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Lived Social Experiences of Ostomates in Ghana: A Phenomenological Study in the Accra Metropolis

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Abstract

Aim: Stoma involves the clinical removal of an affected or diseased portion of the large or small intestine whilst the remnant intestine is fixed to an opening in the stomach, causing normal bodily waste leakage. This paper explored the social experiences of ostomates in order to appreciate their challenges and inform well targeted policies and intervention to enhance their livelihoods.

Methods: A phenomenological lens based on Heidegger's philosophy was used to inform the design of this study. The study was carried out in the Accra Metropolis. The study was conducted with patients with ostomies who were discharged home from the Korle Bu Teaching Hospital (KBTH) living in the Accra Metropolis. A total of nine (9) ostomates were purposively recruited and interviewed. Pseudonyms were used in reporting the finding. Ethical clearance were obtained from the University of Cape Coast Ethical Review Board ethical and KBTH ethical committee.

Findings: the participants reported that, ostomates involvement in social activity was affected. For them getting involved in social activities meant having to deal with the incontinent nature of the ostomy in a less controlled environment and this deterred most participants from engaging in social activities. Ostomates avoided friends, public places, travelling in a public transport system. The study revealed that participants changed several aspects of the way they did things.

Conclusion: In conclusion, despite the enormous challenges ostomates faced, it is worth noting that they received support in carrying out their domestic chores and other activities from family members, friends and church members.

Keywords: Ostomy; Stoma; Social Experiences; Healthcare; Quality of life

Introduction

The it is estimated that about 700,000 Americans ranging from infants to senior citizens have had faecal or urinary ostomy surgery [1]. An ostomy is a surgical procedure in which there is the externalization of a hollow organ such as the intestine or bladder, through a hole in the abdomen called stoma [2]. The presence of a stoma generates dependency of the collector bag of faeces or urine. There are three main types of ostomies- colostomy, ileostomy and urostomy. Either type of stoma may be temporary or permanent. Constructing an ostomy is usually undertaken for a number of conditions, some of them are due to congenital problems, such as anorectal malformations; others are due to disorder or other reasons for failure to function: bowel neoplasia, inflammatory bowel diseases, severe idiopathic constipation, intestinal blockage or internal injury [3]. This procedure (ostomy) is carried out to maintain the function of elimination and causes various changes that may negatively affect the physical, psychological, social and sexual health of people who may have to live with this condition [4].

Surgery may change the way people perceive themselves, physically and psychologically. People with ostomies present difficulties resuming their daily activities, resulting in decreased quality of life and there may also be difficulties related to self-care, body image, sexuality, modes of dressing and interpersonal relations [5]. Individuals often feel stigmatized by the presence of the stoma, and choose isolation as a form of hiding their bodies, now dependent on equipment and without sphincter control [6]. Living with a stoma often causes feelings of fear, anguish and insecurity after hospitalization. Patients could act and adapt themselves to the existence of a stoma better if their forthcoming problems were discussed properly before surgery [7].

The individual, after a stoma creation, undergoes a loss of control of elimination of faeces and gases, and this type of control is a paramount condition for life in society [8]. It was demonstrated that 37%–47% of ostomates had problems related to work, sexual dysfunction, finance, family relations, and emotion. Additionally, >50% had a reduction in social activities. It is reported that patients who had a stoma for at least 6 months, perceived themselves to be socially different from others and were embarrassed by their condition; they deliberately avoided and feared social relations [9]. Studies that investigated problems of stoma patients in the postoperative period also reported patients experienced deterioration in their relationships due to the change in their body image and the new lifestyle limitations associated with their stoma [10]. There has been technological advancement in recent times to improve ostomy equipment, but the psychosocial problems, taboos, and stigma still exist [11]. It is found out that the fear of leakage caused by failure of appliances and inappropriate siting were daily problems [12]. Patients' main complaints were inability to control odours which leads to others' discomfort and subsequently staying away from them. Some individuals suffered from the thought that ostomy is contagious in the family or community.

Having a stoma presents a social issue that influences not only patients with the stoma, but also their partners, families, and close circles. In one study, it is reported that performing care together

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with one's partner has a positive impact on psychosocial adjustment [13]. In another study in Iran, write that ostomates reported having encountered family problems for a few months after their colostomy, which gradually improved with time [14].

Within the social well-being domain, problems with sexual intimacy have been reported. One study exclusively sought to identify and describe the challenges ostomates face in negotiating their sexuality around their incontinence [15]. Such difficulties include a decrease in the sexual activity or perceptions of the person with regards to his/her sexuality after creation of a stoma. Other difficulties included the adjustment of the ostomate's partner to life with a stoma. Several participants described the loss of intimate relationships or the inability to establish new ones due to bodily self-consciousness and feelings of being abnormal. Other challenges included finding a balance between enjoying a sexual act while monitoring the device for leakage. Health professionals therefore need to fully comprehend the life changing events of ostomised patients and their health needs in order to address these needs optimally. Thus, ostomy patients require targeted healthcare and multi-professional specialized follow-ups that meet their biopsychosocial needs and qualified nursing care, and these should be initiated in the preoperative period.

In spite of these, our extensive literature search seemed to reveal that scanty documentation exist regarding the social life and lived experiences of people living with ostomies in Ghana. No support systems are in place for patients with ostomies after discharge and no continuing education exist on ostomy after patients have exhausted their review dates. Further, the Ghana Health Service has no guidelines/policy for ostomates' wellbeing. The challenges of ostomates can be well appreciated if their subjective experiences are explored and well understood. In spite of all these, there is paucity of literature on social lived experiences of persons living with ostomy in Ghana and particularly in the capital of Accra, except the few in Northern Ghana which also failed to explore the social challenges [16]. This stimulates an apparent need to explore the phenomenon deeper with a qualitative design to extend knowledge and insights about the social lived experiences of ostomates from the Ghanaian context.

Material and Methods

Study setting

The study was carried out in the Accra Metropolis. It has a total land size of 200 km^2 with a total population of 1,848, 614 [17]. Participants were recruited from Korle-Bu Teaching Hospital (KBTH) because it is a multisite referral centre for the whole country where major surgeries like ostomies are mostly conducted. Recruitment was done at the Out Patient Department (OPD) of the Department of Surgery. This department is one of the earliest departments established in the KBTH for the purpose of surgery, consultancy, training and research.

Study design

The A phenomenological lens based on Heidegger's (1927/2010) philosophy underpinned this study. Phenomenology is a qualitative research methodology rooted in philosophy and psychology. The methodology does not attempt to provide an answer, but rather contributes to a description of how individuals' with the condition of interest live and their personal experiences [18].

Participants and sampling procedure

The study was conducted among patients with ostomies who were discharged from the KBTH and lived in the Accra Metropolis. Due to the qualitative approach of the study, data redundancy determined the total number of participants used. Data saturation occurs when no new themes or information are emerging from the data gathered [19]. A total of nine ostomates; six males and three females were included. Participants who were eligible for this study included individuals who had surgery for a temporary or permanent ostomy irrespective of the cause and had been discharged from the hospital for at least a month were considered as eligible for the study. Also, only patients who were 18 years or more and could consent to the study were considered for the study.

Selection of study participants

Purposive sampling was employed to recruit participants for this study. Purposive sampling technique, also called judgment sampling, is the deliberate choice of an informant due to the qualities the informant possesses. The researchers decided what needed to be known and set out to find people who can and are willing to provide the information by virtue of knowledge or experience. Ostomates who met the inclusion criteria were selected by a nurse at the surgical ward OPD to provide information on the phenomenon under study [20]. The data collected became redundant on the 9th participant hence 9 participants were included in the study.

Data collection procedure

The A nurse who was in charge of ostomy patients at the OPD identified ostomates who came to buy pouches for eligibility and notified them of the study. She also sought permission from them in order for the researchers to invite them to participate in the study. The researchers allowed a period of one week for participants to decide whether to participate in the study or not. Seven interviews were conducted in participants' homes, one in the office and another over the telephone per participant's request. Participants consented by signing or thumb printing consent forms before the commencement of the interview.

A face-to-face in-depth interview with 8 participants and one telephone interview were then conducted and recorded with a tape recorder with permission from participants. Privacy was ensured during the interview. During the interviews, participants smiled, chuckled, and laughed, but became moody at other moments of the conversation. These were written in the memos (or field notes). Memos were dated for easy correlation with the data. The researchers probed during the interviews to focus responses within the objectives of the study and also to obtain in-depth responses. Interviews ranged between 45 and 80 minutes. Each interview was transcribed verbatim and analysed on the same day of each interview. Participants were allowed to validate key issues at the end of each transcribed interview often the next day. This was done to ensure credibility of the findings. The interviews and analysis covered the period of June and July, 2017.

Analysis

Data analysis occurred concurrently with data collection [21]. This allowed the researchers to explore emerging issues deeper in subsequent interviews. Thematic analysis was used in analyzing the data collected. This is the process of identifying patterns/themes that are important or interesting and the use of these themes to address the research questions [22]. This method is not tied to any epistemological or theoretical perspective. Because of the heideggerian phenomenological lens with which this study was viewed, the meanings that the participants gave to their experiences with ostomies were interpreted.

Each interview was carefully listened to and transcribed. The interviews conducted in English were transcribed verbatim whilst the Twi ones were translated to English before being transcribed. The researcher who is fluent in both languages (English and Twi) ensured that meaning was not lost through translation and transcription. For each audio-recording, this was done by listening to a sentence, pausing the tape recorder, writing down the content and continuing until the whole interview was written down. The mean time for transcription of each interview was 3 hours 30 minutes. Transcripts were then read several times for the researchers to familiarize themselves with the data. Whilst familiarizing with the data, the researchers made notes and documented early impression of the interview being analysed. The researchers then began to organize data meaningfully by coding. Each transcript was coded separately by the Researchers. A graduate student also assisted in coding of the transcripts. We then compared codes and modified them before moving on to the rest of the transcripts. Codes that connote the same idea were labelled as sub-themes. Sub-themes that suggested an idea were also then group as themes. Repetitive codes within a sub-theme were discarded. The researchers subsequently read the data associated with each theme and considered whether the data indeed supported the themes [23-25]. Themes were then defined and meanings were made of participants' narration through interpretation. Quotes from participants were used to support themes in reporting the findings of the study. Pseudonyms were used in reporting. The researchers carried out member checks or follow-up interviews through telephone calls with participants, where they were asked to verify a summary of the preliminary findings to ensure credibility of the data. Member checks revealed that preliminary findings reflected participants' experiences with only minor changes, which were rectified.

Ethical approval

The study received approval from the Institutional Review Board (IRB) of both the University of Cape Coast [UCCIRB/CHAS/2016/11] and the KBTH [KBTH-STC 00031/2017]. All the research participants were informed of the objectives, as well as the benefits and potential risks. Those who agreed were invited to sign/thumbprint a consent form before being interviewed. Participants were informed that they could withdraw from the study at any point and such withdrawal would not in any way affect the care they would receive at the KBTH. They were informed that the data would be used for only academic purposes and that only the research team would have access to the data.

Results

Socio-demographic data of respondents

The mean age group was 10.04 ± 0.904. The majority of children were males (57%) as compared to females (43%) (Table 1).

Social well-being of ostomates

In probing into the social life of the ostomates, the subthemes that emerged (Figure 1) were social activities, travel challenges, recreational activities, intimacy, adjustment difficulty, ostomy care, financial burden and family distress. Change in participants' social life was shown to be connected to other aspects of their lives. Hence, change in one aspect (or category) of participants' way of life did not necessarily occur in isolation; aspects were all interconnected.

Social activities

The participants reported that, their involvement in social activity was negatively affected. Getting involved in social activities also meant having to deal with the incontinent nature of the ostomy in a less controlled environment.

"I mostly want to go for social events like outdooring or funerals but unable to go because I am shy. I fear that when I go for such events the bag might leak and disgrace me due to that, I don't go anywhere. I have the feeling that I am not supposed to mingle with others" Dede.

Variable	Frequency n (%)
Age	
<40	2(22.2)
40-49	6(66.7)
50+	1(11.1)
Sex	
Male	6(66.6)
Female	3(33.3)
Marital Status	
Single	3(33.3)
Married	6(66.7)
Occupation	
Civil Servant	2(22.2)
Self-employed	5(55.5)
Unemployed	1(11.1)
Pensioner	1(11.1)
Religion	
Christian	8(88.9)
Islam	1(11.1)
Educational Level	
None	3(33.3)
Primary	1(11.1)
Secondary	3(33.3)
Tertiary	2(22.2)
Surgery Type	
Planned	6(66.7)
Unplanned	3(33.3)
Indication for Ostomy	
Ulcerative Colitis	1(11.1)
Colorectal Cancer	4(44.4)
Fistula-in-Ano	1(11.1)
Diverticultis	1(11.1)
Prostate Cancer	1(11.1)
Intestinal Obstruction	1(11.1)
Ostomy Type	
Colostomy	7(77.8)
Ileostomy	2(22.2)
Duration of Ostomy	
Temporary	5(55.5)
Permanent	2(22.2)
Not told	2(22.2)
Time Elapsed	
<1 year	3(33.3)
1 year	4(44.4)
2 years	1(11.1)
3 years	1(11.1)
Total	9(100.0)

Table 1: Socio-demography Data of Respondents.

Source: Sena et al., 2017

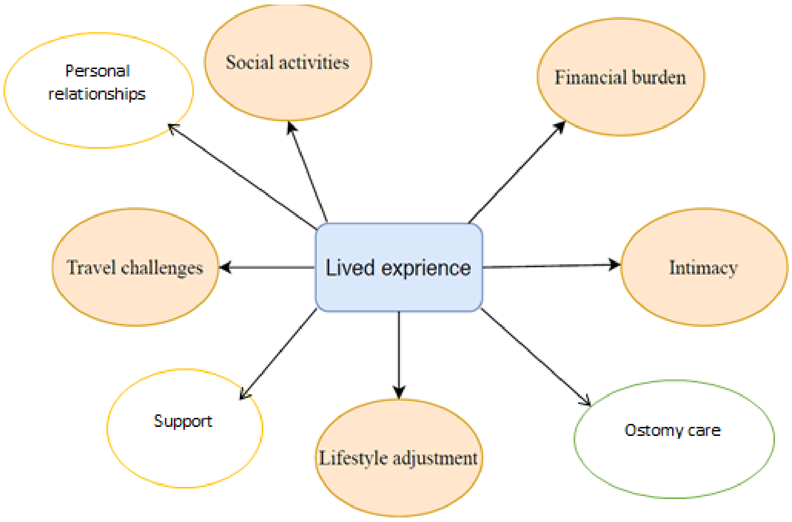

Figure 1: Emerged Themes from Interviews.

“No No No. I know someone in my situation might be able to go for some social events but for me in particular, I don’t go for any social gathering be it wedding, funerals etc….. I have difficulty mingling with them because I feel uncomfortable doing that” Lizzy.

“Not that much of a social person. Not every time, like I don’t go out very much but once in a while when I have some social events I used to but once with the bag issue I couldn’t” Tom.

But for one participant, involving oneself in social activities is a task that depended on the will of the individual.

“I go to church and go everywhere, I do not avoid any social gathering, I go everywhere, it’s up to you. It depends on how you carry yourself “kofi

Travel challenges

Participants encountered difficulties with travel issues. Most reported that travelling would inconvenient the other passengers in the car and others did not travel because they worried about how to manage his output should there be any ‘surprises’.

“I am unable to travel anywhere. My only movement after the operation is from the hospital to Somanya and back to Accra (Mallam) to stay with my siste r…sitting in a public transport with this thing, people would wonder why you smell and sometimes the sound that” ken

“Yes, I do travel but Dropping is my only choice of transport in my current state of health. Using any form of public transport as in trotro might inconvenient others. …No matter how hard you try to be discrete about the whole thing, the smell and sound will definitely give you away. In order to avoid this embarrassment, I always send my daughter if the situation doesn’t demand my presence” Lizzy.

“I have moved around a few times with my daughter within my community not far away using taxi (dropping) as the means for transport” lucy

For some, travelling was a lot easier because they had their own means of transport.

“I never experienced any difficulty with travelling because I have my own car as well as that of my children which always takes us to and from anywhere we to go” AB.

“No. ok wait, I think I travelled with it like twice. Yes. One time I went to Ho with it and I think Aburi the other time for my own personal reasons. One to an engagement and the other to a funeral I think…. But that was with my brother’s private car.” Tom.

Intimacy

Engaging in intimacy, whether sexual or nonsexual, also affected participants. The ability to share a deep, personal connection with a significant other after the ostomy creation defines the sub-theme intimacy. Engaging in sexual intimacy was a difficult task for some participants. They described how the ostomy was a deterrent to engaging in intimacy.

“No. Ever since I got operated on, he (boyfriend) hardly comes closer less to talk about having sex with me. I do not even want to be too close because I am embarrass about the whole thing” lucy.

“I don’t engage in sex anymore, at least for the time being. My wives understand my situation. Sometime ago, I tried to please my wife but the pouch was not well fixed. Some of the faeces spilled on the bed since then we have not tried anything like that again” Mohammed.

Others did not think of intimacy as a problem because their spouse had travelled or were no longer interested in sex.

“Ohhh, I have no problems with sexuality because he isn’t around often. He has not been around from the beginning of all this issue” Lizzy.

“I lost all interest in sex and besides my wife is not the type of women who is demanding when it comes to sex. That part of my life has been turned down at least for the time been” AB.

“We have given up on sex totally but still share an intimate relationship together. My wife has even reached menopause and I have also lost my interest in sex” Ben

“With sexual aspect, I am often tired which prevents me from having sex. ‘Quite apart from that, the weakness I feel doesn’t even make me feel like having sex” Ken.

For some participants, intimacy with their spouses has remained as it was before the surgery.

“My ladies feel that I will get hurt, its still about the same, my sex life has not been affected” Kofi.

“With my spouse, she just understands it. She is educated so she understood it. There was no hindrance between me and her. Even with the bag, we have sex so it didn’t hinder the relationship between me and her. We manage our sexual life very well” Tom.

Adjustment Difficulty

This describes how difficult it is for participants to vary their lifestyle to suit their “new self”. Most participants made efforts not to let the ostomy hamper how they lived their lives. They reported that even though, living as before was not possible after the ostomy was created, they admitted they have change several aspects of the way they did things.

“I sit to wash now instead of bending… and I now wear long and loose dresses to so people won’t see what I have” Dede

“With heavy meals, I know very well how badly it can affect or hurt me so I restrict myself from taking any food” Lizzy

“The uncomfortability came when I got home and faeces started coming from that place. That was when I felt uncomfortable in some way so when I got the Colostomy bag and I started using it, it took some while before I started feeling ok. Since then, I have been trying my best to adjust to the new me” Tom.

Ostomy Care

This sub-theme explains how participants cared for the ostomy. At home care of the ostomy initially was done by family members and participants took over later.

“In the beginning changing of the bag and care of the place was done by my daughter but now I do it myself” Dede.

“When I came back from the hospital, I was still weak so my wife use to change and clean the place (ostomy site). This was like 2 weeks, apart from that, everything else from personal hygiene to wound dressing to changing of the pouch I did for myself”. AB

One participant narrated how he had to force himself to be able to care for the ostomy because the wife will not always be with him.

“My wife did it for me … But I said, ‘I decided to handle it myself. … I should be able to do it’ ‘because what will I do if I have to change and she is not there? She will not always go everywhere with me” Tom.

A challenge shared by a participant involved changing the pouch when the stoma was visible only with a mirror due to its location. He had difficulty coordinating his pouch changes with a mirror.

“When I have to change the pouch, I have to stand infront of a mirror otherwise I would not see the site well because of how large my abdomen is (laughs). I cannot see it well, the mirror confuses sometimes” Ben.

Some participants explained how life would have been much easier if they had continuous support from the health team even as they were home.

“I do everything they tell me to do, the food and changing the bag. As you know, many people have never seen this thing before so it is somehow difficult. why am I saying this? Lets take it that you have a problem with the pouch or even the ostomy, you can’t ask anybody. if we had nurses who could visit like the community health nurses, it would have been easier. Sometimes if you have a problem, you have to board a car all the way to the hospital to complain and they will tell you it’s nothing” Lucy.

“For my own, it is permanent. If I don’t have any problem, I don’t go to the hospital. But how will I even know I have a problem or not, they explained but I am not a health person. If they could organize some of the young nurses to come and see me once a while it would be good. Sometimes you go to the hospital and spend the whole day there but without having any problem. So me, I don’t even go there these days” Mohammed.

Financial Burden

Participants had the expense of affording the ostomy bag. The sub-theme financial burden represents the challenges in obtaining, buying and managing an inventory of ostomy supplies within one’s budget. All the participants expressed some form of obstacle with affording and obtaining the ostomy bag. Some could no longer work due to the creation of the ostomy had challenges acquiring the ostomy.

“Hmmm I really suffered financially even though my family members were giving their support randomly but it wasn’t enough. Because I was jobless for 3 years, I couldn’t work again. I had difficulties buying some medications and bags as it was becoming too expensive. I remember how it took me take close to 2 months to come up with the money for the surgery. So, my brother it’s still not easy”AB.

“The monetary aspect is difficult because my husband been a driver has no car at the moment to work with so when I am due for checkup or my pouch finishes, the one who comes after me(sister) I the one who gives me money for all that. For now, Money issues are tough for me as I don’t have any work doing and anytime I sweat, the bag comes off easily or gets damaged. I try as much as possible not to move about by staying at one place for long to avoid damaging the bag” Dede.

“That was the main headache. It got to a time that I couldn’t afford it because it was ghc10 and I have to use 2 or almost 3 sometimes in a day. That was the big headache. I mean in the whole thing, which was the big headache” Tom

Two participants experienced rectal discharge and required incontinence pads, which added to their expenses.

‘The slimy thing that comes from my anus too is another cost If you don’t take care it can embarass you. So for instance if I have to go out, I wear diapers you never know, sometimes it comes out a lot” Ben.

“At first, I even use to wear diaper because of the rectal discharge. That was another cost. But that one wasn’t faeces, it was slimy. The amount has reduced now” ken.

Some participants lost their jobs because the presence of the ostomy was an obstacle. The nature of their jobs deterred them from carrying about the job.

“My business of selling pastries has collapse as I’m unable to go anywhere near it. When the whole problem started, it was my daughter who took over from me but has to always stop when school reopens. The on and off nature of the way my daughter sells made us loss all of our customers. My daughter’s education on the other hand is been threatened as I am unable to pay her school fees” Lizzy.

“Money…. Hmmm I really suffered financially even though my family members were giving their support randomly but it wasn’t enough. Because I was jobless for 3 years, I couldn’t work again. I had difficulties buying some medications and bags as it was becoming too expensive. I remember how it took me take close to 2 months to come up with the money for the surgery. So, my brother it’s still not easy” AB.

Participants bemoaned the fact that the purchasing of the pouch was not covered under the National Health Insurance (NHIS). They are left to finance their own supplies.

"It becomes a problem when comes to finances. Just this morning I went to buy some for GHc 200.00 for every six days. I use 3 a day but can use up to six a day if running diarrhea. It is not covered by NHIS. Others are using the rubber bags because they cannot afford the drainage bags" Ben

Mine is not drainable, I tried the others before but I had sores all over, I can`t drain. I use Dettol and Savlon, I borrow money from people to buy the bags and pay later. The bag is not covered by health insurance (NHIS). I think these are some of the things the NHIS should take responsibility for. The creation of the ostomy itself is sad and this has to be compounded with a huge financial burden" Kofi.

Participants developed strategies to help relieve their financial burden by using ordinary polyethene bag.

"We buy it (colostomy bag) when what I have get finish. And anytime we buy, we use it along with ordinary polythene bag to supplement it. The bag is quite expensive for me to be changing every day or every time so I add the black polythene bag to make it last longer. The colostomy bag I mostly use when going out either to the hospital or church" Lizzy

"The bags are always available for sale at Korle Bu when I come for review but the issue is the money to purchase enough of the bag to last a while. The use of the polythene bag helps cut down cost as it is way cheaper than the colostomy bag" AB.

"With the colostomy bag, I have none left except the one my nephew bought for me but unfortunately, the size of that one is small compared to the stoma. They are now contributing to be able to buy me some of the bag so in the meantime; I use a polythene bag" Ken.

Another strategy was to wash or reuse bags. One participant shared why associated risks did not deter her.

"My pastor bought some for me but they are disposable. I know it is unhealthy to be using it this way, but that is my only option. I wash it and use plaster to secure it. Sometimes when I do that, you will see that the plaster peels the skin around there (ostomy site), and if it stays for long, it often itches, but that is what I have to do. Getting money for this is not easy" Lucy.

Support

An emerging subtheme under social wellbeing is support. Being supported is defined as the help participants receive from others. Participants were given domestic, financial and emotional support. Participants stressed how invaluable their families have been.

Domestic support

Participants narrated how they received support in carrying out domestic chores from family members, friends and church members. The males mentioned their wives and children as those who offered the most support.

"My family members are supporting me well. Initially, I had wanted to do everything by myself but later on realized I needed others to help see me through and bringing my family and few friends in has really paid off " Tom.

"My friends and church members did their best to visit me regularly with gifts and donations which cleared some of my financial debts" AB.

Financial support

Support also came in monetary terms.

"I suffered financially even though my family members were giving their support randomly but it wasn't enough" AB

"Every once awhile my Mum and siblings send me some money through Mobile Money. They try to pass by also to see how I am faring so they've been helpful" Lucy.

Emotional support

The idea of living with an ostomy was not an easy task for participants. They got emotional support from their loved ones.

"Well the support was so great especially from my children and my wife. They were all by my said 24 hours a day. I have no reason to complain or to say I regret for been sick because they gave me the support really. If let's say my wife and children didn't come to Korle Bu, the whole Catholic church in Kasoa would have love to come but I was given a private room in Korle Bu that's why they didn't get the chance to" Ben.

"They also provide me with emotional support and motivated me to go through my predicament. They know it's not everybody who go for operation that comes back alive. At times, they come home to keep me company as I don't mostly go out" Dede

"Without my wife and family I don't see how I would have gone through this trial. They gave me everything from money to support to encouragement throughout my hospitalization period" AB

One participant narrates how she is avoided by friends because they fear that she will infect them.

"All my friends with the exception of one have neglected me. They don't even respond to my calls or call back. Some say I will infect them with my condition. The only friend I have left is the one who every now and then call to check on me, sends me money and encourages me" Lucy

Discussion

Evidence suggests that ostomates experience varied social challenges [26-33]. However, our extensive search indicated that no documentation exists regarding the social life and lived experiences of people living with ostomies in Ghana. This study therefore investigated the social lived experiences of ostomates in Accra, the capital of Ghana. The study revealed that, living with ostomy adversely impact patients' involvement in social activities and intimacy with others as well as travels. Ostomy also requires some lifestyle adjustments and poses financial challenge to patients.

Some narratives from the study participants included feeling shy to attend social events and possible disgrace due to the incontinence nature of ostomy. For some people, they felt that they need not to interact with others publicly because of the condition. Yet, one indicated that he attends all social events and from his perspective, the decision to attend social events or not is entirely discretionary. These experiences of the research participants indicate that undergoing ostomy could have severe social implications. Such feeling could result in negative thought about one's self-esteem [34]. Despite variation in contextual and socio-demographics, similar experiences have been reported from other parts of the world. For instance, in a focus group discussion among persons with stoma in Denmark, some of the patients revealed that they feel that they are to stay within defined limits6. Some reviews have revealed similar findings [35]. These points to the need for social support services to be incorporated with ostomy services in order to psyche patients for them to admit that their condition is a normal medical condition and everyone is at risk so it is needless to feel ashamed or unworthy of interacting with others. Such a supportive service should be rendered prior and after the procedure in order to motivate the patients consistently and urge them to interact well with others whilst taking all necessary precautions.

Challenge relating to travel was commonly reported by the research participants. A number of them felt that travelling is likely to inconvenience other passengers aboard. Consequently, others decided not to travel because they were worried about how they were going to manage the condition should an unexpected situation avail itself. Meanwhile, travelling was fun and easier for those who had their own means of transportation. In the case of China, fear of leakage was cited as a reason for avoiding travels or social interactions [25]. Travels may be reduced substantially for ostomates if at least one family member is devoted to assist ostomates with usual errands. Healthcare providers who cater for ostomates ought to discuss with the families of the patients for them to understand and appreciate the need to assist them.

A number of the participants were unable to share deep intimacy with significant others. For some of them, engaging in sexual relation was quite challenging. However, among those whose partners had travelled or did not want sex, intimacy was not an issue. Compromised intimate relationship has been noted in the UK among persons living with lleostomy [36]. An account from Finland also highlights how stoma adversely affects intimacy of patients, however, some few participants reported an enhanced intimacy after undergoing ostomy [37]. In the case of Ghana, health professionals who may have to consistently advice and introduce patients to various coping strategies throughout the continuum of care. A sustainable post-surgery support service ought to be instituted in the health facilities together with establishment and continual coordination with community based focal persons in order to monitor the progression of ostomates and support them socially. Having such a structure or intervention in place can facilitate the pace at which patients recover socially and live normal life.

Financial burden was also acknowledged as an issue of concern. The cost usually arose from acquisition of ostomy bag(s) as well as acquiring and managing an inventory of ostomy supplies within the budget or financial capacity of ostomates. Indeed, all the participants expressed some financial challenges of a sort and some of them were unable to engage in paid roles as well. Some participants used polyethene bag or wash and re-use bags as strategy to reduce the cost. The financial burden for ostomates is not unexpected because the current health insurance of Ghana does not cover ostomy care and patients pay out-of-pocket for all their expenses. Similarly in Uganda, it was noted that none of the patients had been able to purchase a formal ostomy bag and in the case of children, caregivers were compelled to relinquish their jobs to cater for the patients. Plausibly, adding ostomy care to the list of items covered by the National Health Insurance Scheme (NHIS) may be beneficial for ostomates to access healthcare without much financial burden. Even if the full cost cannot be absorbed by the NHIS, a subsidy for ostomates who are subscribed to the scheme may lessen the financial burden.

Strengths and Limitations

This study appears to be the first empirical study to explore the experiences of ostomies in Ghana. The qualitative nature has aided to explore the lived experiences of persons living with ostomy. Yet, the study has some limitations. Due to the qualitative approach used, outcome of the study, conclusions and recommendations cannot be generalised to the whole population of patients with stomas.

Conclusion

The study has revealed that people living with ostomy face enormous challenges. The study has highlighted the need for Ghana's health sector to institute livelihood support mechanisms for persons living with ostomy in the country. Health care providers who carry out the procedure may engage one or a few close relatives about the situation, its possible implications on social life and possible ways the relatives can help the ostomate cope and feel comfortable in social circles.

Further Studies

Further study may explore the thoughts of ostomates about disclosure and factors they would consider before disclosure.

Conflict of Interest

The authors declare no conflicts of interest.

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