak on me, no matter the amount of Imodium I take, the faeces will not constipate. When that happens, I could apply about five bags for a day. So, for now, I do not eat corn foods unless refined corn foods. Although they were my favourite foods..." (CP011)

"Beans, eggs and milk are protein food and nutritious, but I get bloated and pass out air frequently, hence, I have stopped eating them." (CP009)

"I stopped eating foods that contains a lot of fiber and green leafy vegetables although I used to like them a lot. I stopped because when I eat them, I experiences a lot of diarrhoea and stomach pains." (CP008)

The above submission suggests that for some persons living with a colostomy, diets must be carefully chosen to avoid challenges associated with caring for the stoma. This brings to bear another challenge faced when caring for the stoma as discoursed below.

Difficulties caring for colostomy:

The findings revealed further that some participants had difficulties caring for their stoma. This is because some participants did not receive education on how to dress their stoma prior to their discharge and visits to the hospital. This was typified by a participant, CP011, who argued that he had problems applying the colostomy bag on his stoma personally, despite several attempts at learning how to do it:

"...Even today before the arrival of the ostomy nurse I could not dress after bathing. I only have put wipes on it and waited for her. I have tried on my own to learn how to apply the colostomy bag, but I am not able to. I was not taught how to do it during my discharge." (CP011)

CP001 narrated the difficulty faced in taking care of her stoma, even at the hospital when the stoma was initially created: "...When it was first done at KATH, the doctors said the stoma has a gap (dehiscence). They could not use the colostomy bag on the stoma... So I am not able to do it on my own."

Skin disorders:

Skin allergies from leakages and stoma care-related accessories such as plaster were recognised among some participants. In some situations, participants were presented with the difficulty of determining which plasters their skin was allergic to, and this could be known only when they get rashes from using specific plasters, as explained by some participants:

"...Other times too, the plaster could give me rashes when I use the one my body is allergic to. Mmmm... for this condition, it is not easy living with it..." (CP006)

"...I get rashes on my skin when the colostomy leaks." (CP003)

However, these skin irritations depended on the duration of the colostomy bag, and leakages of the faeces on the skin. To CP005, he starts to experience rashes when he uses a colostomy bag for a very long time due to monetary constraints:

"...But at times when I do not have money, I buy the ones that cannot be opened. I wear it for a long time which gives me a lot of rashes around the skin of the stoma." (CP005).

The problem of skin irritations caused by the leakage of faecal matters on Colostomates skin was identified in the narratives of another participant who explained that her stoma had a gap, making it impossible for the stoma bag to be used, causing leakages which in turn resulted in skin wounds: "...They were using pampers, any time it gets to soak it pours on my skin; this gave me many wounds... I could not even use the normal adhesive plaster because it gives me..." (CP001). This finding from participants, especially on the difficulties faced in caring for their stoma gives credence to the fact that not only are stoma accessories important, but financial prowess as well.

Cost of colostomy accessories:

The cost of care and stoma care-related accessories were found to be a major economic challenge encountered by individuals living with a colostomy. Although the National Health Insurance Scheme (NHIS) is one of the initiatives in the healthcare sector that reduces the cost of healthcare for Ghanaians, the case was different for those with a colostomy. The NHIS policy does not cover some health conditions with colostomy surgeries inclusive. Due to this, participants have to bear the high cost of colostomy bags and other commodities needed to care for their stoma. One participant explained this: "...Also, we buy everything; the gloves, the normal saline, the wipes, the colostomy bag - everything I buy to clean the stoma... The NHIS does not cater for the cost of anything when I go for reviews" (CP002). She added the cost incurred when dressing her stoma at the hospital daily, suggesting that financially, those with colostomy are burdened: "...Even when I go to KATH to dress the stoma, they charge 20 Ghana cedis [USD 2.7]... So, if I decide to dress it every day, each day is 20 Ghana cedis [USD 2.7]. Just imagine the cost involved for this for the months that I have lived with it..." (CP002).

The cost of the colostomy bag was noted to be expensive according to participants. To CP003, changing her colostomy bag frequently, i.e., every three days coupled with reviews, require lots of money. And this had burdened her financially. She indicated:

"The colostomy has really affected me financially changing the colostomy bag every three days. All require money... and the reviews charges as well." (CP003)

The high-priced colostomy bags which pose financial burdens on participants was further reiterated by another participant. To him, he required 7 colostomy bags during his travel but could not afford that since it is very expensive: "...The colostomy bag is very expensive, and I cannot afford seven colostomy bags in order to travel..." (CP004). This evidence explains that adequate financial resources are central to proper stoma care (i.e., frequent change of colostomy bags and use of adhesive plaster with no or less discomfort). This denotes that individuals without sufficient money could not afford proper and comfortable care for their stoma, as seen in the following response by CP011:

"The colostomy bag too, it is very expensive, 20 Ghana Cedis [USD 2.7] for one. I could not even use the normal adhesive plaster because it gives me rashes. The one that is good for me is about 120 Ghana Cedis [USD 16.7]. I buy one each month." (CP011)

Work restrictions:

The financial constraints faced by persons living with a colostomy, and their inability to afford high-priced stoma accessories are tied to the fact that they are not able to work. While participants were mainly employed in the informal sector, they were faced with work restrictions. Persons living with colostomy found it difficult to work after the colostomy was created for them. CP010 who was a farmer before his condition shared how the colostomy prevents him from working, affecting him financially:

"I am not able to work with the after the colostomy. I am a farmer but I'm not able to work with it, it has really affected me financially... Most of the times I am very weak and not able to do work on the farm again. (CP010)

A participant, CP006 explained how his condition results in loss of job opportunities from his customers: "Before the colostomy was created, I used to do carpentry work but after the colostomy, I don't get work to do anymore." He claimed additionally that upon customers getting to know his condition, he

losses these job opportunities. These customers are of the view that they fear complications could arise from honouring their requests and might be blamed for such complications. Hence, they will not even attempt to offer him any work opportunity in the first place:

"...My customers feel I may get injured if they give me work to do... mmm... people say maybe when I climb up it may cause more injury, so I should wait until the colostomy is returned. I sometimes feel I can work but my customers are scared that if they give me work to do and an injury occurs, to them, the public may blame them. So, nobody gives me work to do." (CP006)

Complications characterising the use of a colostomy condition vindicated the notion held by CP006's customers. Some participants confirmed that they experienced severe waist pains in an attempt to perform some work duties: "...when I bend down and get up after picking my working tools from the ground, I feel so much pain at the site of the stoma" (CP005). He explained however that this restricts his roles at construction sites when called by his friend to work with them, to avoid serious complications: "...Even sometimes they want me to also climb up for the construction work but I do not because I am scared it may bring me many problems. My friends sometimes get annoyed but I do not climb." (CP005)

4.2.2 Coping strategies (protective factors) of colostomy patients

The experiences and challenges outlined above notwithstanding, persons living with colostomy continue to negotiate such challenges and experiences. This section highlights responses on the colostomates' sources of resilience to these risk factors (experiences and challenges associated with living with a colostomy). That is the protective or promotive factors that enhance the resilience of colostomates. Five sub-themes are identified: (i) social support; (ii) spirituality and religion; (iii) lifestyle modifications; (iv) nutritional and pharmacological strategies; and (v) improvised stoma accessories.

Social support:

This theme addresses the support persons living with colostomy received from their families, friends, community members, and religious institutions (churches). The findings depict that social support extended to participants was multidimensional and varied in terms of the source. Most participants received support in the form of physical care and financial assistance. Some participants, CP001 and CP003, indicated how instrumental financial remittances from families and friends contributed to their resilience:

"...What helped me is that most of my family members lived outside Ghana. They bring me money for my care. So, I am able to pay the stoma nurse who comes home to take care of me every other weeks..." (CP001)

"...It is my friends and my classmates that support me. Please, it is my friends that send me money. When it is time for me to come for review, I call my friends and they send me money... Mmmmm... my father is a cocoa farmer, but his farming is down now. He is always borrowing from people to assist me for review and cater for me when my friends do not send me money." (CP003)

Different kinds of care, aside from financial support, were identified as a form of support provided to participants. These were shown among some participants, CP011, and C005 for instance, who detailed the kind of care support they receive from others: While CP005 shared that he gets food from his sister, CP011 however was physically cared for, having his colostomy dressed and the bag applied by his daughter:

"...My elder sister, when she cooks, she gives me some to eat..." (CP005); "...I have a daughter who is at the nurses training school, so she sometimes comes home to dress the stoma and applies the colostomy bag for me..." (CP011)

Moreover, one participant added that he was given information on how to care for his stoma and control the bad odour. His narrative explains that, unlike the others who obtained instrumental supports, his was augmented with informational support:

"...It is the nurses who dress the stoma that tells me that if I do not keep the stoma clean, it will smell. They also teach me how to dress the stoma and control the odour... I can now do it myself at home" (CP006)

As well, a few participants made it known that they received emotional support from others. This includes calling to check up on them and encouraging them amidst their woes. This was shared by some participants as follows:

"...As for my church... but they sometimes call to find how I'm doing." (CP002); "...My pastor sometimes calls to enquire about my health and encourages me emotionally." (CP008)

"...One stoma nurse really helped me and gave me words of encouragement. He was the one who has made me who I am today..." (CP004)

These findings are consistent with literature [53, 54]. These studies opine that social support is in four forms: emotional, instrumental, appraisal/evaluative, and informational. In this study, however, supports received by persons living with colostomy reflected the characteristics of emotional support, instrumental support, and informational support, mainly from three sources including friends, family, and significant others.

Spirituality and religion:

According to the findings, participants expressed hope and faith in God as a major source of resilience to cope with adversities associated with their condition. Their responses express the fact that persons living with colostomy rely on their religious beliefs to cope with the challenges they are subjected to. This is illustrated in the expressions below:

"...I am only praying for the day that the colostomy will be returned for me, for everything to be normal for me." (CP010); ...I am only praying that I get money so that when the time is due, the doctors will reverse it for me." (CP003) ...I have a lot of hope that God will help..." (CP001)

Some participants, in affirming how their faith helps them to cope with their experiences and challenges, cited instances that make them take solace in God and their religion:

"...When I encountered this colostomy, I realized that my God has power. When the colostomy was created at KATH, I was on admission with one woman at C4. Her colostomy was created at another hospital. She came to me to inform me that she is awake from bed, it is left with me. Just a day after, the nurse informed me that she is dead. The nurse also added that for you God loves you. So, I have hope that God has saved me, it is left for it to be manifested for human beings to see." (CP003)

"...But I know God does what he wants. Yes, I have 100% hope in Christ. If not Christ, where would I have been by now? When I was still on admission, a friend of mine was bitten by his puppy and he died. But for me, I was shot at my abdomen and my intestine protruded out. But I'm still alive. I have a lot of hope in Christ." (CP006)

Confirming the use of spirituality as a coping mechanism, CP010 explained how his faith manifested in situations where he was hard-pressed financially: "...it is God who is my helper. Sometimes when I don't have any money, when I cry to God, before I realized, He will just bring someone to assist me." (CP010)

Self-acceptance/accepting one's condition:

To remain resilient in the face of their experiences and challenges, the choice to accept one's condition (i.e., stoma condition) was identified among some participants. This psychological adaption expressed by participants portrays how willing they are to adjust their life to cope with the stoma. This was shown by CP010: "...Though I'm unhappy about it, I have to accept it and wait for the day they would close it for me." Another participant added: "...Mmmm... I accept it like that because it has already happened..." (CP006)

Lifestyle modification:

For some participants, lifestyle modification was used as a strategy to cope with the challenges faced. This technique was popular among individuals who experience stigma from other members of society, and leakages. One lifestyle modification strategy used by participants was to confine themselves at home. For CP006 however, he had to confine himself in the room due to how his colostomy bag leaks: "... and stay at home." In most parts of Ghana, it is difficult to access public places of convenience (i.e., toilet facilities), which in the case of these participants, is not helpful. Also, the design of public toilet facilities is not Colostomates friendly, hence participants modified their life to be more home bound. This was confirmed by another participant, CP001, who stated that she stays at home so that she can easily empty the colostomy bag when it is full: "...I normally stay at home so that the moment the colostomy bag is full, I can easily empty it into my closet. You know our public toilet facilities have no privacy and resources for this...". For CP001, and CP005, aside from staying at home, when it is necessary to go out, they change the kind of dresses and style of the dresses they wear and wear corsets to make the colostomy bag less visible or invisible to others:

"...I have even changed my dresses to maternity gowns so as to make it invisible to the public..." (CP001).

"I go out, it is just that any time I want to go out, I put on a corset especially if I want to be among gatherings. This is because the colostomy bag bulges out when it is filled with faeces or air. So, when I put on the corset, it reduces the bulging out of it." (CP005)

Findings on modification of one's dresses and dressing style as documented in this study support the concept of camouflage, as a means to address social withdrawal and isolation. Similar to literature [55, 56], persons living with colostomy exhibit behaviours comprising masking or hiding aspects of their body (i.e., stoma) from other members of the public using clothing.

Nutritional and pharmacological strategies:

With this strategy, some participants who lived with colostomy relied on medications prescribed for them by health experts, and dietary modifications to remain resilient amidst the challenges faced with leakages. For example, CP004 and CP006 explained how they coped with leakages by taking medications such as Imodium to constipate the bowel:

"...The problem occurs when my abdomen gets distended but I try to manage it with the medicine." (CP002)

"...I take Imodium so that I can constipate for the faeces not to leak on myself. It was prescribed for me by the hospital." (CP004)

Besides, participants who desired to attend social gatherings took these medications to cause them to constipate throughout the period they spend outside their homes:

"When I am about to go for weddings that I think the colostomy may bulge out, I take Imodium and DF118 (Dihydrocodeine), about one tablet each. It was prescribed by my doctor but I take it because I know it causes constipation and that may help my outing. I don't take it every day but when I am going out, I take it. When I take it, the faeces constipate so throughout the day I don't see any faeces." (CP003)

While others relied on medications, some participants also modified the contents of their diets. This approach is evidenced in the responses of CP010 and CP011 who explained:

“For now, I don’t eat roughage-based foods..... This has reduced my bowel movement drastically... ” (CP010)

“The moment I eat corn foods or ‘kontomire’, the colostomy gets filled up and the faeces will just start to leak on me, no matter the amount of Imodium I take, the faeces will not constipate... So for now, I do not eat corn foods or roughage diets unless refined corn foods. Although they were my favourite foods.” (CP011)

Improvised stoma accessories:

To cope with the highly expensive colostomy bags which were unaffordable to participants, improvisations were made. Diapers were used as substitutes for the colostomy bags till participants could afford to purchase a colostomy bag. CP006 describes how he uses diapers when he has no money to purchase a colostomy bag:

“...Even I was left with only one colostomy bag that I apply to come here for the interview. Sometimes, when I don’t have money to purchase the colostomy bag, I use the adult size diapers. I apply the adult diaper around my waist...” (CP006). He added that in most situations, he is given a colostomy bag on credit by a nurse: “...Most at times, I get some of the colostomy bags from the colostomy nurses on credit... It is one of the ostomy nurses who has been giving me some on credit. Even currently, I’m owing her.”

In the same vein, CP008 also confirmed using diapers and purchasing colostomy bags on credit from health providers, when he has no money to buy a colostomy bag:

“...Other times too I even use the adult diapers as colostomy bags if I do not have money to purchase a colostomy bag. I sometimes even buy the colostomy bag from the nurses on credit...” (CP008)

¹Kontomire also known as Taro leaves in English, is a leafy vegetable mostly used in preparing Ghanaian dishes. Usually, kontomire serves as an accompaniment to dishes like yam, rice and even used in preparing soup in some parts of Ghana. The word ‘kontomire’ is of an Akan origin.

Discussion

The study has highlighted the experiences and coping mechanisms of persons living with colostomy in Ghana. We conceptualized that the social stigma combined with the social isolation and withdrawal experienced by participants served as risk factors; conditions that could threaten the capacity of persons with colostomy to remain resilient. This is because in this study, the findings showed that family members, friends with other members of society stigmatised against persons living with colostomy. However, an important source of social support to individuals within Ghana are family members and friends [57, 58]. Hence, being socially stigmatised by these group of persons could have significant implications for the wellbeing and self-esteem of Colostomates. Moreover, isolation and withdrawal from families and society due to one’s colostomy condition can be a source of risk and affect the resilience of persons with colostomy since the availability of social support or lack of it has implications for resilience [57]. These findings, thus, have implications for health professionals, especially, public health workers to create public awareness on colostomy and stoma conditions and encourage family members, as well as significant others of persons living with colostomy to provide support. The resilience of Colostomates were also challenged by their inability to engage in sexual activities, having implications for procreation and family continuity, a function of the marriage and family institution that is much emphasised and prioritised within the Ghanaian traditional society [59, 60]. Poor psychological health was identified among Colostomates in this study which manifested in the form of depression, shame, worries and anxiety and subsequently suicidal ideation. This is because their condition was characterised by leakages, odour, inability to cater for their dependents (i.e., children), and uncertainties regarding the likelihood of the stoma being reversed. These findings are consistent with that of earlier studies that found evidence of worry, anxiety, depression and suicidal intentions among persons living with stoma-related conditions such as colostomy [13, 61]. Findings on the poor psychological health among Colostomates underscores the need for a multidisciplinary team-based care approach to the management of colostomy within the Ghanaian context. Such a team may include clinical psychologists, social and palliative care workers to meet the multidimensional needs of patients. In addition to the above experiences and challenges, Colostomates faced challenges with their diets since they had to intentionally restrict themselves from some nutritious diets. This involved not eating gas-producing foods such as protein-based foods including eggs, fish and beans which may result in bloating and increased flatulence, as well as avoiding higher fibre foods owing to the fear of frequent bowel movements and potential leakages, thus posing a negative effect on their physical strength and health. Among the physiological risks encountered by participants in this study include pains, bloated abdomen and abdominal pains. Similar to the findings of prior studies [62, 63], Colostomates in this study further shared the difficulties they faced caring for their stoma. This was linked to the lack of skills in self-caring for their stoma. Unlike their counterparts in developed countries, Ghana lacks trained stoma nurses, hence, participants in this study did not benefit from meaningful support and discharge preparation towards the management of the stoma at home [64–66]. Furthermore, limited resources, particularly the financial inability of participants, was identified as a risk factor posed to the resilience of Colostomates [62]. For example, participants revealed how financially incapable they were to afford the stoma bags and related accessories. As a result, the frequent change of stoma bags and accessories were constrained. These challenges were due to the absence of work and income since Colostomates were unable to work because of their stoma and associated complications. The fact that participants were mainly informal sector workers (i.e., self-employed), characterised by low returns could explain their inability to frequently afford stoma bags and accessories which are highly priced. Another reason is that Ghana’s current National Health Insurance Scheme (NHIS) does not cover the cost of colostomy care, suggesting that such costs are catered for by patients and in some cases, their network relations. This highlights the need for support in terms of health policies and support from the social welfare department. These negative

experiences and challenges highlighted by Colostomates in this study are risk factors according to the theory of resilience, which threatens the wellbeing of those living with either permanent or temporal colostomy conditions [26].

The above notwithstanding, Colostomates in this study revealed significant protective factors, which enhanced their resilience and helped deal with risk factors faced by them. The protective factors they possess have characteristics of both assets and resource as opined by [27] and [29]. For Colostomates, religious beliefs serve as important inherent factors that encourages resilience. As shown in this study, even amidst the negative reactions (i.e., stigma and isolation) from families, friends and society, psychological challenges, and limited resources characterising their experiences, religious beliefs facilitate the survival of Colostomates. This is because religion constitutes an integral component of the Ghanaian society that guides social interactions and facilitates the Ghanaians worldview. This therefore means that it is practically impossible to alienate Ghanaians from their religion [67]. The study portrays how religion and religious beliefs offer positive reflections and thoughts for Colostomates, making it an essential resilience mechanism to them. This makes it possible for them to possess features of resilience including perseverance, optimism and determination [27]. Another important asset used by participants in this study to cope with their negative experience was self-acceptance. This serves as form of psychologically adaptive mechanism that facilitates resilience. This confirms the findings of [68] who found that stoma self-acceptance was used as a coping strategy among a sample of Chinese patients. Numerous lifestyle modification strategies were revealed in this study. These include confining one's self at home.

Confinement becomes an option since public toilet facilities are not friendly to persons with colostomy. The nature of these toilet facilities does not offer an opportunity for Colostomates to empty their stoma bags with privacy. There is thus the need for public facilities to have avenues for persons living with colostomy, to enhance their adjustment with their condition while sustaining their ability to interact with their society. Camouflaging, where specific kinds of dresses are used to make the stoma and stoma bag invisible or less visible to others was noted. This strategy (i.e., camouflaging) helps Colostomates to socially integrate and become less withdrawn or isolated from society [55, 56]. Challenges associated with frequent bowel movements and leakages were addressed using dietary modifications and medications. This strategies aided some of the participants to attend social events. Since most colostomates could not afford stoma accessories to enhance their ability to care for their stoma, such accessories were improvised. This involves the use of diapers, plastic bags, pieces of clothes as stoma bags and in some cases, procure these accessories on credit. Thus, prior findings highlighting that patients with stoma commonly adopted plastic bags, cloth and leather pieces [64] was hence confirmed in this study. When faced with challenges, a person's support networks could facilitate resilience. A major resilient resource employed by colostomates in this study was social support. These include emotional, instruments and informational supports [53, 54] from family members, friends, religious body, and significant others. This is because in the Ghanaian sociocultural context, collectivist values where long-term commitments to each other and responsibilities towards 'in-group' members (i.e., be it a family, extended family, or extended relations) are considered important and accepted by all [69].

Conclusion

Experiences and coping strategies of persons living with colostomy in Ghana has been illuminated in the present study. Colostomates in Ghana face numerous challenges which pose risks to their wellbeing. Significant challenges were faced with caring for the stoma, and affordability of stoma accessories. This has implications for policy interventions. Patients and their families need to be given pre-and-post-operative education to enable the acquired skills in self-care and capacity to assess stoma-related conditions. This further has implications for the recruitment of nurses specialised in stoma care, and provision of specialised stoma care training. Insurance-funded systems could be expanded to cover the cost of colostomy treatment either in whole or in part by the Ghanaian government. Furthermore, the study revealed stigma against colostomates. While it is important to enhance the resilience of persons living with colostomy, it is equally important to address the sources of challenge (i.e., stigma) that demands their resilience. It is important that public education on stoma conditions be provided to Ghanaians to ameliorate the stigma attached. This should further be supported by the need for network members, particularly family members to be involved in collaborative homecare programmes for managing colostomy. Thus, understanding the source of resilience among persons living with colostomy within the context of a resource-constrained setting could form the basis for stoma patients' resilience, while instigating new strategies for healthcare practice for persons who undergo stoma surgeries.

Study Strengths And Limitations

We acknowledge some limitations. The study was limited to one tertiary health facility and the views of only participants accessing the colostomy clinic were captured due to eligibility. However, the study provides rich and in-depth information on participant's experiences and challenges as well as coping strategies of colostomy within the socio-cultural context of Ghana, strength of qualitative research. The findings can be used to improve colostomy care in Ghana and other countries with similar context. Further, all the participants were diagnosed a few months to years prior to being interviewed, hence, retrospective recall may affect accuracy of shared information. However, participants were recruited at different periods of diagnosis and similar experiences from participants with recent and past diagnosis were heard. The study highlighted existing challenges faced by persons living with colostomy, needing urgent attention. To our best of knowledge, we are the first to report on the phenomenon in Ghana. Our findings may have implications for practice guidelines and policy on colostomy care in Ghana.

Declarations

Ethics approval and consent to participate

The study was approved by the Komfo Anokye Teaching Hospital Institutional Review Board (KATH IRB) (CHRPE/AP/236/20). All methods used for data collection, management and analysis as well as reporting of findings were carried out according to the Declaration of Helsinki. The participants received written information about the study, their informed consent was sought through writing and participation was voluntary and anonymous.

Consent for publication

Not Applicable (NA)

Availability of data and materials

All relevant dataset on which conclusions of this manuscript were made are within the manuscript.

Conflict of interest

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Authors' contributions

ABBM: Conceptualization, methodology, data curation, formal analysis, investigation, project administration, supervision, validation, writing – original draft, writing – review & editing

VYD: Conceptualization, methodology, data curation, formal analysis, investigation, project administration, writing – review & editing

EA: Methodology, formal analysis, writing – original draft, writing – review & editing

KBM: Conceptualization, methodology, supervision, validation, writing – original draft, writing – review & editing

GK: Investigation, Supervision, writing – review & editing

FA: Writing – review & editing

V.M.D: Writing – review & editing.

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Tables

Table 1: Participants' profile

No	Participant code	Age	Sex	Marital status	Colostomy type	Duration of stoma	Number of children	Religion	Occupation	Languages Spoken	Educational level
A	CP001	26	Female	Divorced	Temporal	6months	one	Christian	Learning a vocation	Twi	Primary
B	CP002	28	Male	Married	Temporal	7months	one	Christian	Carpenter	Twi	primary
C	CP003	18	Female	Cohabitation	Temporal	6months	one	Christian	Learning a vocation	Twi/Bono	primary
D	CP004	58	Male	Married	Temporal	3months	four	Christian	Farmer	Twi/Bono	primary
E	CP005	39	Female	Married	Temporal	9months	two	Christian	Hair beautician	Ewe/Twi	primary
F	CP006	37	Male	Single	Temporal	12 months	one	Christian	Commercial driver	Ewe/Twi	SHS
G	CP007	42	Female	Married	Temporal	4Months	two	Muslim	Trader	Twi/Hausa	Primary
H	CP008	39	Male	Divorced	Temporal	12 months	one	Christian	Trader	English/Twi	SHS
I	CP009	38	Female	Married	Temporal	8months	two	Christian	Caterer	Fanti/Twi	primary
J	CP010	40	Male	Married	Temporal	9 months	one	Christian	Trader	Twi	primary
K	CP011	38	Female	Divorced	Temporal	10 months	two	Christian	Seamstress	Twi	primary
L	CP012	39	Male	Married	Permanent	4months	three	Christian	Commercial driver	English/Twi	Primary
M	CP013	56	Female	widow	Permanent	3 months	Three	Christian	Trader	Fanti/Twi	Commercial school
N	CP014	50	Male	Married	Temporal	5 months	Four	Christian	Trader	Twi	Form 4
O	CP015	65	Female	Married	Permanent	19 months	Four	Christian	Pastor	Twi/English	Form 4

Table 2: Main theme and sub-theme

SN	Main Theme	Sub-themes
1	Experiences and challenges (risk factors) of colostomy patients	<ul style="list-style-type: none"> i. Social stigmatisation ii. Social isolation/withdrawal iii. Sex-related challenges iv. Psychological experiences and challenges suicidal ideation v. Physiological experiences and challenges vi. Dietary/eating challenges vii. Difficulties caring for colostomy viii. Skin disorders ix. Cost of colostomy accessories x. Work restrictions
2	Coping strategies (protective factors) of colostomy patients	<ul style="list-style-type: none"> i. Social support ii. Spirituality and religion iii. Lifestyle modifications iv. Nutritional and pharmacological strategies v. Improvised stoma accessories

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