

UNIVERSITY OF CAPE COAST

LIVED EXPERIENCES OF PEOPLE WITH OSTOMIES IN THE ACCRA  
METROPOLIS

AISHA SENA

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BY

AISHA SENA

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and Allied Sciences, University of Cape Coast, in partial fulfillment of the  
requirements for the award of Master of Nursing

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## DECLARATION

### Candidate's Declaration

I hereby declare that this thesis is the result of my own original research and that no part of it has been presented for another degree in this university or elsewhere.

Candidate's Signature: ..... Date .....

Name:.....

### Supervisor's Declaration

I hereby declare that the preparation and presentation of the dissertation were supervised in accordance with the guidelines on supervision of thesis laid down by the University of Cape Coast

Principal Supervisor's Signature: ..... Date .....

Name:.....

Co-Supervisor's Signature ..... Date .....

Name:.....

## ABSTRACT

An improved quality of life is the utmost expectation of patients after any surgical intervention. However, people with ostomies have reported varying degrees of experiences with impacts on their activities of daily living. Ostomy surgeries are common in Ghana but little is known regarding the lived experiences of people with ostomy. This study gave insight into the lived experiences of people with ostomies in their homes in the Accra Metropolis. This study employed a phenomenological approach as its design. Recruitment was done at the Korle- Bu Teaching Hospital. A face- to -face interview was conducted using a semi-structured interview guide and the data gathered was analyzed using thematic content analysis. The findings of the study revealed that ostomates did not have all the necessary information they needed for a smooth adaptation. Physically, participants experienced unpleasant smell, sound, and leakage of effluence from the ostomy. Psychologically, they did not know what to expect from the ostomy and this made them adjust the way they did things. Participants avoided social activities lest they inconvenience others and bemoaned the financial burden that comes with living with an ostomy. Support from family and friends helped them to cope with the condition. Participants had their religiosity affected whilst spirituality remained intact and they were hopeful for brighter days ahead. It is hoped that the findings will help healthcare providers tailor care towards the specific needs of people with ostomies.

**KEY WORDS**

Education

Lived Experiences

Patients

Ostomies

Phenomenological

Quality of life

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## DEDICATION

This work is dedicated to my children; Naem Jnr, Sianna, Kaila and Hamad.

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## LIST OF ACRONYMS

COHQOL-O	City of Hope Quality of Life Ostomy Model
EN	Enterostomal Nurses
HRQOL	Health Related Quality-Of-Life
IOA	International Ostomy Association
KBTH	Korle-Bu Teaching Hospital
OPD	Out Patient Department
QOL	Quality Of Life
SQLI	Stoma Quality of Life Index
WOC	Wound, Ostomy, Continence

## CHAPTER ONE

### INTRODUCTION

#### Background to the Study

“Can you imagine how a person who was always clean, with a fragrant body and having a healthy life style, has been changed to a person with bad body odor who cannot even tolerate himself”? (Dabirian, Yaghmaei, Rassouli, & Tafreshi, 2011 p. 4). This statement echoes how a person with an ostomy may focus on the negative aspects of the stoma rather than its function to the detriment of self-image, acceptance of a new lifestyle, and ability to self-care. Ostomies are created to save an otherwise detrimental ailment but most often and unfortunately, several studies have shown that many people do not have pleasant experiences with ostomies and that their Health-Related Quality of Life (HRQoL) tend to be significantly low (Tawil & Nightingale, 2013; Vonk-Klaassen, de Vocht, den Ouden, Eddes & Schuurmans, 2016).

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 (Mota et al., 2015). 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 and two main types of colostomy and ileostomy – loop and end. 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 (Tawil & Nightingale,

2013). 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 (Ang, Chen, Siah, Ele, & Klainin-Yobas, 2013; Altschuler, Ramirez, Grant, Wendel, Hornbrook, Herrinton et al., 2009).

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 (Mota & Gomes, 2013). 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 (Danielsen, Soerensen, Burcharth, & Rosenberg, 2013). Living with a stoma often causes feelings of fear, anguish and insecurity after hospitalization. Surgeons and nurses are required to do counseling with patients prior to creating the stomas. Patients could act and adapt themselves to the existence of a stoma better if their forthcoming problems were discussed properly before surgery (Keighley, & William, 2007).

It is estimated that more than 120,000 ostomy surgeries are performed each year in the USA (Cooke, 2009). More than 700,000 Americans ranging from infants to senior citizens have had faecal or urinary ostomy surgery (United Ostomy Association of America, 2015).

In 2004, the House of Delegates of the International Ostomy Association (IOA) issued the “Charter of Ostomate’s Rights” for individuals with an ostomy. According to this document, individuals who undergo ostomy



surgery should receive preoperative counseling and be provided with facts about living with a stoma. The individual also should have a well-constructed stoma placed at an appropriate site and receive medical support, ostomy nursing care, and psychological support during the preoperative and postoperative phases, both in the hospital and in the community. In 2012, the Iranian Ostomy Association reports that there were over 3,000 people living with ostomy. These ostomates are educated on ways to improve their quality of health and yet Anaraki et al., (2014) found out in a study that sexual disorders and depression were the major problems they face which results in a low quality of life.

The increase in life expectancy, the industrialization process, the globalization and the effects of urbanization implies that the global population is exposed to more health problems, among which cancer, trauma and degenerative chronic diseases stand out which may imply the creation of ostomy during treatment. Because of these emerging current trends, there is the need for health professionals to have adequate knowledge of innovative resources and position themselves to promote autonomy for self-care with the aim of providing a better quality of life and well-being. This can be achieved through studies of this nature which reveal the lived experiences of patients with ostomies when they are discharged home and still have to deal with keeping an ostomy. This better places health professionals particularly nurses in a state to give them what they need in terms of care.

Additionally, in the quest to improve the life of persons with ostomies, different reasons for assessing QOL have led to the development and use of different generic and disease-specific instruments. Several instruments have

been developed to measure health related quality-of-life (HRQOL) among Ostomy patients. Such instruments include quality of life from the patient's perspective, stoma care QOL index, City of Hope-quality of life-Ostomy questionnaire (COH-QOL-Ostomy questionnaire), Ostomy adjustment scale, Ostomy adjustment inventory-23, coping strategies inventory, QOL index, survey of pre-operative factors of Ostomy adjustment and stoma-QOL (Aronovitch, Sharp, & Harduar-Morano, 2010).

In Ghana, there is no central registry of the incidence of either ostomy creation per year or persons living with an ostomy. Furthermore, there is scarcity of data on demographic variables of persons with ostomies, neither is there any nation-wide data on reasons for stoma creation. Also, there is paucity of literature related to the quality of life or the lived experiences of ostomates living in Ghana. Anecdotally, there are a substantial number of people living with ostomies in their homes but there has been no use of any of the instruments for assessing quality of life of persons living with ostomy or related studies conducted to explore their lived experiences. Unlike some other countries, Ghana has no support groups for ostomates. There is also the absence of specialist nurses for ostomies called Wound, Ostomy, Continence (WOC) nurses or Enterostomal Nurses (EN). Despite the presence of EN nurses and the availability of support groups in China, Brazil and Iran, studies report that the quality of life of people living with ostomies is often not good enough (Liao & Qin, 2014). Little is known regarding challenges people with ostomies in Ghana are confronted with, how they cope and the kind of life they live after discharge from the hospital.

Many Ghanaians have probably never heard about ostomy and hence people living with ostomies may find many reasons to isolate themselves lest they are asked questions that they may not even have answers to. They may also isolate to avoid causing discomfort to people around them due to the disgust that is often associated with bodily output culturally. Due to resource limitation, most hospitals in Ghana often have few pouches for these output and these are sold to patients at exorbitant prizes. The result is that, patients in their bid to minimize cost, wear the pouches past the designated time often resulting in loss of efficiency of the pouch with unpleasant consequences for ostomates. Meanwhile, Liao and Qin (2014), in a study positively correlated the quality of the pouch to quality of life of people living with ostomies. They added that the lack of understanding about which factors influence QoL post ostomy hinders the ability of health care professionals to provide appropriate instructions and care needed.

This study aims to explore the experiences of patients with ostomies after they have been discharged from the hospital to stay at home.

### **Statement of the Problem**

An ostomy is intended to relieve unpleasant intestinal or urinary symptoms that a patient may be experiencing. A patient is expected to have a relatively better quality of life after ostomy creation than in the diseased state. In developed countries, the costs of stoma management supplies are often met wholly or in part by state or insurance-funded health systems, patients with stomas can choose from a range of disposable collection systems for ostomy management that afford hygienic, discrete, and reliable collection (Wound, Ostomy and Continence Nurses Society, 2010). In addition, an entire specialty

of nursing has grown that focuses on stoma care and guidelines have been developed for best practice in pre-operative and post-operative care, often including elements of counseling and ostomy management education as well as medical care (Wound, Ostomy and Continence Nurses Society, 2010). Despite the health care and products that are available, the undoubted difficulty in adjusting to having an ostomy results in considerable psychological stress in many, and the incidence of dermatitis and other complications around stomas is relatively high (Salvadarena, 2008; Black, 2004). The life changing events of ostomized patients are a phenomenon that must be understood by professionals who are part of the nursing care process for people with this type of change. Marquis, Marrel, and Jambon (2003), concluded in their investigation that because the degree of problems experienced by ostomy patients largely relates to their experience and skill in self-care, patients have the best chance of returning to their usual lives if they receive continuing education during the transition from hospital to their homes.

Ghanaian ostomates do not have these supports. Ostomy patients need specific care, multiprofessional specialized follow-up that meets their biopsychosocial needs and qualified nursing care, which should be initiated in the preoperative period and continue throughout the period in which the patient should be with the stoma, and this could be permanent. However, there is no available documented evidence on the experiences or the health related quality of life of people living with ostomies in Ghana. The records at the Statistics Department for the Surgical unit of the KBTH, which is the largest hospital in the country, could not produce the exact number of ostomies the

department had created over the years neither were there any support systems for patients with ostomies after discharge. There is also no continuing education on the ostomy after patients have exhausted their review dates. However, a lot of literature show that ostomy patients experience many challenges in relation to their quality of life (Mehraban, Ashoori, Moladoost, & Aghayi, 2008; Symms, Rawl, Grant et al., 2008; Coons, Chongpison, Wendel, Grant, & Krouse, 2007). These challenges can be well appreciated if the subjective experiences of these ostomates are unravelled. In response to these, the researcher sought to explore the lived experiences of patients who have ostomies in order to reveal their challenges and how they cope after they have been discharged from the hospital.

### **Purpose of the Study**

The purpose of the study is to explore the experiences of people with ostomies after they are discharged from the hospital in the Accra Metropolis.

### **Objectives of Study**

The study is guided by the following objectives:

1. To explore the physical well-being of people living with ostomies.
2. To explore the social well-being of people living with ostomies.
3. To investigate the psychological well-being of people living with ostomies.
4. To explore the spiritual well-being of people living with ostomies.
5. To investigate how persons living with ostomy cope.

### **Research questions**

The research sought to address the following questions:

1. How is the physical well-being of people living with ostomies?
2. How is the social well-being of patients living with ostomies?
3. How is the psychological well-being of patients living with ostomies?
4. How is the spiritual well-being of patients living with ostomies?
5. How do people living with ostomies cope after they have been discharged from the hospital?

### **Significance of the Study**

Findings from this study will bring to light how people who have ostomies live, the challenges they face and their expectations. The results of this study is expected to make the nurse and other members of the health team who deliver care to ostomates appreciate what their experiences, challenges and coping strategies are, so as to help inform the care they would render to these patients in an edified thoughtfulness. Based on these findings educational information will be provided to people living with ostomies during the discharge process to help them adjust better to living with the ostomy. Findings of this study will also be made available to the KBTH and other hospitals through the Ministry of Health to help management and policy makers consider policies that will improve on care for patients with ostomies to improve their quality of life. Based on the findings, people will come to understand what people with ostomies go through and this awareness may be necessary for the formation of support groups for people with ostomies.

### **Limitations of the Study**

The transferability of the findings of this study is limited as the lived experience is subjective, and may differ for patients who live in different regions, or who have had their ostomy for more than three years. The severity

of the disease which caused the creation of the ostomy may have also influenced their experiences of life with an ostomy. Because a qualitative method was employed, few ostomates were interviewed hence the findings of the study may not be generalizable.

### **Delimitations of the Study**

The study was conducted with patients discharged at the Korle-bu Teaching Hospital of Greater Accra Region of Ghana, a multisite tertiary facility serving as a referral centre for the whole country. Again, the study is limited as data was collected from ostomates discharged from hospitals that were living in the community. Further, the study employed a phenomenological approach and used interview guide only to collect data.

### **Definition of Terms**

The operational definition of the key terms used in the study are as follows:

- Ostomates: A person living with an ostomy.
- Quality of Life (QOL): A person's subjective perception of the impact of the ostomy on various aspects of his or her daily life.
- Lived experience: An ostomate's perception of living with an ostomy.
- Stoma: An opening made the abdominal wall to allow faeces or urine pass out.
- Enterostomal nurse (EN): A specialist nurse responsible for the management of patients with ostomy.
- Ostomy: A surgical procedure that creates an opening (stoma) on the abdominal wall for faeces to move out of the body.
- Pouch: A prosthetic bag connected to a stoma for the collection of faeces.

## **Organization of the Study**

This study report is organized into five chapters. Chapter one presents with the background of the study, statement of the problem, research objectives, research questions, significance of the study, limitations, delimitations and organization of the study. Chapter two presents a review of related literature on the topic, while chapter three focuses on the methodological issues considered in carrying out the study. Chapter four presents the results and discusses the findings of the study and the final chapter, chapter five, presents the summary, conclusion and recommendations of the study.



## CHAPTER TWO

### LITERATURE REVIEW

The aim of this literature review is to explore research that has been done on the lived experiences of patients who are living with ostomies after hospital discharge. Literature search was done using Pubmed, JSTOR, Google Scholar, Science Direct, EBSCO host, HINARI, Willey Online Library, and Taylor & Francis Online Library. The key words “ostomy”, “stoma”, used together with physical, psychological, social and spiritual and quality of life were used in the search. The search identified few studies on the specific research topic even though there was a plethora of studies on ostomies. Many of these studies identified focused on QOL of patients. This literature review focused on the historical background of the City of Hope QoL Model – Ostomy and justification for the use of the theory. The rest of the chapter reviews studies on living with an ostomy, the physical, social, psychological, spiritual well-being and the role of nurses in the well-being of patients who live with ostomies.

#### **Conceptual Framework**

The City of Hope Quality of Life Model for ostomy patients is used as a framework to describe the experiences of ostomates. This model consists of four domains: Physical Well-Being and Functional Status, Psychological Well-Being, Social Well-Being and Spiritual Well-Being. The model guided the study’s design and analytical procedures. This framework was developed from the findings of qualitative and quantitative studies on ostomy-related changes in the quality of life. The model depicts the interrelationships of the four quality-of-life dimensions and their general and disease- specific effects.

This holistic model illustrates that comprehensive management of all domain-related effects is needed to support improvement in overall quality of life (Grant et al., 2013)

### **Historical perspective of City of Hope Quality of Life Model-Ostomy**

Many specific quality of life changes occur for patients with ostomies. The City of Hope Quality of Life Model is used as a framework to describe the experiences of these patients. Quality of life is considered as a multidimensional concept that measured the dimensions of psychological well-being physical well-being body image responses to diagnosis or treatment and social cancers (Adamakidou & Kalokerinou, 2011). In 1989, Ferrel, Wisdom and Wenzl used Padilla and Grant's model as a conceptual framework in order to develop and test a quality of life instrument. After this, the instrument was revised and used to gather data about the relationship between pain and QOL (Adamakidou & Kalokerinou, 2011). From these two studies a conceptual model emerged and was referred to as City of Hope Model. This model illustrates the influence of pain on the dimension of quality of life.

The model supports that quality of life has four dimensions: physical well-being and symptoms, psychological well-being, social well-being and spiritual well-being. It was shown that was pain is an experience that influences all dimensions of QOL (Chopra & Kamal, 2012). Further studies were done whereby the instrument was used to gather data about the relationship between pain and QoL. Since the development of this first model, other models have been developed. This includes the City of Hope Quality of Life Ostomy Model (COHQOL-O) applied to patients with ostomy (shown in

fig 1). In this model, issues were summarized from several large data sets collected from patients with ostomies in order to create an intervention for patients.

According to the COHQOL Model applied to patients with ostomies, the physical well-being refers to the physical functioning of the ostomate. Health problems that may arise could be disease specific effect of physical well-being such as odor/gas, leaking, skin problems and diarrhoea and general quality of physical well-being such as fatigue, strength, aches/pains, sleep disturbance and overall physical well-being. The social well-being involves the interaction of the ostomates with others. It is the social adjustment to the ostomy. The parameters under the social well-being are social activities, personal relationships, isolation, travel challenges, recreational activities, intimacy, adjustment difficulty, ostomy care, embarrassment, difficulty looking, financial burden and family distress. The psychological well-being refers to the emotional functioning of the ostomate. The ostomate may experience disease specific effects on psychological well-being which includes depression, anxiety, uncertainty, fear of recurrence, difficulty meeting new people and a general quality of psychological well-being such as loss of control, changes in appearance, fear of recurrence, inability to cope, and increased privacy needs.

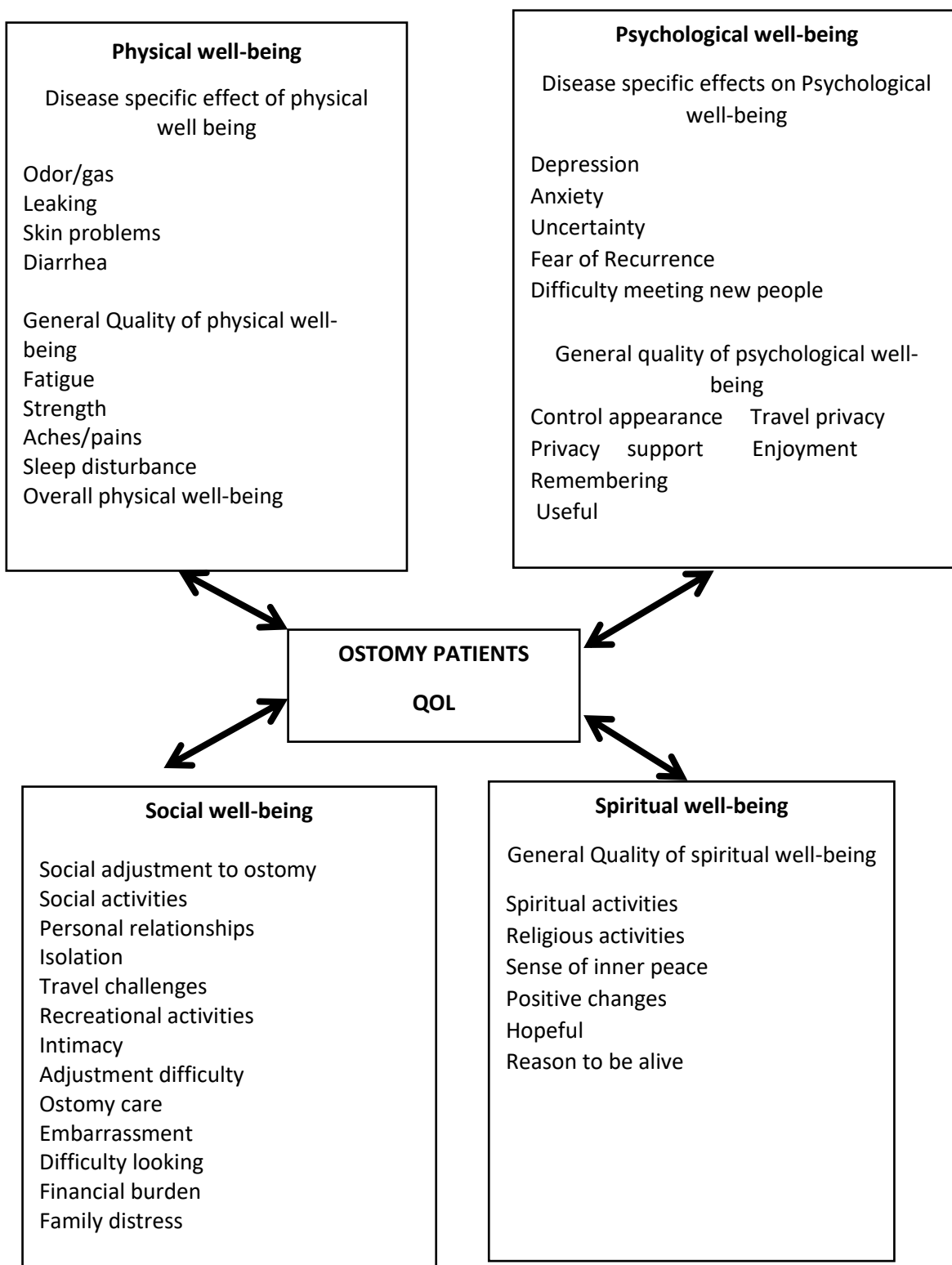


Figure 1: City of Hope Quality of Life –Ostomy Model (Grant et al., 2013)

Studies on ostomy have focused on the quality of life for ostomates. Many studies on experiences of patients with ostomies have employed the COHQOL model. In exploring the self-management of ostomates, the COHQOL model was used as a framework for the research (Ercolano et al., 2016) . In another study, Anaraki et al.(2014), evaluated the reliability and validity of the COH-QOL-Ostomy questionnaire and concluded on its usability on Iranian patients Fakhrialsadat Anaraki, Vafaie, Behboo, & Maghsoodi (2012) used the COH-QOL ostomy questionnaire to find out the quality of life of patients living with ostomy in India. Maydick (2016) used it in a comparative descriptive study to assess the relationship between QOL and preoperative stoma site marking in a sample of adults with permanent ostomies.

### **Living with an Ostomy**

In recent years, the increase in life expectancy has contributed to the worldwide increase in the incidence and prevalence of chronic diseases, especially diseases in which people receive stomata (Moreira, Marques, Salomé, Cunha, & Pinheiro, 2016). Stoma creation is a surgical operation where the surgeon makes an artificial opening on the abdomen from where the bowel is taken out. It is a radical treatment with permanent physical signs of bodily change. Although every effort is made to preserve intestinal and tissue integrity, a large number of patients undergo ostomy surgery each year. The purpose of ostomy is to treat and reduce patients' pain and discomfort. The creation of a stoma may also be surrounded by positive feelings as it is part of a lifesaving or relieving treatment (Scheidbach et al., 2009). However, in many cases, ostomy leads to intensified distress and suffering for patients, and

causes severe stress. In general, it leads to loss of a central and personal physical function (Danielsen, 2013).

The individual, after an ostomy surgery, not only lose a segment of his/her body but also undergoes a change in physical appearance and goes on living with the loss of control of elimination of faeces and gases, which now occur through the abdomen, and this type of control is a paramount condition for life in society (Sampaio, Aquino, De Araújo, & Galvão, 2008). It is claimed that the time spent with the stoma will depend on the causative factor and on the clinical outcome after its making (Moreira et al., 2016). Thus, an originally temporary stoma may become permanent, depending on the impeditive factors to the reconstruction of intestinal transit, taking into account that in many cases the diseases of the gastrointestinal tract lead to a radical surgery, resulting in a temporary, or even definitive ostomy (Aguiar, Santos, Soares, Ancelmo, & Santos, 2011).

With an ostomy, the patient experiences moments of conflict, concerns and difficulties in dealing with this new situation. This leads the individual to visualize his/her limitations and to face the changes in his/her daily life. It is important that the patient receives support from family, friends and even from those professionals who are helping. This will enable the patient find strength to overcome the difficulties and barriers related to self-care and the changes that are being experienced in his/her daily live (Moreira et al., 2016).

Health related quality of life and the functional output after surgery are very difficult to evaluate and have an impact on the individual's life with a stoma (Danielsen, 2013). Studies have explored the question of the impact on health related quality of life without reaching a shared conclusion (Nugent,

Daniels, Stewart, Patankar, Johnson 1999; Camilleri-Brennan, & Steele, 2002). Altered body or self-image of persons with ostomies tend to make them withdraw and isolate themselves socially, further hampering their quality of life and that, in turn, has physical, psychological and social consequences for them and their environments (Dabirian et al., 2011). The physical and psychological dimensions may be affected by the lack of guidance in the preoperative period, making it difficult to face the postoperative period (Pereira, Cesarino, Martins, Pinto, & Netinho, 2012).

### **Physical Well-being of People with Ostomy**

After surgery, many patients with a stoma experience a variety of physical problems leading to reduced quality of life. Stoma often appear as swollen, and large immediately after surgery, which is unpleasant for the patient's body image and confidence (Dabirian et al., 2011). Body image can be defined as the perception of physical appearance and function that forms gradually following birth, which can be impaired easily, in particular in people with diseases treated by ostomy (Brown & Randle, 2005). Several studies reported on patient's perception on the effects of ostomy on their body image (Brown & Randle, 2005; Piwonka & Merino, 1999). In a cross sectional study by Aktas and Baykara (2015), it was reported that patients who did not like seeing and touching their stomas perceived that their partners had similar feelings had low Body Cathexis Scale (BCS) scores. The BCS is an instrument employed to assess levels of satisfaction with one's body. This translates into feeling that he/she has lost some of his/her beauty and attractiveness. This study however did not evaluate the body perception of the patients before the ostomy creation hence the results may not be generalizable.

Furthermore, people with ostomies often present with a plethora of other problems that affect other aspects of their physical well-being. In a qualitative study to determine the quality of life of patients with stoma, it was found that most participants complained of irritation and rash around the ostomy site, with sleep disturbance, bad breath, and gas emission, physical weakness and loss of energy (Junkin & Beitz, 2005). Altered sleep pattern related to fear of leakage, pain or discomfort, lack of adjustment in activity of daily living, impact on the overall health; altered skin integrity related to irritation by the stoma contents and effect on the clothes worn have also been reported in another study (Shaffy, Das, & Gupta, 2012). The authors however did not reveal the time that elapsed since the diagnosis and the creation of the ostomies as a study reported that longer elapsed time has a positive effect on how a person with ostomy adjusts (El-tawil & Nightingale, 2013).

Stoma brings a major change in physical appearance and bodily function and patients with stoma are challenged with a number of quality of life (QOL) issues. If there are problems associated with the stoma, it is more difficult to learn to adjust to life with a stoma than without such complications. The occurrence of stoma complications is multifactorial; from the making of the stoma till its location, obesity, and influence of the age factor. Thus, when these factors are associated with the physiological changes of aging, the expected outcome is a greater vulnerability with respect to the incidence of complications in the stoma (Moreira et al., 2016). Salter (1992) compared people with a stoma and people with an internal pouch who no longer had a stoma. One issue that six out of seven ostomates identified was that the stoma appliance was noisy and there was gaseous distension of the appliance, which



at times led to the appliance leaking. This resulted in patients expressing concerns regarding choice of clothing and cleanliness. In recent times, in the developed world, clothes, including underwear and swimwear, are available that are specifically designed to disguise stoma appliances (Burch, 2014).

Age is a factor that also affects physical well-being of people who have intestinal stomas. According to a study by Nicholas, Swan, Gerstle, Allan and Griffiths (2008), teens, due to their natural curiosity, cope with the presence of the ostomy better than adults; they accept the device more easily, explore strategies for dealing with their situation, and feel the stoma saved their lives. In a retrospective study to examine how age affects postoperative stoma-associated outcomes, including self-efficacy and QoL, results suggest that the QoL of older people is equal to, if not higher than, that of younger patients. Because older patients are physiologically and psychologically different from their younger counterparts, understanding the effect of an ostomy on their QoL is crucial to addressing their needs (Selina, Pang, Sandy, & Rachel, 2013). The study was designed primarily to compare older and younger patients in terms of overall self-efficacy and QOL and did not measure other physiologic and psychosocial domains that likely also account for differences in QoL that are not explained by self-efficacy alone.

In another study by Scarpa, Barollo, Polese and Keighley (2004) involving 34 patients with ileostomies following colorectal cancer findings showed that QOL scores were consistent in three age groups (<50, 50 to 70, >70 years of age), but older patients required additional assistance taking care of their stomas.

Physical changes have significance to the individual, emotionally, socially and psychologically (Brown & Randle, 2005).

### **Social Well-being of People with Ostomies**

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 (Sampai, Aquino, Leite de Araújo, & Galvão, 2008). A study conducted 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 (Pringle & Swan, 2001). This study did not indicate whether, the problems above were assessed before the creation of the ostomies as it is likely that the problems may have existed even before the ostomy creation.

Simmons, Smith, Bobb and Liles ( 2007) 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. Studies that investigated problems of stoma patients in the postoperative period also reported patients experienced a deterioration in their relationships due to the change in their body image and the new lifestyle limitations associated with their stoma (Sprunk & Alteneder, 2000; Brown & Randle, 2005).

There has been technological advancement in recent times to improve ostomy equipment, but the psychosocial problems, taboos, and stigma still exist (Gautam, Koirala, Poudel, & Paudel, 2016). Sarabi, Navipour, and Mohammadi, (2015), found out that the fear of leakage caused by failure of appliances and inappropriate siting were daily problems. Patients' main

complaints were inability to control odors 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. However, the study results may not be generalizable to the larger society because results are limited to patients who were recruited from International Ostomy Association and they may be different for patients with no access to the resources of the association.

A cross-sectional study conducted to examine the psychosocial adjustment in patients with ostomy visiting selected stoma clinics of Nepal showed moderate impairment in the psychosocial adjustment among ostomates (Koirala, Poudel, & Paudel, 2016). Although overall psychosocial adjustment was moderately impaired, a detailed analysis of the subscales demonstrated multiple concerns in their life, where the majority of them had difficulties in sleeping, bathing, and enjoying foods and drinks as much as before the surgery. Most of them were conscious about stoma leakage, smell, or noise. Restrictions in activities due to stoma, difficulty in mixing within society, and less sexual attraction were major concerns for them. They were particularly fearful about the reaction of others. The study may not reflect an overall picture of the many ostomates who have no access to stoma clinics.

A similar finding was noted in a previous study by, Cheng, Meng, Yang and Zhang (2013) wherein patients with ostomy had a moderate level of psychosocial adjustment. Other studies by Piwonka and Merino (1999); and Haugen, Bliss, and Savik (2006) reported good overall adjustment on social, occupational, and family concerns. The conflicting result should be interpreted by considering the differences in conceptualization of psychosocial

adjustment, the use of different tools for measurement, and different timing during measurement in various studies. Increased time since ostomy surgery significantly predicted a higher psychosocial adjustment score (Dabirian et al., 2011).

A study by Cheng, Meng, Yang, and Zhang (2013), with colostomates from an outpatient clinic used Ostomates Adjustment Inventory to assess the level of psychosocial adjustment. The results a moderate level of psychosocial adjustment. However, the score was lowest for social life adjustment, and this implies that despite the advancement in supplies and technologies since the nineteenth century, no significant changes have been reported in the adjustment problems faced by this group of patients.

In Turkey, a prospective study conducted to assess social adjustment using the Ostomy Adjustment Inventory-23 (OAI-23) in patients with an intestinal stoma revealed significant improvements in adjustment among married patients over time (Karadag et al., 2015). Support from one's partner has been identified as being a contributing factor to adjustment (Wade, 1990). Social support provided by an individual's family, children, or friends also had a positive influence on adjustment (Piwonka, 1999). In another study, it was demonstrated that family support and personalized professional care are crucial for the individual to adapt to the new condition and consequently, to have a better quality of life (Salles, Becker, & Faria, 2014). Others have used other scales like the psychosocial adjustment scale to determine how ostomates adjusted psychologically and socially (Koirala, Poudel, & Paudel, 2016). Therefore, findings of studies that used assessment tools should be

interpreted carefully because of varying conceptualization of psychosocial adjustment and the use of different assessment tools.

Having a stoma presents a social issue that influences not only patients with the stoma, but also their partners, families, and close circles. In a study, Altschuler et al. (2009), reported that performing care together with one's partner has a positive impact on psychosocial adjustment. In another study in Iran, Dabirian et al. (2011), write that ostomates reported having encountered family problems for a few months after their colostomy, which gradually improved with time. From the ostomates' perspective, an ongoing relationship with the Iranian Ostomy Association improved mood and ability to relax when they were able to have contact with fellow members of the association.

Within the social well-being domain, problems with sexual intimacy have been reported. Manderson (2005) exclusively sought to identify and describe the challenges ostomates face in negotiating their sexuality around their incontinence. The strength of the Manderson study is its provision of rich descriptions of the sexual difficulties faced by ostomates. 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. Grant et al. (2013), in a study also reported that people with ostomies have difficulty developing and keeping relationships, and sexual activity can be challenging because of

changes in appearance, the potential for visibility of fecal material, and the loss of control that comes with sexual activity.

### **Psychological Well-being of People with Ostomy**

The impact caused by a presence of a stoma interferes with the intrapsychic sphere and the self-image of the body. This transformation has, as consequence, various negative reactions and reduces self-esteem as well as fostering a perception of loss of life on the part of a patient with a stoma (Mahjoubi, Mirzaei, Azizi, Jafarinaia, & Zahedi-shoolami, 2012). The body image is one of the fundamental components of identification. Any alteration arising from a bodily mutilation (intestinal stoma) confronts the person with the representation an ideal body – based on concepts of harmony, beauty and health, and may lead people to feel aversion to their own bodies (Kimura, Kamada, Jesus, & Guilhem, 2014). White and Hunt (1997) reported that about a quarter of patients experienced significant psychological symptoms. The commonest problems are adjustment disorders with anxious and/or depressed mood, major depressive disorder, panic disorder with or without agoraphobia, social phobia and generalized anxiety disorder. Hunt added that patients who had a history of psychological difficulties are at particular risk of developing psychological problems after surgery and that patients who were dissatisfied with their preparation are more likely to develop significant psychological morbidity than those patients who perceive their preparation as satisfactory. They emphasized the importance of routinely asking patients preoperatively about the presence of a past psychiatric history indicating that patients who have such a history should be prepared thoroughly for surgery

and followed up soon after discharge from hospital in order that psychological symptoms can be identified if present and appropriate measures taken.

Uncertainty may also manifest as fear of embarrassment, where incidents such as ostomy leakage, odour, gas, and noise have been shown to affect quality of life (Annells, 2006; Mitchell et al., 2007). For example, embarrassment in American Veterans with an ostomy (n = 239, 51.2% return rate) was examined using the modified City of Hope Quality of Life-Ostomy questionnaire and open-ended questions related to living with an ostomy (Mitchell et al., 2007). Among the findings, researchers noted that higher levels of embarrassment were linked to poorer quality of life socially, psychologically, physically, and spiritually; and increased reports of anxiety, depression, intimacy issues, and feelings of isolation. Uncertainty may also lead to worrying about leakage or flatulence (Andersson, Engström, & Söderberg, 2010; Lynch, Hawkes, Steginga, Leggett, & Aitken, 2008) and having enough ostomy supplies and disposal of the ostomy pouch in public.

Nurses are able to help patients anticipate problems and manage their emotional distress. For example, nurses can educate patients with ideas to help them decrease the probability of encountering embarrassing situations (Mitchell et al., 2007). Nurses can also assist patients with confronting the circumstances surrounding the altered reality to help them reduce their uncertainty, such as acknowledging the permanency of their altered reality and the ensuing changes, providing education and information, and encouraging “normal” behaviours (Selder, 1989). Mindfulness training, or the practice of being open to change in a non-judgmental, trusting, and accepting manner, is another strategy to help patients with an ostomy transition (Trunnell, 1996).

However, evaluation of this intervention is not apparent. More research on the emotional care needs of patients with an ostomy and interventions to address these needs is required

The length of time that elapsed since the creation of an ostomy is also essential in the psychological well-being of patients with ostomies. In a quantitative study, to find out the effect of the long term effects of patients with a stoma, it was concluded that participants with a longer elapsed time after diagnosis were more likely to feel better, to have better self-perception, to be more satisfied about their sexual performance, and to enjoy the things they used to before contracting the disease (El-tawil & Nightingale, 2013).

### **Spiritual Well-being of Patients with Ostomy**

According to the National Institute of Cancer (2009), spirituality is defined as an individual's sense of peace, purpose, and connection to others, and beliefs about the meaning of life that may be expressed through religion or other means, while religiosity, one type of expression of spirituality, is defined as a set of beliefs and practices associated with a particular religious tradition or denomination. Spirituality is something broader and more personal, and is related to a set of inner values, inner wholeness, harmony, and connection with others; it stimulates an interest in others and in ourselves and looks for a unity with life, nature, and the universe (Moreira et al., 2016). Spirituality is what gives meaning to life, regardless of one's religion, and thus, generates the capacity to endure debilitating feelings of guilt, anger and anxiety; furthermore, spiritualist aspects can mobilize positive energies and improve the quality of life (Moreira et al., 2016).



In a quantitative study to evaluate the association of socio-demographic factors with hope for cure and levels of religiosity and spirituality in patients with venous leg ulcers (VLUs), religious people were found to be physically healthier, have more healthful lifestyles and require less health care. It was recognized that the health of individuals is determined by the interaction of physical, mental, social and spiritual factors (Salome, de Almeida, & Ferreira, 2015). Spirituality contributes to the well-being of ostomized people, favoring their resilience in the success of self-care and rehabilitation. Certain religious and spiritual behaviors and beliefs are directly related to overall happiness and physical health, considering that they discourage an engagement in unhealthy behaviors. Moreira et al. (2016), in a quantitative study concluded that ostomized patients believe that can control their health and that those people involved in their care and rehabilitation can contribute to their improvement. They believe in a divine influence on the cure or improvement, through religious practices or beliefs.

In a study to find out the quality of life of Muslim patients with stomas, Ahmad et al. (2011), reported religious well-being was preserved with a statistically significant difference to other health related QOL domains. This was contrary to the belief that Muslim patients will lose their feeling of effective hygiene necessary to perform religious rituals (ghusal/bath and wudhoo/ablution). They concluded that, probably Muslim religious leaders better counsel their followers about religious matters and they have greater influence and control over the followers than doctors, nurses and psychologists. However, the researcher could not find any studies validating

the Quality of Life Scale for Muslim Stoma Patients, (QOLS-MSP) that was used for the study.

Another study in Nepal revealed that patients expressed that they were “Asuddha” [impure] because of the ostomy bag that they carried, and thus, they refrained themselves from performing religious activities. This is due to the effect of cultural value given to “Suddha” [pure] body for performing religious rituals in Nepal, where, to worship God, people often bath and even change their dress that had been worn during the elimination of body waste (Gautam et al., 2016).

Transitions from any state in life are influenced by meanings individuals attach to the transition experience, as well as cultural beliefs and attitudes (Meleis, 2007). For example, using the Ostomy Adjustment Inventory-23 scale, it was found that Japanese participants with an ostomy (n = 484), were less accepting of their ostomy and the changes it entailed compared with British participants with an ostomy (n = 464) (Simmons, Maekawa, & Smith, 2011). Findings were attributed to possible cultural beliefs and attitudes, including the notion that Asians may perceive disabilities as morally based, self-imposed, and preventable. Hence, the study suggests that individual cultural beliefs and attitudes may influence adjustment to an ostomy. Cultural beliefs and attitudes are often shaped by religion and spirituality but remains unknown how culture will manifest among the Ghanaian population with stomas experiences.

In another study conducted on ostomized people in Brazil, the findings showed that these individuals have hope and faith in God that they will improve and that they pray to God for obtaining help to face the difficult

situations they are experiencing (Moreira et al., 2016). For ostomized people, spirituality can be contemplated as one of the coping resources in performing self-care and rehabilitation. Spirituality contributes to the well-being of ostomized people, favoring their resilience in the success of self-care and rehabilitation (Moreira et al., 2016). Certain religious and spiritual behaviors and beliefs are directly related to overall happiness and physical health, considering that they discourage an engagement in unhealthy behaviors (Moreira et al., 2016). It was concluded that ostomized patients believe in a divine influence on the cure or improvement, through religious practices or beliefs. This study did not mention the use of the statistical method in determining the sample size therefore generalization of the findings may not be accurate.

Spirituality and religiosity is also perceived as a negative force in healing (Puchalski, 2010). Some investigations have found that spiritual and religious experiences and practices cause depression, poorer QOL, and callousness towards others if people saw their ailments as a punishment from God. They often feel excessive guilt, or if they had an absolute belief in prayer and cure and cure did not occur (Puchalski, 2010).

In summary, spiritual care needs are important, but little is known about its effectiveness in patients with an ostomy, highlighting the need for more exploration into interventions that effectively address the spiritual care needs of patients with an ostomy especially in Sub Saharan Africa.

### **Coping with an ostomy**

Lazarus and Folkman (1984) identified that coping strategies of individuals may be in the form of problem-solving coping strategies and

emotion-focused coping strategies which refers to efforts to manage or change problems or improve the relationship between people and the environment respectively. He explained that strategies that could be adaptive, which are more closely related to reality and to the possibility of removing or minimizing the stressful source. Emotion-focused coping strategies involve the attempt to replace or regulate the emotional impact of stress on the individual. They mainly stem from defensive processes which cause individuals to avoid conscious confrontation with a threatening reality (Lazarus & Folkman, 1984). In a study, Knowles et al. (2014), reported that maladaptive coping style (e.g., ignore problems) exacerbated depression and anxiety symptoms, while self-efficacy and emotion-focused coping style (eg, seek advice) ameliorate depression. They further reported that the increase in the number of months since the ostomy surgery increased emotion-focused coping.

In another study, it was revealed that the strategies the patients highlighted that enabled them to cope with their situation were focused on technical issues regarding self-care (irrigation, eating, skin and stoma hygiene and care, pouch change and use of other kind of devices) and technical aspects to solve problems related to gases and the escape of faeces; they also underlined actions focused on the adaptation to the bodily change and self-help (Barnabe, Cristina, & Dell, 2008). Irrigation has beneficial effects to the ostomates and is an effective way of coping with an ostomy (Rooney, 2007). The benefits of irrigation grant the subjects the possibility of living a fuller life and with less limitations, endorsed by the autonomy this technique endorses in ostomates (Varma, 2009). Nevertheless, it has been observed that lack of

knowledge about this technique can make the people feel reluctant to practice it, despite the benefits it offers (Krouse et al., 2009).

The set of coping forms ostomates adopt to face their new situation include a range of answers, centered on the problem as well as on emotions, such as the mood, the acknowledgement of positive changes, repression, denial, normalization, resignification or cover-up (Krouse et al., 2009).

According to Bonill-de-las-Nieves et al. (2014), peer groups are instrumental in coping at the level of individuals or associations, in that ostomates consider information from peers as very credible and are more likely to abide by them.

In a qualitative study, Krouse et al. (2009), found that the most frequently expressed issues and advice for veteran ostomates were the need for positive thinking and insight regarding adjustment over time. Their coping strategies included the use of humor, recognition of positive changes resulting from the stoma, and normalization of life with an ostomy.

### **The Specialist Nurse and the Patient's Pathway**

Since the education of the first enterostomal therapist in the 1960s the teaching and guiding of patients related to handling the stoma has been performed by registered nurses, who have specialized training in this special area of the surgical treatment and care (Turnbull & Erwin-Toth, 1999). Their primary role is informing and preparing patients and relatives preoperatively, and in addition, they stay in contact with patients after surgery in the rehabilitation course (Perrin, 1999; Doughty, 1992).

The current approach to ostomy care is based on the patients' need to be self-sufficient and being in personal control. The aim is to let the person at

risk of living a restricted life due to social, physical or mental restricting conditions have the possibility to live a self-determining and coherent life. Self-care for ostomates is considered the most important factor that minimizes the complaints and complications rate as well as providing good health state (Patwardhan, 2000). In addition to this, hospital stays are shorter nowadays, often leaving patients little time to adapt and adequately prepare to take care of their stoma upon release from the hospital.

Patient education is one of the main duties of the EN towards an ostomate. Studies have shown that ostomates with more knowledge report better stoma function (Lorig & Holman, 2003). Healthcare providers play a critical role in educating stoma patients and these providers teach the patients strategies to cope with stoma-related issues, such as the foods and fluids that can produce gas and ways to remove flatus from the appliance without causing unnecessary odor-related embarrassment (Liao & Qin, 2014).

In a study to find out whether patient education has a positive effect in patients with stoma, Danielsen (2013), reported that patient education had a positive impact in several areas including shorter hospital stays, less time until proficiency in stoma management is reached, an increase in quality of life, increased knowledge about the stoma, and increased self- efficacy. Gaber and El-gamil (2006), in a study reported that significant positive relation between patient's knowledge about self-care performance and the following domains in the quality of life (psychological well-being, physical well-being, body image, pain, sexual activity and nutrition concerns, in addition to patient's satisfaction, self-efficacy and teaching). Also, it was found that patient's knowledge related to definition of colostomy and complication of mucus

membrane of stoma had a significant relation with the majority of quality of life domains. This implies that when the patient's knowledge increased about stoma it had its effects of patients' psychological, physical and social well-being and his satisfaction and self-efficacy. It might be related to patients more understanding to his/her condition (Gaber & El-gamil, 2006). This study however did not specify how long the stomas had been insitu as other studies have shown that the length of time since ostomy creation correlates positively with patients overall well-being and QOL (El-tawil & Nightingale, 2010).

In the Montreux study, (Marquis, Marrel, & Jambon, 2003), it was reported that satisfaction with the care received, confidence in changing the appliance, and the relationship with the enterostomal therapist all appear to affect patient quality of life. Patients who reported that the stoma care nurse took a genuine interest had the highest quality-of-life index post- surgery.

Nurses caring for individuals with ostomy have an important role to play in relation to information provision and reassurance. Nursing role in the management of patients with colostomy has become increasingly significant within healthcare provision due to increased incidence and prevalence of this condition. It is necessary that the nurse understands the impact that colostomy can have upon an individual's quality of life (Gaber & El-gamil, 2006). It is important to help these patients to adapt successfully to a new phase in their lives by providing appropriate pre and postoperative education. Pittman, Rawl and Schmidt (2008) found that many factors, including age, income, employment, preoperative care (stoma site marking and education), and time since surgery, were related to severity of ostomy complications. Patients who receive appropriate care, can cope with their ostomies and regain their

independence over a period of 2–3 weeks or less (Dabirian et al., 2011). Because the degree of problems experienced by ostomy patients largely relates to their experience and skill in self-care, Dabirian et al. (2011), reported that patients have the best chance of returning to their usual lives if they receive continuing education during the transition from hospital to their homes. Nurses have an important role to play in ongoing training and guidance.

Stott et al. (2013), reported that a third of patients were not confident in their stoma care at the time of discharge, although satisfaction with the stoma care service was high. Conversely, most Chinese patients felt confident caring for their stoma following discharge (Wu, Chau & Twinn, 2007). It could be presumed that although some people with ostomies were not very confident, they were able to undertake some basic care of the stoma. This suggests individuals may benefit from training on the practical care of the stoma to increase their confidence. Burch (2014) reported that during the time in hospital, ostomates may not be able to fully focus. In some cases, survivors adapt to ostomy and appliance care needs based on trial and error, where effective and ineffective solutions are tried in order to find the best strategies to manage the practical aspects of ostomy care on issues such as returning to work or other social activities (Popek et al., 2010). Therefore addressing topics of education at a subsequent dates when ostomates are out of the hospital is important.

Anecdotal evidence reveal that nurses in Ghana often give interventions to ostomates in Ghana without having focused on a research-based exploration of the effects of their interventions. With this study, the researcher hopes to be able to gain perspectives of consumers of these



interventions reading their life experiences with stomas to inform health professionals in clinical setting.

### **Chapter Summary**

The literature reviewed so far revealed that the creation of an ostomy has physical, social, psychological and spiritual effects on ostomates. With the main aim of improving the quality of life of ostomates, ostomies present with a plethora of issues most of which are not desirable. The extent of physical changes to a reasonable degree has a role to play on the social, psychological and spiritual well-being of the ostomate. Each of these dimensions however is dependent on the other and are important determinants of QOL of ostomates. All of these dimensions are important in the determination of the QOL of ostomates. Many scales like the ostomy inventory scale, psychosocial adjustment scale, Stoma quality of life index and others are invented and used to assess the well-being of ostomates but there were limited qualitative studies.

Family members, spouses and stoma care nurses play a major role in the adaptation and the improvement of quality of life of ostomates. Ostomates who had knowledge and guidance from nurses during the transition from hospice care to home had a better quality of life. Most of the studies reviewed however, are from developed countries and therefore may not reflect the experiences of ostomates in Ghana. There is a gap in knowledge about experiences of ostomates and the outcome of the health care rendered to ostomates in Ghana. In this study, the experiences of ostomates in Ghana will be brought to the fore. It is hoped that findings from the study will help develop appropriate interventions that will address the needs of ostomates.

## CHAPTER THREE

### METHODOLOGY

This chapter describes the study design, study area, target population, sampling procedure, data collection instrument, data collection procedure and data analysis.

#### Study Design

A phenomenological lens based on Heidegger's (1927/2010) philosophy was used to inform the design of this study. Phenomenology is a qualitative research methodology rooted in philosophy and psychology (Polit & Beck, 2008). The methodology does not attempt to provide an answer, but rather contributes a description of how an individual lived an experience on a deeper level of understanding (Bassett, 2004). Earlier studies conducted using quantitative methods (Herlufsen et al., 2006; Simmons et al., 2011) provide an understanding of the outcomes of ostomy surgery for patients and the multiple factors that may influence quality of life. However, these studies do not provide for a deeper understanding of the lived experience of patients with an ostomy. Phenomenology "allows the 'things' to speak for themselves while at the same time contextualizing them" (McConnell-Henry, Chapman, & Francis, 2009 p. 8). Hence, the goal of phenomenological research design is to examine an individual's lived experience regardless of the philosophy underlying the phenomenological lens (McConnell-Henry, Chapman, & Francis, 2009). The following section describes the two major philosophical approaches within phenomenology: Heideggerian and Husserlian, and the reason for choosing the Heideggerian approach in this study.

### **Husserl's phenomenological philosophy**

Edmond Husserl, considered the Father of Phenomenology, believed knowledge came from the conscious awareness of things and that the essence of an experience was pure (McConnell-Henry et al., 2009). For him, context was insignificant. He contended that the understanding of human experience could be achieved by studying the natural state of things in a thorough and unbiased fashion using the phenomenological reduction (Dowling, 2007), or the critical examination of something prior to exposing it to influencing prejudices. Hence, he believed that bracketing or the suspension of the investigator's prejudices (epoche) facilitated the emergence of the phenomenon's essence (Dowling, 2007). Consequently, in this type of phenomenology, knowledge is the understanding of the lived experience stripped of context; it is purely descriptive (McConnell-Henry et al., 2009).

### **Heidegger's phenomenological philosophy**

One notable critic of Husserl's phenomenology was his student Martin Heidegger. Unlike a Husserlian phenomenological lens, which is descriptive, a Heideggerian phenomenological lens is hermeneutic or interpretive (Polit & Beck, 2008). Heidegger believed that to understand a phenomenon, one had to understand what is meant by, to be in the world (Dasein). Heidegger believed that an individual's experiences and the meaning of those experiences could not be separated (Bassett, 2004) hence, bracketing could not be accomplished. Context was important to Heidegger because he believed temporality and spatiality were central to being in the world since nothing could be gained statistically. Time, according to Heidegger, was fluid, where past experiences influenced present and future experiences (McConnell-Henry et al., 2009);

therefore, understanding the meaning of any experience required context (Johnson, 2000).

A Heideggerian phenomenological lens is chosen to guide this study because it acknowledges the importance and influence of context and time, as well as space, in understanding the meaning of the lived experience of patients. By applying a phenomenological lens, insights into patients' lived experience, and how to support patients effectively after hospital discharge can be achieved.

### **Investigator's background and assumptions**

Interpretation follows all experiences and this is often based on an individual's background (historicity) (Koch, 1995). Individuals are born into the world with a background that is shaped by a culture which existed before their birth, and it is this culture which facilitates understanding (Bassett, 2004; Koch, 1995). Hence, individuals have a pre- understanding or fore-structure of the world that is already present at birth and so, cannot be bracketed (Bassett, 2004; Koch, 1995; McConnell-Henry et al., 2009). In other words, an individual's experiences and the meaning of those experiences cannot be separated (Bassett, 2004; Johnson, 2000). To be understood, individuals must bring their background into the foreground (fore-conception) (Bassett, 2004; Koch, 1995). It is individuals' backgrounds that allow them to be in the world or Dasein; to find meaning in the world (Bassett, 2004; Koch, 1995). My assumptions were made explicit prior to data collection to increase credibility, or confidence in the truth of the data and interpretations. My being was shaped by my experiences as a general nurse who has worked in the surgical ward for three years caring for patients with ostomy and other surgical conditions. The

being of participants in this study was shaped by their experience of having undergone ostomy surgery and how they identified themselves as a person. Consequently, because my background cannot be bracketed, the understanding of participants' experiences can never be neutral because I inevitably co-participate in making the data (co- constitution) (Johnson, 2000; Koch, 1995). My attempt to understand the lived experience of patients with an ostomy following hospital discharge was approached with the beliefs that a) healthcare professionals influence patients' transition experience through the care that they provide to them, including direct clinical practice and education; b) patients are multidimensional, and their care needs are assessed best using a holistic approach to care; and c) following ostomy surgery, patients must learn to live a different way of life.

### **Study Area**

The study was carried out in the Accra Metropolis. It has a total land size of 200 square kilometres. Accra "district" is an urban metropolis with a total population of 1,848, 614 (Population Census Report, 2010). It is the most densely populated part of the Greater Accra Region. As at 2004, it was divided into 6 sub-metros namely Ablekuma, Ashiedu-Keteke, Ayawaso, Kpeshie, Okaikoi, and Osu-Clotey, but later it was increased to 13 by a legislative instrument. The health sector within this Metropolis continues to work according to the old system of 6 sub-metros. Towns in the Metropolis are grouped into: first class, second class, third class and fourth class residential areas. The sectors of Accra Metropolis economy consist of Primary Sector (farming, fishing, mining and quarrying), Secondary Sector (manufacturing, electricity, gas, water, construction) and Tertiary Sector (Wholesale trade,

retail trade, hotel, restaurant, transportation, storage, communication, financial intermediation, real estate service, public administration, education, health and other social services).

Generally, there are several levels and categories of health facilities within Accra and these are categorised into government, quasi-government, mission and private health facilities. The levels of health facilities include Hospitals, Health Centres/Health Post and others. There are 28 Hospitals in Accra Metropolis. One of such hospitals is the KBTH which served as the recruiting point for the study. KBTH was chosen as the recruitment centre because it is a multisite referral centre for the whole country where major surgeries like ostomies are mostly done. Recruitment was done at the OPD of the Department of Surgery. This Department is one of the earliest departments established in the KBTH to provide surgery and consultancy services as well as offer training and conduct research.

### **Population**

The study was conducted with patients with ostomies who were discharged home from the KBTH living in the Accra Metropolis. Because the study is qualitative, data redundancy determined the total number of participants used. A total of nine ostomates- six males and three females were used.

### **Inclusion criteria**

Eligible patients for this study included individuals who:

- a) had surgery for a temporary or permanent ostomy irrespective of the cause
- b) had been discharged from the hospital for at least a month

- c) were 18 years or more and could consent to the study

### **Exclusion criteria**

The study excluded the following as participants:

- a) ostomates less than 18 years
- b) ostomates with other illnesses or disabilities
- c) ostomates who were home for less than a month
- d) ostomates who could not speak Twi or English

### **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 (Polit & Beck). The researcher decides what needs to be known and sets out to find people who can and are willing to provide the information by virtue of knowledge or experience (Lewis & Sheppard, 2006). Ostomates who met the inclusion criteria were selected by a nurse at the surgical ward OPD to provide information on the phenomenon under study. A deliberate attempt was made to ensure the inclusion of male and female perspectives from different ages, and in various stages and time since the creation of the ostomy. The data collected became redundant on the 9<sup>th</sup> participant hence nine (9) participants were used for the study. Saturation or the replication and/or redundancy of data, establishes the final number of participants to be used (Bowen, 2008).

### **Data Collection Instrument**

Eight face-to-face interviews and one telephone interview were conducted with each participant using a semi-structured interview guide. A

face-to-face interview allows participants to narrate experiences in-depth and also allows the researcher to redirect participants' response when out of context (Creswell, 2014). The interview guide comprised of section two sections: A and B. Section A contained demographic information of the participants such as age, gender, employment status, indication for the ostomy, type of ostomy, religion, time that elapsed since the creation of the ostomy whilst section B contained questions based on the objectives of the study (See appendix C).

### **Pretesting of the interview guide**

Pretesting or piloting of the interview guide is the process of interviewing a few participants who share similar characteristics as participants in the study setting to ensure appropriateness of the interview guide (Hennink, Hutter, & Bailey, 2011). The interview guide was pretested on two ostomates identified at the Ridge Hospital. One question which stated "how did you get the ostomy" led participants giving answers like "I was sick and I went to the hospital and they did the operation"; they (doctors) did it in the hospital". The researcher realized that was not informative enough hence changed the question to "can you narrate the events that led to the need for you to have the stoma"? Pretesting ensured that questions were clear and understandable. The rest of the questions remained unchanged. Data gathered from the pretesting was not included in the main study.

### **Methodological rigour**

Rigour or trustworthiness in qualitative research ensures that findings accurately represent exactly what participants intended to say and that findings can be trusted (Lincoln & Guba, 1985). To ensure rigour the criteria of



credibility, transferability, dependability and confirmability must be met (Lincoln & Guba, 1985).

Credibility is achieved when the findings from the data reflects reality (Shenton, 2004). In order to ensure this, the researcher purposefully recruited participants who met the inclusion criteria and could give in-depth information on the lived experiences of ostomates. Member checks were conducted to verify responses of participants by discussing themes arrived at with them. In addition each interview was transcribed and coded before the subsequent ones. The researcher requested an independent coder to code some of the transcripts to allow for comparisons to be made.

The second criterion, transferability, is the extent to which the findings of the study can be applicable in other settings (Shenton, 2004). The researcher provided a detailed description of research setting, methodology and background of participants who were used in the study for other researchers to apply when transferring the conclusions of this study to other similar cases. All transcribed data and field notes were kept for audit trail.

Dependability, the third criteria pertains to whether or not the study can be replicated by another researcher (Gethins, 2012). To achieve dependability, the researcher worked with her supervisors from beginning of the research to the end. She provided detailed description of research setting, methodology and background of participants who were used in the study. All participants were interviewed with the same interview guide. Each transcript was subjected to the same method of arriving at themes and sub-themes. A peer researcher was allowed to examine data and this data was also re-coded to ensure accuracy. All documents were also kept for audit trail.

The last criterion, confirmability, is the ability of the researcher to present findings that reflect participants experiences and not that of the researcher (Shenton, 2004). To achieve confirmability the researcher sought in-depth experiences of ostomates. The researcher ensured reflexivity by making any biases known or declared. Additionally, observations made during the interview were entered into the field diary. The researcher strived to understand the realities ostomates face. In addition, interviews were transcribed immediately to prevent mixing of information.

To ensure reliability, a graduate student researcher, was allowed to code a selected transcript. Any disparities in the findings were noted and debated until a consensus was reached.

#### **Data Collection Procedure**

A nurse at the surgical unit OPD in charge of the ostomy patients of the KBTH identified ostomates who came to buy pouches for study eligibility, notified them of the study, and asked for their permission for the researcher to contact them and invited them to participate in the study. The researcher contacted them and sought their consent for the study. The researcher allowed a period of one week for participants to decide whether to participate in the study or not. When they agreed, the researcher asked the participant to choose a place convenient to them and approved by the researcher for the interview to be carried out. Seven interviews were conducted in participants' homes, one in the office and another over the telephone per participant's request. Participants signed or thumb printed consent form (See appendix A) before the commencement of the interview. In instances where participants could not read, English, the researcher sought input from an expert in Twi to ensure that

the right translation was done. A face- to-face in-depth interview and one telephone interview was then conducted and recorded in a tape recorder with permission from participants. Privacy was ensured during the interview. At times during the interview, participants smiled, chuckled, and laughed, while at other moments of the conversation they became moody. These were written in the memos (or field notes). Memos were dated for easy correlation with the data. The researcher probed during the interview to focus responses within the objectives of the study and also to get in- depth responses. Interviews ranged between 45 and 80 minutes. Each interview was transcribed verbatim and analysed immediately the researcher reaches her office. It took between three (3) to four (4) hours to transcribe each interview. Participants were allowed to validate key issues at the end of each analysed 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.

### **Ethical Considerations**

Ethical approval was obtained from the Institutional Review Board (IRB) of both the University of Cape Coast and the KBTH. Permission was sought from the surgical department of KBTH through the KBTH-IRB and an introductory letter from the School of Nursing and a copy of the ethical approval from UCC-IRB. The purpose, benefits and potential risks were explained to participants verbally and in the consent sheet. This was done a week before data collection to enable them think through to consider participation or otherwise. Only the participants who met the inclusion criteria and agreed to participate were given consent form to sign or thumbprint to indicate their consent. 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 raw data would be used for only academic purposes and that only the researcher, and the supervisor would have access to the raw data.

Anonymity of participants was ensured by assigning pseudonyms to participant during the recruitment. The pseudonyms were used when the participants were being quoted in the findings chapter. Privacy was ensured during the interview. Participants were informed that data and other study documents such as consent forms, audiotapes and transcripts would be kept under lock and key for at least five years after the study. The sheet containing demographic data and other identifiable information is being kept separately from transcripts under lock and key. Participants were informed that appropriate ethical clearance would be sought if the data has to be used in future for any other purpose.

### **Data management**

Prior to data collection, the date, time and venue of interview were recorded in a field diary. After each interview, with permission of respondent, data was transcribed verbatim and stored in word document. After transcription, hard copies of each document, audiotapes, field notes and diaries were locked in a safe cabinet in the researcher's office. The background information was labelled with the same pseudonyms used for the interview and stored safely in the same cabinet. Information will be discarded after five years.

## Data Processing and Analysis

Data analysis occurred concurrently with data collection. This allowed the researcher 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 (Braun & Clarke, 2006). 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 two ones were translated to English before being transcribed. The researcher did the transcription all by herself. She would listen to a sentence, pause the tape recorder, write it down and continue 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 to familiarize with the data. Whilst familiarizing with the data, the researcher made notes and noted down early impression of the interview being analysed. The researcher then began to organize data into a meaningful way by coding. The researcher was concerned with addressing specific research questions and analysed the data with each question in mind. Given this, the researcher then coded each segment of data that was relevant to or captured something interesting about the research question. Each transcript was coded separately. A graduate student also coded the transcripts. We then compared codes, modified them before moving on to

the rest of the transcripts. Codes that connote the same idea was labelled as sub-themes. This was done according to each research question. Sub-themes that suggested an idea were also then group as themes. Most codes were associated with one sub-theme whilst others were associated with more than one. Repetitive codes within a sub-theme were discarded. The researcher read data associated with each theme and considered whether the data indeed supported it. There were a total of five themes with twenty three sub-themes. The researcher then identified the essence of what each theme was about. Themes were then defined and meaning was made of participants narration through interpretation. Quotes from participants were used to support sub-themes in reporting the findings of the study.

The researcher carried out member checks, or follow-up interviews through telephone 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. Figure 2 shows how codes and subthemes were generated leading to the emergence of the theme; social well-being of ostomates.

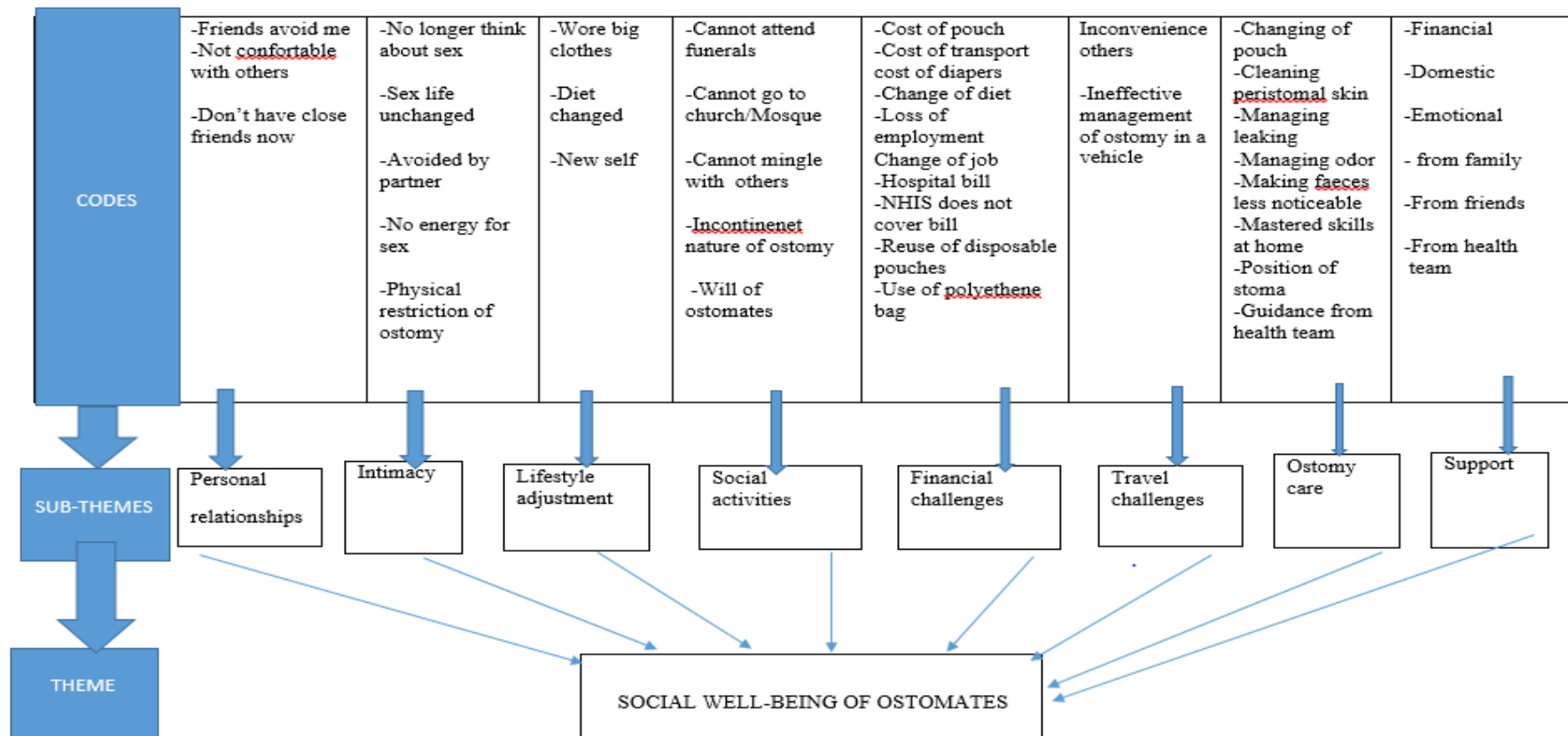


Figure 2: Codes, Sub-themes and Themes (Social Well-being of Ostomates)

## CHAPTER FOUR

### RESULTS AND DISCUSSION

This chapter presents the results after the analysis of data that was gathered from participants on their experiences of life with an ostomy. The study sought to explore the lived experiences of patients with ostomy living in the Accra Metropolis. Eight Face-to-face and one telephone interview was conducted. Data analysis was done using thematic analysis. Analysis was done taking into consideration the field notes that was taken to provide context and also to give a deeper understanding of the experiences of ostomates. Experiences that were common to participants as well as peculiar are also presented. The findings are presented according to the objectives of the study. The five themes that emerged are physical well-being of persons with ostomy, social well-being of persons with ostomy, psychological well-being of persons with ostomy, spiritual well-being of persons with ostomy and information needs. The main themes and their corresponding sub-themes are presented with verbatim quotations. In total, there are five (5) themes and twenty three (23) sub-themes.

#### **Demographic Data**

All participants were currently living with an ostomy. Table 1 provides a summary of participant characteristics. All participants in the study were assigned pseudonyms. Six male participants and three female participants were interviewed with ages ranging between 26 and 72 years. Diagnoses were received prior to surgery or shortly afterwards. Unplanned surgeries were urgent or emergency surgeries which resulted in an ostomy. Six participants stated that they were fully informed that their surgeries would result in an



ostomy and/or what having an ostomy entailed preoperatively, while three participants stated that they were minimally informed of this possibility. Ostomy types included both permanent (n = 5), temporary status (n = 2) and two were not told about the status and in one case, the ostomy changed from temporary to permanent status after two failed attempts to reverse it.

Two participants had ileostomy, and seven participants had a colostomy. Time elapsed between hospital discharge and interview ranged from 4 months to 3 years. The living state of participants included: married (n = 5), single (n = 2) and separated (n=1). There was a wide range of work status, including civil servant (n=2), retired (n = 1), self-employed (n = 5), unemployed (n = 1). Seven interviews were completed in participants' homes. One interview took place at a work office (as per the participant's request), and one over the telephone (as per the participant's request). All the respondents resided in urban settlements within the Accra Metropolis and spoke English and Twi.

**Table 1: Demographic Characteristics of Participants**

No.	Pseudo nym	Age	Sex	Marital status	Employment	Surgery type	Indication for ostomy	Ostomy type	Duration of ostomy	Time elapsed	Religion	Education level
1.	Kofi	38y	M	Single	Civil servant	Planned	Ulcerative Colitis	Colostomy	Temporary	11 months	Christian	Tertiary
2.	Dede	47y	F	Married	Self employed	Unplanned	Colorectal Cancer	Colostomy	Not told	1 year 5 months	Christian	JHS
3.	Lizzy	45y	F	Separated	Self employed	Planned	Colorectal Cancer	Colostomy	Temporary	2 years	Christian	Primary
4.	Tom	41y	M	Married	Civil servant	Planned	Fistula-in-Ano	Colostomy	Temporary	1 year 2 weeks	Christian	Tertiary
5.	AB	43y	M	Married	Unemployed	Planned	Colorectal Cancer	Colostomy	Permanent	1 year 9 months	Christian	None
6.	Ken	46y	M	Married	Self-employed	Unplanned	Diverticulitis	Colostomy	Not told	4 months	Christian	Secondary
7.	Ben	72y	M	Married	Pensioner	Planned	Prostate Cancer	Ileostomy	Temporary	9 months	Christian	Tertiary
8.	Lucy	26y	F	Single	Self employed	Unplanned	Intestinal obstruction	Ileostomy	Temporary	1 year	Christian	None
9.	Mohammed	50y	M	Married	Self-employed	Planned	Colorectal cancer	Colostomy	Permanent	3 years	Islam	None

Source: Field Survey (2017)

### Themes and sub-themes

There was a total of 5 themes and 23 sub-themes that emerged from the study results. Table 2 shows the themes and sub-themes.

**Table 2: Themes and Sub-themes**

1	Physical well-being of ostomates	Odor/gas Leaking Strength Sleep disturbance Overall physical wellbeing
2	Psychological well-being of ostomates	Uncertainty Getting on with life Anticipating problems Secrecy
3	Social well-being of ostomates	Social activities Travel challenges Intimacy Lifestyle adjustment Ostomy care Financial challenges Support
4	Spiritual well-being of ostomates	Spirituality Religious activities Hopefulness
6	Information needs	Doctors Nurses Internet

Source: Field survey (2017)

## Physical Well- Being of Ostomates

In response to the research question “what is the physical well-being of ostomates”? Five sub-themes were realized under this theme. These were odor/gas leakage, skin problems, strength, sleep disturbance and overall physical wellbeing.

### Odor/gas

Most of the participants complained of either unpleasant odor emanating from the ostomy creation or uncontrollable sound made by gas in the intestine.

*“the smell of the faeces was unbearable to me. The only scent you hear of is that of the toilet” Lizzy*

*“The reason I say that is because mostly when I pass gas from the stoma, it’s usually unconsciously or involuntary which can be smelly and embarrassing. Imagine having a visitor of reputable caliber visiting you then you start to give off all this gas unannounced” Dede*

*“Mostly before the toilet empties completely into the bag, you have to massage the stoma or your abdomen around the stoma to help it drain well. Now, the problem with this massage is the indiscriminate farting with its offensive odor. No matter how hard you try to be discrete about the whole thing, the smell and sound will definitely give you away” Tom*

*“My daily life was also affected drastically as I couldn’t go to work or perform some daily activities e.g. washing again due to pain and smell. I find it difficult mingling with others hence I had to quit my job. The*

*smell is unbearable to even me more to talk of others. It also comes unannounced anytime, anyplace”***AB**

### **Leaking**

Only two participants complained of leaking of the effluence when they use carrier polyethene bags. Using an ostomy pouch did not present them with the problem of leaking.

*“My main problem is when the faeces spill when I use the rubber bag. I sometimes use the “olonka rubber” especially when I am at home. As you know I can’t be using the proper bag everytime. I don’t have enough cash”.* **Dede**

*“If I don’t clean the area well and I place the bag, it leaks around”*

**Mohammed**

*“Sometimes when you use the rubber and you are not lucky, it bores a whole without your knowledge and before you know the faeces would have leaked on your clothes”* **Lucy**

### **Strength**

Most of the participants reported that the ostomy has made them loose their strength and unable to go about their daily activities as before. Some have had to stop working and others just stay at home because they do not have enough energy. Others said the lack of strength came from the sickness that indicated the ostomy and that the ostomy has come to make them even weaker.

*“It has made me very weak making it impossible for me to go anywhere as a result, I am always in the room, even as we speak. I cannot even walk well”* **Ken**

*“When I go somewhere, I often sit at one place I do not want to walk about because I do not have much energy. I do not even attempt to lift anything heavier than a pale of water”* **Dede**

*“Yes, it has hindered my daily activities. It has hindered my movement too. I wasn’t able to work for some time now. I was weak”* **Tom**

*“Hmmm, this thing (pointing to the ostomy) has turned made me to an old man. When I had the cancer, I was weak but when they did the surgery, I am even weaker now. I am even surprise that basic thing have become difficult for me to do but inshallah, everything will be fine”* **Mohammed**

### **Sleep disruption**

Sleep disruption was reported by some of the participants and it was for various reasons. Some could not sleep because they were in pain.

*“...sometimes I am not able to sleep due to the pain. i wake up and sit on the bed. So the following morning you see that I am so tired. Sometime, I am careful not to lie on the pouch, so that keeps waking me up”* **Dede**

*“I find it difficult sleeping sometimes especially when there is pain”*

**lizzy**

Others could not sleep because they were thinking about how soon they will recover or even whether they will ever be like they used to be.

*“As for sleeping, my sister, anytime I lie down to sleep, I am always thinking. I think a lot about the ostomy and whether I will ever be the same again. I know I have to sleep because it is good for my health but sometimes I find it difficult sleeping easily”* **Mohammed**

*“Like I said earlier, I believe in what the doctor told me, that this is temporary. Even though, I find it difficult sleeping I am sure with time, I will be fine. maybe it is because I think a lot about this thing”* **Ben**

*“... I had lots of sleepless nights thinking about it (the ostomy). I later on realized how it wasn't helping me in any way. Instead, my energy was drained due to the stress and sleepless nights”* **AB**

For some, frequency to the washroom to empty the pouch was what disrupts their sleep.

*“I get up now ... in the night, and I have to go maybe twice in the night to drain myself if you don't ,you will be sorry the following morning”*

**Kofi**

### **Overall physical well being**

Overall physical well-being refers to participants' awareness that changes have occurred following ostomy surgery. Ostomy changed how all participants perceived themselves. This was evident whether participants compared themselves to their past self or to others with regards to the ostomy.

*“When I woke up from the anaesthesia and everything was totally different! I had the stitches and all that and everything, tubes everywhere”!* **Kofi**

Participants notice a changed body image and their overall lifestyle changed, which were difficult to ignore.

*“everything just changes all of a sudden and everthing you used to do will have to change too. life just changes you can’t pretend or ignore”*

**Ben**

*“to adjust to a new state of going to toilet like that is not easy. ... other than the place one knows”* **Lizzy**

In addition to the physical change influencing their body image, participants also felt different since having the surgery

*“When you look around, you feel totally different. You feel like you’re a different person.”* **Dede**

When participants compared themselves to others feeling different about their body image was further illustrated. They reported that only a person with an ostomy could understand the situation.

*“Unless you actually have one, you won’t really know how it is”* **AB**

Having an ostomy required diet changes because diet affected bowel output (stool, flatus, noise)

*“It can really inflate much. It depends on what you have been eating or drinking”* **Kofi**

Participants learned to manage their bowel output through their diet, resulting in changes to their diet. Changes in diet included having to stop eating certain types of foods and introducing others. Others even had to skip dinner.

*“With heavy meals, I know very well how badly it can affect or hurt me so I restrict myself from taking any food. For instance, I took plantain some time back and I realized it didn’t help me at all just like some Fufu I took about a week ago, which also didn’t help me hence, I*



*decided never take any of these two diet again. The only food I eat now is one or let's say two if not Tuo Zaaŋi then Yam. With the yam, I boil it very well till it becomes soft then I take it with Kontomire” Lizzy*

*“My eating habit is bad now. In the first place, my stomach has become big and when I drink water, it tastes salty. Mostly I eat just once a day (i.e. porridge in the morning) because of how big (bloating) my abdomen feels. Due to that, I am always worried especially if I am about to eat again after breakfast. It's like anytime I eat, my abdomen gets bigger (bloating)” Ken*

*“When you eat, within a few minutes or hours, the thing (faeces) begins to pour.so because of that, I don't even eat supper” Ben*

### **Psychological Well-being of Ostomates**

In answering the question, “what is the psychological well-being of persons living with ostomy” Findings show that participants had no control over the behaviour of the ostomy, which affected them psychologically. Sub-themes that emerged were uncertainty, getting on with life, anticipating problems and secrecy.

#### **Uncertainty**

Participants feared that the ostomy could misbehave at any time making them not certain of what to expect.

*“You are not always sure about what will happen next, because you could end up with diarrhea or something else. So you're always in this state of discomfort almost because you do not know what to expect. This thing sometimes can be full of surprises (pointing to the ostomy)”*

### **Kofi**

As a result, participants began to prepare for possible problems.

*“Now I think twice everytime. ... I worry if I get out and if I have use the bathroom, I am always wondering how I will empty this and all that. For the house, I’m always Ok; a public place that is when there is a big problem. Anytime I go out, I’m always looking around to see what I can do should there be a problem”* **Ben**

*“Anytime, I have to leave the house, I carry an extra bag (ostomy bag). You never know what will happen”* **Ken**

A participant also worried about managing the ostomy output

*“I was to open the pouch to empty it and my hand slipped and everything was spilled everywhere”!* **Mohammed**

The lack of control over the unpredictable behaviour of the ostomy created fear of an unpleasant situation occurring.

### **Getting on with Life**

The sub-theme getting on with life is defined as accepting the ostomy and carrying on with everyday activities. All participants discussed experiences related to this sub-theme, which centered around the psychological aspect of how participants revealed an unenthusiastic acceptance and positive attitude to moving forward with life.

*“If you don’t have this done, your other alternative is you’re dead. ... what was my choice? Either this or I’m gone. ... I think you have to realize that and think, so, you have to get used to it because it saved your life and you’re going to be all right”* **Lucy**

*“I had to consent to the surgery otherwise it would have meant that I am choosing death”* **Mohammed**

Participants were averse to the ostomy surgery because the thought of living with an ostomy was a scary

*“it was easy at all.it seem like the worst thing that could ever happen to you. ... to me it was like, eei that would be very terrible to deal handle”*. **Kofi**

*“In fact, when he told me about the surgery, I was silent for a while. I didn't know what to say the other patients on the ward advised me to say Yes to the operation. I didn't know what it was so I told the doctor to explain things to me properly if he can but for the sake of my life I agreed. Due to the nature of the thing if only I would still be alive, then I will accept. But I was afraid of how the ostomy would be”* **Lizzy**

For one participant a positive attitude helped him continue living life.

*“I had hope that it was through this operation that I would be regaining my health and be ok”* **AB**

However, in some cases, when reversal surgery was not confirmed, it was difficult planning their next move

*“I don't know whether I will ever be the same. the nurses did not tell me if they will reverse the ostomy or not. I do not know what I can do now or later”* **Dede**

### **Anticipating problem**

Anticipating problems refers to minimizing the risk of an uncomfortable or embarrassing situation from occurring by preparing ahead of time and/or deliberately adjusting their activities. This bothers on the

uncontrollable nature of the ostomy, which compels them to continuously think about preparing for and preventing uncomfortable situations from occurring.

*“So what I sometimes do is to carry a jacket when I leave home, when I feel the thing (faeces) pouring out, then I wear the jacket. That way, the odour and sound is not noticed as it would have been” Lucy*

*“Like when I even go to church, I sit at the far end, not near anyone. I am more comfortable that way” Dede*

When preparing was not enough to minimize risks, some participants deliberately adjusted their lifestyle.

*“I asked the nurse and she told me I can always bath if I remove the pouch, but the problem is when you are in the bathroom and your body expels the faeces it a big mess.so you allow water at the site, some of the pouches can detach, so for me most often my daughter cleans me with towel and soap” Ken*

### **Secrecy**

This sub-theme is defined as the unwillingness associated with disclosure of the ostomy surgery to others. Participants’ described how their level of comfort varied, and was determined by the relationship they had with the audience and their potential reaction, the environment and participants’ circumstances, and personal perspectives.

*“My daughter and husband are the only people who know about it”*

**Dede**

*“My husband does not know about it. He knows I have been operated upon but he does not know I have an ostomy. I intend to keep it that way”* **Lizzy**

*“I hid it from her (girlfriend) for about 3 months. It took me 3 months before I could explain to her. She thinks this thing is taking so long. For me I’m prepared for anything, if she decides to leave... and nothing will affect me”* **Kofi**

The audience and strength of the relationship determined the level of comfort participants had about revealing their secret.

*“My wife and children are the only people who know about it. I also have my brother-in-law staying with us. He is also aware. You can’t be telling everyone your problem. You never know who you are talking to”* **Ken**

For one participant, he revealed the secret after the change in his ostomy status from temporary to permanent.

*“In the beginning I was not telling anyone except my family members who knew, I had hope that they will reverse it. But now what is the point in still hiding it. It will never go so I tell those all those who are supposed to know”* **AB**

Two participants shared how their significant other had shared their secret with others despite their request for privacy. They (significant other) did not want to be blamed in case anything unexpected happens.

*“When they did the operation I didn’t think it was necessary to tell some people but my first wife told them. She told some of my extended*

*family members. I told her not but she said that if it is kept a secret and anything happens they will blame her” Mohammed*

*“One day I was there and our pastor came to the house to pray for me. I thought it was one of those prayer but he stated saying things that meant that he knew about it. When he was gone, I asked my wife and she confirmed she told him and that she needed to. I didn’t like it but it has happened” Tom*

To one participant, disclosure meant potentially being overwhelmed by people asking how you are and wanting updates on the state of the ostomy.

*“...I don’t tell outsiders because every time they see you, they will always want to ask about the ostomy. They will ask for updates on the state of the ostomy and you have to keep explaining and reminding you of it. In the end, they can only pity you without helping” Lucy*

### **Social Well -being of Ostomates**

For the third research question “ what is the social well-being of persons living with ostomy, the subthemes that emerged were personal relationship, social activities, travel challenges, intimacy, lifestyle adjustment, ostomy care, financial challenges and support. Change in participants’ social life was shown to be connected to other aspects of their life. 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 outdoorings 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*

*“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 inconvenience the other passengers in the car and others did not travel because they worried about how to manage the 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 sister....sitting in a public transport with this thing, people would wonder why you smell and the sound too” 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**

Intimacy refers to the ability to share a deep, personal connection with a significant other after the ostomy creation. Engaging in sexual relation was a difficult task for some participants. They described how the ostomy was a barrier 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 not comfortable with the fact that I have a sore on my body”* **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 lady feel that I will get hurt, it’s 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**

### **Lifestyle Adjustment**

This describes how participants had to vary their lifestyle to suit their new situation. They changed several aspects of the way they did things such as their way of dressing, diet and the new person they now are.

*“I sit to wash now instead of bending.... and I now wear long and loose dresses 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 uncomfotability came when I got home and faeces started coming from that place. That was when I felt uncomfotable 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. The ostomy care involves changing the ostomy bag and cleaning the peristomal skin. 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 make the effort 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*

Regardless of the education received while in hospital, mastery of the skills required to manage the ostomy and the appliance occurred at home and participants expressed challenges faced.

*“The way the nurses taught me how to remove the pouch was not very good. When I went home I was spilling faeces anytime I had to empty the pouch. It’s okay now. I have learnt how to do it better now” Mohammed*

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 in front 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? Let’s 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.

*“The monetary aspect is difficult because my husband being 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, that 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 embarrass 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 also 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 by 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 polyethylene bag.

*“I buy it (colostomy bag) when what I have get finish. And anytime we buy, I 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. I mostly use the colostomy bag 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 participants developed was to wash or reuse bags. One participant shared why associated risks did not deter her.

*“My pastor bought some for me but they were 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**

### **Spiritual Well Being**

In relation to the research question “what is the Spiritual Well-Being of ostomates?” The sub-themes that were found in participants were religious activities, spirituality and hopefulness.

## **Spirituality**

Participants' spirituality remained intact. This is the belief in a higher authority. They acknowledged the importance of maintaining connection. Participants even now were closer to God. They pray often and thank Him for the gift of life. They believe they have been given a second chance to live; this helps them to cope with the situation.

*"It has strengthened me and brought closer to God. Whenever I went to church, the Parish Priest and the Choir sing and hail me during church services. I had no cause to complain because for the first time in a long time during my admission, all my children were gathered at one place which made me very happy even though I was sick. Am really grateful to God almighty for my life and how far he has brought me. It is what keeps me going"* **Ben**

*"Ohhh. When I wake every day to see my children and family without hearing or encountering any danger in my life, all I can do is to thank God Almighty. Aside thanking God what else can one do? Think and think until when? With God all things are possible"* **Lizzy**

## **Religious activities**

This involves engaging oneself in issues that pertain to the participant's religion. There are those activities that enable participants maintain a relationship with a deity. Some participants avoided any religious activity mainly because they may inconvenience others. Spirituality was maintained.

*Yes, it has had some effect. Throughout the time, I wore it, I couldn't go to church much. It has however not stopped me from praying. I'll*



*say it has made my faith stronger than before. Now that I have gone through all these, I know that yes, God can do it. Tom*

*“I was a regular church goer at least until after the surgery was done. And like I said before, I hate been a nuisance or the reason why someone will be uncomfortable. I would rather stay at home and pray than to visit the church and risk smelling all over the place. Nonetheless, I wouldn’t say I am growing away from God but rather the means through which I pray to him is what have changed” Ken*

*“Yes and No. Yes, because I don’t go to church regularly like I used to and no because I still have faith and pray to God almost always. I only attend prayer sessions and camps every once a while to be prayed for by my church members” AB*

*“...so you know as for prayer it is compulsory. I still do all my five daily prayers. I was told (by an imam) that I should not bother about the faeces . I make sure my clothes are clean and I perform wudhu (ablution) normally. The only thing is that, I do not go for congregational prayer. You won’t know when there will be sound “kruuu”, people will think its flatulence and that you have spoilt your wudhu. I just stay at home to pray I no longer go to the mosque. Allah knows best” Mohammed*

### **Hopefulness**

Participants were hopeful that their circumstances will get better and hoped that God will heal them.

*“For me I keep praying to God. I keep praying to God to save and make me well again so that I can continue with worshipping Him. With worship, I still have faith God will do it for me”* **Ken**

*“Looking back to the past, when my wound gapped and I had no hope of surviving, I thought to myself that this shouldn’t be happening to me. My children were all in tears when from nowhere I had some faith so I told them not to cry because I have seen someone who was in a worst ordeal then this yet the person survived.... It is not everybody who goes through such predicaments that comes out of it alive, you as a worker in the hospital should know that. My only prayer to God is for the doctors to be able to finish the rest of the operations successfully”*

**Lizzy**

*“When I was diagnosed of the disease (ulcerative colitis) I just said this is it. I thought it was a death sentence because the pain was too much, but the doctor explained that they could remove the disease if only I will consent (laughs). Why wouldn’t I agree to save my life? In fact, this thing (points to ostomy) saved me. I have hope that I will live to the time God has ordained for me to die”* **Kofi**

### **Coping with an Ostomy**

In addressing the question of how ostomates cope, it was realized that many were able to cope because of the support they received from others. Coping refers to the strategies a patient adopts to manage the consequences of undergoing ostomy surgery and the distress it entails so that a positive adjustment may be achieved. Participants mentioned support from others as their main coping strategy.

## **Support**

Support 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. The support offered was domestic, financial and emotional.

### **Domestic support**

Participants narrated how they received support in carrying out domestic chores from family members and friends.

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

*“I used to sweep round the whole house, it’s now my co tenant who does it. I find it difficult bending down”* **Lizzy**

*“I call my younger sister to wash my things when they are dirty. Sometimes, I don’t even call, she comes by herself to ask me if she should help me to do something. It has even made my little daughter active, sometimes I send her to run errands for me”* **Lucy**

### **Financial support**

Support also came in monetary terms.

*“I suffered financially even though my family members were giving their support randomly, it wasn’t enough”* **Mohammed**

*“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**

*“... the church brought me some money to aid with my expenses” Ben*

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

### **Emotional support**

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

*“Well the support was so great especially from my children and my wife. They were all by my side 24 hours a day. I have no reason to complain or to say I regret for being 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 calls to check on me, sends me money and encourages me”*

**Lucy**

### **Information needs**

Information needs is the knowledge resource that would enable ostomates manage their ostomy well to eventually regain their independence, accepting their ostomy as a means to survive, living positively, and moving forward. Sub-themes were information generally received from the doctors, nurses and the internet.

### **From the doctor**

Participants narrated that the information they received from the doctor was preoperative when he informed them about the need for the surgery. Useful information on how to manage the ostomy did not come from him. For some participants, in general, answers provided by physicians were helpful, but for some, physicians provided vague or insufficient information regarding the ostomy.

*“All that the Doctors; Dr. C, Prof T, Dr. A and the others told me was to be very very careful so I don’t fall down. They advised my children about my diet too; what to eat and what not to eat, when to eat and when not to eat and so on. They only talked so much about my diet and walking. In all, the advice was helpful”* **Ben**

*“I don’t have any problem with the doctors, I remember the only thing he said was that I need to have the operation and asked me to go and prepare and come. He explained that if I did not do the operation, the cancer would get worse”* **Mohammed**

*“They didn’t tell me what specifically my problem is but only told me I needed to be operated on. They never told me whether they will do it twice or once. They just operated that’s all. I only remember them referring to the Hematologist who also requested for some tests to be ran. After I went for the results of that test which took two months, the haematologist asked for more labs which I am yet to present those results. The doctor then told me that they will take care of the whole thing (my problem) immediately all labs and tests results are done”*

**Ken**

#### **From the nurse**

Many participants mentioned that the information they received from the nurses have been very useful and they have adhered to it. Some were specifically taught by the nurses on how to manage themselves whilst on admission. Others said there was no planned education; they just observed what the nurse on the ward did when changing the pouch.

*“The nurses told me what I should do when I am living at home with the ostomy; like how I should bath, what to do so that I don’t get problems from the site. They also told me things to eat and those to avoid. So I don’t eat beans and cabbage. I don’t also drink alcohol too”* **Tom**

*“They took very good care of me while I was on admission. The medications, assisted personal hygiene and series of education they gave me helped me during my recovery. Unfortunately, I don’t recall the details of most of them. I remember the advice on what time of the day I should eat and what kind of food to eat. I receive every necessary*

*support I believe I should have received from the team. One of the nurses' I recall, told me about another colleague from whom I can buy the colostomy bag from which to me was very helpful. The nurse who sells the bag hence taught me how to change the bag regularly and also how to keep myself clean always” Ben*

For two participants, the education the nurses gave was not adequate nor helpful; they had to do trial and error until they could figure out what works best for them.

*“...and on the day I was to be discharged from the hospital, a nurse came, I think she was a student, and say some confusing things like use gauze( laughs) , I didn't know what that was, to clean the area and that I should eat lots of fruits. So in the beginning I was eating lots of fruits but it didn't help at all. The faeces was too watery and the sound was something else. I don't eat many fruits, only banana and pear; like twice a week” Mohammed*

*“The nurses in the ward didn't teach me how to use the pouch. They showed me where I could buy the bag, it was that lady, she is a nurse who taught me how to use it. She is good. Anytime I come for review she is the one I ask anything I want to know but what I have realized is that when I sweat, the attachment becomes poor. So I try to keep the place as dry as possible but the nurses didn't tell me that” Kofi*

#### **From the internet**

Two participants cited the internet has being very helpful in seeking information about managing an ostomy.

*“I sometimes surf the internet to find out information about the ostomy. It is not everything you have to run to the doctor. When you go online, you will see that others have similar problems. I even tried to do some of the things I read on the net like irrigation, but I couldn't do it well” Ben*

*“My son helps me with information from the internet. Some time ago, he showed me pictures of what could happen to the skin around the stoma if I do not manage the area well. Since then, I am always very careful and particular about that area” AB*

### **Summary of Findings**

The findings of this study reveal the various dimensions of the experiences of ostomates living in the homes in Accra Metropolis. The findings reveal that the ostomates adjusted several aspects of their lives to adapt well to their new self. Many experienced sleep disruption and had to change their diet, and way of dressing. The ostomy affected the way they mingled with people and the uncontrollable nature of the ostomy brought about some level of uncertainty. Many had their religiosity affected whilst their spirituality remained unaffected. Participants had domestic, financial and emotional support from family members which helped them to cope. Constant awareness of the ostomy to the ostomates compels them to continuously think about preparing for and preventing uncomfortable situations from occurring. Appropriate information about management of ostomy is vital in creating a positive pathway.



## **Discussion of Findings**

The aim of this study was to describe the lived experiences of patients with an Ostomy following hospital discharge in the Accra Metropolis. The discussion is organized under demographic characteristics followed by physical, social, psychological, spiritual well-being and information needs.

### **Demographic Characteristics**

The commonest indication for ostomy surgery was colorectal cancer. This perhaps led the ostomates to consent to the ostomy creation despite perceived inconveniences as they feared that death could occur without this life saving surgery. A study found that colorectal cancers were the leading indication for ostomy creation in high income countries where most of their diet lack fiber (Repić & Ivanović, 2014a). Most diets have changed from the fibre laden meals to refined diets. Although the etiology of colorectal cancer is still unknown many studies have linked it with such factors as obesity, high consumption of red meats and moderate to heavy consumption of alcohol (Kirkegaard, Johnsen, Christensen, Frederiksen, Overvad & Tjønneland, 2010). The researcher's memo revealed that three out of the four participants with colorectal cancer were obsessed.

The result also indicated that, a previously temporary ostomy could be changed to a permanent one. The designation of an ostomy status being temporary implies that the ostomy will be reversed in the future. This however was not the case in one of the participants. Failure of the reversal of the ostomy could be due to the indicating disease worsening or things getting out of control. A study has reported that it is often difficult to predict if and when a temporary ostomy can be reversed, given potential complications associated

with surgery for ostomy closure (e.g., anastomotic leakage; bleeding) (Taylor & Varma, 2012). Literature has it that the time for ostomy reversal was influenced by advanced age, post-operative treatment for cancer, stoma and surgical complications following surgery for ostomy creation, and type of stoma (e.g., loop ileostomy, sigmoid colostomy, double-barrel ostomy) (Taylor & Varma, 2012). The optimal time to closure of a temporary ostomy remains unknown, and more research is needed.

This study also found that there were no large discrepancies between the responses made by those who had the ostomy for longer period and shorter period. This may have been so because the study did not explore a wide range of differences in the time that elapsed since the ostomy surgery. Meanwhile, studies have shown that individuals with longer time of ostomy showed a greater degree of life satisfaction and that the adaptation of the ostomized individual to a life new condition is a long and continuing process, being related to the underlying disease, degree of disability, individual values and personality (Salles et al., 2014). It was demonstrated in a study that the gender of the ostomy patients may influence the social adaptation. Women were found to demonstrate significant levels of despair, depression and fear in the preoperative period but the adaptation tends to take less time. Men were also found to take longer time to satisfactorily respond to daily activities, and presented with more difficulties concerning self-care (Sasaki et al., 2012). In this present study however, there were no discrepancies in responses by gender. This could be because this current study did not delve into issues related to gender.

### **Physical Well -being of People with Ostomy**

In physical terms, ostomates encountered a number of problems. These include odor/gas, leakages, skin problems, reduced strength, sleep disturbance and issues bothering on overall physical well-being. The participants reported experiencing unpleasant smell as a result of the gas produced at the ostomy site. This is similar to flatulence and brings about an uneasy feeling and embarrassment. They perceived the odor/gas as a sanitary nuisance. This perhaps may be due to ostomates thinking that other people will see them as untidy and lacked personal hygiene since most of them conceal the ostomy in their clothes. This finding was also reported by Dabirian et al.(2011), where ostomates reported not being able to tolerate themselves because of the odor. In recent times they are however pouches that come with flatus filters to minimize the gas effect (Burch, 2014) but most ostomate in Ghana may not have access to this modern apparatus.

Participants also reported leaking around ostomy site. This was often experienced when ostomates did not use pouches specially made for ostomy and improvised for the designated pouch. The leakages could have occurred because the improvised pouch “olonka rubber” which is often secured with a plaster might not be firmly secured or the rubber could have burst causing the leakages. Studies have linked leakages around ostomy site to skin irritations around the site (Shaffy et al., 2012). None of the participants in this study complained of any skin complications even though they experienced some leakages. This might have being as a result of the frequent change of the improvised pouch which comes with frequent cleaning around the stoma such that the effluent did not stay for a long time on the site to cause irritation. A

study has indicated that wearing an ostomy bag far past the wear time might result in skin irritation (Liao & Qin, 2014). However, a study found that there was no statistically significant difference in the prevalence of skin infection between commercial and non-commercial device users, but that the prevalence of skin excoriation was significantly more common in non-commercial device users compared with commercial device users (Buckley, Gonzalez, Razon-Gonzalez, & Lopez, 2012).

Findings of the study reveal that participants did not have enough strength to carry out their daily activities. This might have been so because the ostomy surgery is often a major surgery which could make the ostomate lose some strength. Besides, depending on the time that elapsed since the creation of the ostomy, the condition that caused the ostomy to be created could have contributed to the loss of strength. Similar findings were reported where ostomate lost their strength after the surgery (Repić & Ivanović, 2014b).

Some of the participants had problems getting adequate sleep. They experienced pain which made them unable to sleep well while others could not sleep because they kept thinking about whether their lives would ever be as it was. Others had disrupted sleep because of trips to the washroom to empty the pouch. For this reason, participants had to skip their supper or eat it early which could contribute to them not having enough strength for their daily activities. This is consistent with Shaffy et al. (2012), who reported that most ostomates had problems related to sleep because of fear of leakage of the bag at night, pain or discomfort.

Ostomy changed how all participants perceived themselves. This was evident whether participants compared themselves to their past self or to

others with regards to the ostomy. Participants described how their way of life had changed. Changes however were context dependent because each individual lived a unique lifestyle and a certain complexity of illness and surgery. Hence, the change experienced among the participants differed, and its impact was dependent on the magnitude of change incurred on the individual lifestyles. Changes involved the various aspects of the ostomates' lives. Changes were experienced in the negative way they perceived their body image. Participants feared that their ostomies might be undesirably detectable and therefore wore big and loose clothes to conceal the ostomy bag. The location of the stoma may affect what clothing can be worn post-surgery (i.e. trousers cannot sit directly on the stoma, they must fit above or below). This finding was similar to a study where the body image of ostomates were undermined due to presence of the stoma and the bag (Repić & Ivanović, 2014b). Findings also reveal that participants learnt how to manage their effluence through their diet, which resulted in changes to their diet. They had to stop eating certain kinds of foods whilst introducing others. Floruta (2001) similarly reported that ostomates changed their diet because they encountered problems with blockage and gas production.

### **Psychological Well-being of Ostomates**

This dimension deals with the ability to cope with the ostomy experience and its consequences. Findings from this study show that ostomates were faced mainly with uncertainty of the conduct of ostomy output. This puts them in a state of not knowing what to expect which affects the way they carry on with their daily activities which leaves them planning in advance for any accidents. This might have been so because of the negative

perceptions often associated with loss of continence control socially. Uncertainty may be as a result of fear of embarrassment due to the unusual noise, ostomy leakage, odour, gas, and the unpredictability of the ostomy output. This finding is consistent with other studies where it was concluded that an ostomy may elicit negative psychological experiences such as uncertainty and discomfort due to the loss of continence control, increased attention to and insecurity about ostomy output.(Annells, 2006; Brown & Randle, 2005; Grant et al., 2011; 2006; Mitchell et al., 2007).

The subtheme getting on with life revealed an unenthusiastic acceptance and positive attitude to moving forward with life despite the presence of the ostomy. Participants unenthusiastically acknowledged and accepted the ostomy, which was motivated by an understanding of the reason for its being. Participants noticed that the ostomy was an apt remedy to their illnesses. They probably realized that but, for the ostomy their situation would have being worse than it was. Hence, even though the ostomy had other undesirable consequences they were still willing to endure it and therefore made efforts to continue living with it. McMullen et al. (2008), reported that accepting the ostomy was worthwhile, because living with it was better than dying of the debilitating disease. This notion is embedded in statements about reframing any existing challenges positively, because the alternative (dying) is worse.

Participates took steps to minimize the risk of an uncomfortable or embarrassing situation from occurring by preparing ahead of time and/or deliberately adjusting their activities. A study also reported that ostomates demonstrated that adjusting ones activities to adapt to the new way of life to a

greater or lesser degree, was based on one's internal resources (power of adaptation) (Hernán & Umpiérrez, 2013).

Gautam et al. (2016), reported in a study that ostomates were fearful of the reaction of others should they know about the existence of their ostomies. In this current study, participants' were hesitant about revealing the existence of the ostomy to others because participants were not certain about how the audience will react. The level of comfort of disclosure of this information varied, and was determined by the relationship they had with the audience and their potential reaction, the participants' circumstances, and personal perspectives. Participants kept the ostomy a secret from some people because they thought that revealing the secret could not change anything for the better apart from people pitying them. A similar finding was realized by Sarabi et al.(2015), where compassionate behavior with pity had caused great emotional harm in the participants.

### **Social Well-being of Ostomates**

The social well-being refers to how well the ostomates social life is maintained. In this study, it entailed social activities, travel challenges, recreational activities, intimacy, adjustment difficulty, ostomy care, and financial burden.

Participants avoided participating in social activities. They feared that the incontinent nature of the ostomy output was not good enough to mingle with people. They did not want to embarrass themselves with the smell of the gas, sound and inadequate energy levels. This finding is consistent with a study which revealed that leakage, odour, and noise from the appliance were the primary sources of embarrassment identified by ostomates (Mitchell et al.,

2007). This could be so because most of the participants were secretive about the ostomy. They feared that perhaps if they mingled with people questions may be raised about the odour or sound or even their way of dressing. Answers to questions of this nature will mean that ostomate must reveal what has been kept in secrecy. Participants might also want to avoid the unpleasant situation of being discriminated against once people found out. One participant, however, was not hindered by the ostomy in social activities. He thought that what mattered was the will of the person. This could be because this ostomate was young, single, educated and had a good job and therefore has a whole life ahead him despite the downs the ostomy presented. This is in line with a study that revealed that respondents attained full lives in spite of their ostomies and conceptualized their ostomy as an inconvenience to be transcended or a challenge to be overcome (Danielsen, 2013).

Findings from this study also show that participants had travel challenges. They escaped travels if they were to use public transport lest they cause inconvenience to the other passengers due to the stoma output. A similar finding was reported by studies where ostomate had travel challenges (Wen et al., 2007; Grant, McCorkle, Hornbrook, Wendel, & Krouse, 2013). This could be because public transport had designated stop points. It may be very unpleasant for an ostomate should there be a leakage or spillage or the need to empty the pouch. They feared that they could not have any privacy in a public transport. Liao and Qin (2014) highlighted that, the loss of control over bodily behaviors, such as bodily noises, embarrasses the ostomates through loss of privacy and feelings of marginalization.



Participants also reported how profound changes in body image, physical problems and embarrassment about the ostomy brought about disruptions in intimate relationships and sexual functioning. This is consistent with a study that reported that anxiety about the ability to have sexual intercourse and worry about the stoma equipment during sexual intercourse can cause the ostomates to refuse intimacy with their partner (Susanty & Rangki, 2016). A female participant revealed how she feels uncomfortable with her body that deterred her from intimacy. Stoma, either permanent or temporary, can make the patient feel unattractive and undesirable to his/her partner. This probably could be because body image is often linked to sexual appeal and the presence of an ostomy may be view as deformity. This is similar to studies that reported that sexual health is influenced by physical problems of gas, odor, and leakage from the ostomy. (Grant et al., 2011; McMullen et al., 2008).

Findings from the study also stated that sexual relation may be hampered because a partner may feel he/she will hurt the ostomy. This causes the significant other to avoid sexual intimacy. This finding was reported in a study where fear of damaging the stoma may cause partners to distance themselves from the ostomate (Marjorie, 2000). This reaction may adversely affect the patient's already uncertain view of his/her own body. This might have been so because the partner may not have been educated on issues pertaining to sex with relation to the ostomy. Often, a healthy stoma may look reddish most likely like a fresh sore but lacks nerves that cause pain thereby leading partners to think they could hurt their ostomy partners. Hiding the device from the view of the partner is, in essence, a way to minimize a

person's own discomfort with his/her appearance. Findings also showed that intimacy was not hindered by the presence of the ostomy because the partner was informed about care of stoma ostomy should not be a hindrance to intimacy.

Participants reported that the family members in the initial stages of the ostomy cared for the ostomy by changing the pouch and cleaning the peristomal skin. This task was later taken up by ostomates themselves because they felt that family members will not always be with them. This may have been so because during the hospitalization participants could not have been able to focus enough to fully grasp how to manage the ostomy. This is consistent with Burch (2014) who reported that during the time in hospital, ostomates may not be able to fully focus during education on management of the ostomy. This present study also revealed that participants mastered care of the ostomy based on trial and error, where effective and ineffective solutions are tried in order to find the best strategies to manage the practical aspects of ostomy care. Popek et al., (2010) reported similar findings in a study where ostomates figured out what to do based on trial and error. It is therefore important to address topics on ostomy care again at a subsequent date when ostomates are out of the hospital and can focus well.

Financially, participants had some challenges. These challenges emanated from the frequent cost of transportation to and fro the hospital and two ostomates reported additional cost they incurred buying diapers for the mucoidal rectal discharge. This challenge may be because most of them could no longer work as they did or were jobless. This supports a finding where ostomates lost or changed their job after the operation (Mahjoubi et al., 2012;

Dabirian et al., 2011)). Additionally, the cost of the ostomy supplies was high this made ostomates who could not afford the bag use polythene bags commonly called “olonka rubber” or wash the bags for reuse even when they were disposable. This often resulted in leakages as the improvised ostomy bag do not fit well. Leakages bring about unpleasant smell and makes life unbearable for the ostomates. One study with similar finding report that the quality of the pouch an ostomate wears has a great bearing on the quality of life of the ostomate (Liao & Qin, 2014).

### **Spiritual Well-Being of Ostomates**

Findings from this study show three subthemes under this dimension; religious activities, spirituality and hopefulness. Participants had their spirituality intact whilst religiosity was compromised. This was because most religious activities are performed with other people and participants feared that interacting with others, they (ostomates) could be seen as nuisance. A muslim participant reported that he did no longer join in congregational prayer because of fear of indiscriminate flatus passage. This was also found by Ahmad et al., (2011) who reported that it is difficult for a stoma patient to offer prayer in mosque in Jamat (congregation) because the fellow Muslims offering prayer may react negatively on hearing the sound of flatus being passed.

Eventhough, carrying out religious activities had reduced, an intact spirituality probably meant that participants were coping well. This supports a study that found that people with a strong spiritual well-being coped better with adjusting to their stoma than did people without spirituality(Li, Rew, & Hwang, 2012). The finding from this current study is probably because

Nukunya (2003) indicates that the Ghanaian society is a highly religious one, as most of the people believe in either the supreme God or lesser gods/deities. There is therefore the tendency to attribute every occurrence to a supreme being which reinforces their spirituality. It is therefore important to address spirituality after an ostomy creation.

Another way of expressing their spiritual well-being was in the form of hope. Participants were hopeful that God will grant them total healing. This hope for total healing was as a result of participants believing that they have been granted a second chance of living since they did not die from the indicating disease. This finding is consistent with that of McMullen et al. (2008), found that many participants conceptualized their ostomies as a second chance at life and were hopeful of a better life. Because participants attributed their state to God, and hoped for a better life, the experience drew them closer to God. This however contradicted a study that reported that Muslim ostomates stopped praying daily and fasting during Ramadan (Holzer & Rosen, 2009).

### **Information needs**

This subtheme entails the knowledge resource that would enable an ostomate adapt soundly. Every patient has the right to complete information about his/her disease and its treatment and providing this information is a task of all the health team. An important aspect of adaption to life with an ostomy is the role of the healthcare professional in assisting the person with an ostomy from hospice care to home. Wu, Chau, and Twinn (2007) suggested in their study that a comprehensive assessment of each patient will enable the health care professional to be able to identify the patient's needs and how to cope

with various situations. In this study however, planned education did not seem to have been purposefully delivered on the management of the ostomy. This left some participants employing trial and error to be able to manage their ostomies. This was similarly reported in a recent study in which participants complained that after the surgery, they did not receive adequate education at the hospital (Sarabi et al., 2015). Grant et al.(2013b), reported that creating an educational support program for patients after surgery may increase adaptation, and help the patient create a new normal much quicker than trying to learn care solely by trial and error. In some instances, patients were not told about the duration (temporary or permanent) of the ostomy which further suggests that education delivered to ostomate may not have been comprehensive. The inadequacy of information delivered may probably be due to the lack of specialist nurses in the care of these ostomates. Additionally, due to shorter hospital simple ostomy management tasks such as emptying and changing a pouch is often not adequately taught. The increasingly brief hospital stays restrict teaching time and, most importantly, limit the time allowed for the client and family to assimilate knowledge and psychomotor skills required for successful ostomy management. This should therefore be taught preoperatively.

Some participants mentioned the internet as having a lot of information which could benefit ostomates. Ostomates or family members find the information they need to solve their doubts through the internet. This information does not always entail positive and can cause the development of feelings of fear and despair, create doubts about their trustworthiness, as they may come from contexts with resources that do not exist in the patients' own

context (Barnabe et al., 2008). Ostomates may also risk injuring themselves if they try to learn new procedures from the internet since not all information found on the internet is genuine or safe enough for consumption. In the findings of this study, an ostomate tried to irrigate his ostomy. This is a procedure analogous to an enema done to clean stool directly out of the colon through the stoma often done to avoid the need to wear a pouch (United Ostomy Associations of America, 2015). Irrigation promote independence and must be encouraged (Rooney, 2007) but the indication of this method is medical, and the training is the responsibility of a nurse, preferably, a stoma therapist (Cesaretti, Santos, Schiftan, & Vianna, 2008). Anecdotally, information on the internet is viewed by a variety of people that include patients, and is often available in a language which puts patients who do not have formal education at a disadvantage. This further emphasizes that much is required from the care providers in terms of education to ostomates.

### **Coping with an ostomy**

Findings indicated that ostomates were able to cope with the ostomy because they had support from others. This study indicated that participants support network acted as a facilitator to meeting participants care needs. They were supported domestically, financially and emotionally. This finding is consistent with previous studies that have also reported the positive influence of interpersonal relationships (Simmons et al., 2007) and significant others on patients' psychosocial adjustment to (Altschuler et al., 2009; Piwonka & Merino, 1999) and physical care of the ostomy (McMullen et al., 2011). Participants stressed how invaluable their family support is. This support helped to ease the patient's adaptation and helped him/her create a positive

attitude toward his/her new condition. This may be so because the family is a constructive element of a sympathetic relationship, and hence provided support for strengthening the patient's self-esteem and self-image to diminish his/her suffering. Again, the family, being a care unit, makes the patient feel safer not only with regard to the ostomy, but also by providing support for domestic, financial, and emotional concerns. This is in line with what Lopes and Decesaro (2014) found in a study that the family was found to provide emotional and social support, bonding with the patient to cope with problems when facing this new situation(ostomy). Findings also show that if they (family) continue to offer support for a long time, they could inhibit the transition to self-care, because the person would not become autonomous, but will be insecure and dependent. This was similarly reported by (Mota et al., 2015) where prolonged support hindered autonomy in ostomy adaptation. One participant however was avoided by friends because she perceived that they feared they would be "infected" with the ostomy. This may probably be due to lack of adequate information about what an ostomy is and how one may come to acquire it. This is consistent with a study that reported that some individuals perceive ostomy to be contagious in the family or community (Sarabi et al., 2015).

## CHAPTER FIVE

### SUMMARY, CONCLUSION AND RECOMMENDATIONS

This chapter presents the summary of the study, implications of the study to nursing practice, education, research and management. It also includes the limitation, conclusion and recommendations of the study.

#### **Summary of the Study**

A phenomenological study design was employed to explore the experiences of people who have ostomies and living in their homes. The study was carried out in the Accra Metropolis and participants were recruited at the OPD of the Surgical Unit of the KBTH. Data collection begun after ethical approval was given by the Institutional Review Board of the University of Cape Coast. The researcher also sought for approval at the KBTH institutional Review Board (KBTH-IRB) and the KBTH Scientific and Technical Committee (KBTH-STC). Participants were purposefully recruited and data was saturated on the 9th participant. The interview guide was pretested on a patient from the Ridge Hospital to ensure that participants understood it and that it was able to elicit data needed.

Interviewing of participants and transcription of the interview were done concurrently between June and July. The participants who agreed to take part in the study signed a consent form. All the interviews were audio taped and transcribed verbatim. Thematic analysis was used in analysing the data.

The key findings were that the physical well-being of ostomates bothered on issues that had to do with the unpleasant odor that emanated from the gas produced by the ostomy. The ostomy bag if worn past its designated time, or when improvised with an “olonka rubber” often leaked which further



compounded the problem of unpleasant odour. However, despite the difficulties surrounding acquisition of the pouch and its use, the expected skin problems (irritations, soreness) that are often associated did not present in any of the participants. Most of the participants reported that the ostomy has made them loose their strength and unable to go about their daily activities as before. Others said the lack of strength came from the sickness that indicated the ostomy and that the ostomy has come to make them even weaker. Sleep disruption was also reported and related to pain, trips to the washroom to empty filled pouch and thoughts of whether life would change for the better for them. Ostomates changed their way of dressing, diet and daily routine as a way of adapting to the ostomy.

Participants had no control over the conduct of the ostomy and hence were always uncertain about the next thing that will happen as a result, they always prepared for any problems (leakages, sound, odor). This uncertainty caused them some psychological unrest. Despite the uncertainty, participants revealed an unenthusiastic acceptance and positive attitude to moving forward with life. The uncontrollable nature of the ostomy compelled ostomates to continuously think about preparing for and preventing uncomfortable situations from occurring. They minimized risks by preparing ahead of time and/or deliberately adjusting their activities. Telling other people about the presence of the ostomy was determined by the relationship they had with the audience and their potential reaction, the environment and participants' circumstances, and personal perspectives.

Getting involved in social activities meant having to deal with the incontinent nature of the ostomy in a less controlled environment and this deterred the most participants from engaging in social activities. This inhibition was however dependent on the how the participant view the situation. Travelling in a public transport system was avoided by participants for fear of being a nuisance to other passengers. There was an also financial challenge arising from cost of the collector bag, transport to and fro KBTH for review and the added expense of buying diapers for the mucus that passes out from the anus.

In relation to participants spiritual well-being, it was found out that some participant religiosity was affected whilst spirituality remained intact and some even got closer to God for giving them a second chance to live. There was also hope that their situation would get better. Participants were given domestic, financial and emotional support from family and friends which was invaluable to their coping.

Finally, participants expressed that the information they received from the health team (nurses and doctors) was not adequate for a smooth adaptation to the new life. The internet was considered as a source of information for some ostomates.

### **Implications of Findings**

The findings of the study have implications that must be addressed. There are implications for, nursing practice, nursing education, and nursing administration.

### **Nursing practice**

The findings of this study suggest that nurses need to be mindful of the significant role they play in patients' adaptation to life with an ostomy. The quality of life of a patient after ostomy creation depends to a large extent on the comprehensiveness of the education given him/her on how to manage the ostomy. This can be achieved by nurses planning the information that is to be delivered to client systematically and keeping in touch with ostomates to know how they are faring with the ostomy at home and possibly reminding them of what is required of them. Responses of the participants revealed that most of their experiences centered on the COHQOL model for ostomy. Nurses should therefore consider using items in the framework for ostomy management.

### **Nursing education**

An ostomy is not a chronic condition, but living with an ostomy requires that the ostomates learn many of the self-management skills. However, many nurses lack the ostomy related knowledge and skills to provide education and clinical support to enable ostomates to make informed decisions and achieve self-efficacy. The courses for surgical nursing must be expanded to provide a comprehensive coverage of self-management of ostomy to better equip the would-be nurse for better education of ostomates.

### **Nursing administration**

Findings from the study reveal that participants probably did not receive adequate information on self-management on ostomy because there are no specialist ostomy nurses. Nurse administrators should get at least one specialist ostomy nurse in hospital where ostomy surgeries are performed.

## **Conclusion**

The life of a person is changed drastically when an ostomy is created. Even though ostomy creation comes with its lows, the creation often comes to alleviate an otherwise detrimental condition. Ostomates endure a myriad of problems irrespective of the ailment that caused the ostomy creation. This study revealed that the four domains of quality of life (physical, social, psychological and spiritual) were all affected with the social domain being the most compromised. Participants shunned away from endeavours that would have them interacting with others who did not know about the existence of the ostomy. Support in the form of domestic, financial and emotional offered by family was what helped ostomates to cope with the adaptation process. An ostomy has the potential to not only be a sudden change, but forces the recognition and physical confrontation of the patient's serious illness. Since support has had great impact on adaptation and coping, it is therefore important that ostomy support groups are formed. Findings also reveal that a good adaptation to a large extent depended on the quality of education offered by the health team. Though the participants acknowledged the work done by the nurse, they wished more was done in terms of their education.

This study has provided a deeper understanding of living with an ostomy. It is hoped that this understanding will help to benefit persons in similar circumstances in the future, and inspire nurses to be mindful of how they themselves can significantly influence their patients' experience with an ostomy.

## **Recommendation**

With reference to the findings of this study, the following recommendations has been made to persons living with ostomies, nurses who care for ostomates, KBTH, and the Ministry of Health.

### **Persons living with ostomy**

1. There should be a concerted effort on the part of ostomates and other stakeholders to form support groups to help them share feelings, problems and ask questions that bother them.
2. Ostomates should keenly participate in matters that concern them particularly with regards to ostomy management to facilitate the adaptation to the new life.

### **Nurses**

1. Nurses should use the COHQOL Model for ostomy as the framework for caring for ostomates.
2. Nurses should intensify pre and post-operative teaching of ostomates
3. Religious leaders should be involved in the provision of care to ostomates since the study has indicated that spirituality helped them in coping.

### **Korle-Bu Teaching Hospital**

1. The hospital should prepare and make available educational materials tailored to suit ostomates living in their homes.
2. Opportunities should be made available for nurses to specialize in areas that pertain to care of patients with ostomies.
3. The hospital in collaboration with other stakeholders should endeavour to form ostomy support groups.

### **Ministry of Health**

1. The ostomy bags should be made available in hospitals where surgeries for ostomies are done.
2. The Ministry of Health should endeavour to have the cost of the ostomy bag covered by the National Health Insurance Scheme.
3. The Ministry should sponsor nurses to specialize in ostomy care.

### **Suggestions for Further Research**

Participants were secretive about the existence of the ostomy. Further researches could be conducted to explore in-depth why this is so. Future researches could be conducted to ascertain the experiences of ostomates post ostomy. Perspective of spouses and children of ostomates could also be sought to understand the impact of ostomy on the family.

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## APPENDICES

### APPENDIX A

#### INFORMED CONSENT FORM

**Title:** Lived Experiences of People with Ostomies in the Accra Metropolis

**Principal Investigator:** Aisha Sena

**Address:** School of Nursing, University of Cape Coast

#### **General Information about Research**

I will like to seek information about your experiences of living with the stoma you have. The information that will be given by you will help others to understand the challenges people who have stomas face and how they cope. I will have a conversation with you in English or Twi which will last between forty five to sixty minutes. There is no right or wrong answer and you will not be judged for your answers therefore you should be comfortable in answering any question asked you. You will be asked to sign an informed consent form before the interview begins. The interview will be audio taped with your full permission.

#### **Procedures**

You are being invited to take part in this interview because we feel that your experience as a person living with a stoma can contribute much in determining the challenges and coping strategies people living with stomas have. If you accept, you will be required to participate in an interview with myself.

If you do not wish to answer any of the questions posed during the interview, you may say so and the interviewer will move on to the next question. The interview will take place at a place convenient to you and no one else but the

interviewer will be present. The information recorded is considered confidential, and no one else except the researcher and her supervisors will have access to the information documented during your interview. The expected duration of the interview is about 45-60 minutes.

### **Possible Risks and Discomfort**

It is not foreseen that your participation in the research will cause you any physical harm.

### **Possible Benefits**

The findings from this study will inform nurses and other health professionals about what the health needs of people with stomas are so that services can be tailored towards the real needs.

### **Confidentiality**

Although the interview will be audio taped, your name and any other information that will identify you will be deleted. However, you will be given a code number or a coined name that will be attached to the information you give during the interview. Only my supervisors will have access to the information.

### **Compensation**

You will not receive any compensation

### **Voluntary Participation and Right to Leave the Research**

Your participation in this study is voluntary and therefore, you have the right to withdraw at any point during the interview without any explanation. Withdrawal will not affect the care KBTH will give you.

### **Contacts for Additional Information**

Aisha Sena

Phone number: 0246175265

Email: [senaisha@gmail.com](mailto:senaisha@gmail.com)

Dr. Jerry Paul Ninonni

School of Nursing, University of Cape Coast

Phone number: 0503280047

Email: [jerry.ninnoni@ucc.edu.gh](mailto:jerry.ninnoni@ucc.edu.gh)

Dr Victor Nuvor

School of Nursing, University of Cape Coast

Phone number: 0205853850

### **Your rights as a Participant**

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCC-IRB) and KBTH-IRB. If you have any questions about your rights as a research participant you can contact the Administrator at the UCC-IRB Office between the hours of 8:00 am and 4:30 p.m. through the phones lines 0332133172 and 0244207814 or email address: [irb@ucc.edu.gh](mailto:irb@ucc.edu.gh) OR the administrator at KBTH-IRB through phone lines 0302667759 and 0306730346.

## VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title, **Lived Experiences of People with Ostomies in Accra Metropolis** has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

\_\_\_\_\_

\_\_\_\_\_

Date

Name and signature or mark of volunteer

### **If volunteers cannot read the form themselves, a witness must sign here:**

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

\_\_\_\_\_

\_\_\_\_\_

Date

Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

\_\_\_\_\_

\_\_\_\_\_

Date

Name Signature of Person Who Obtained Consent

**APPENDIX B**

**BACKGROUND INFORMATION FORM**

**SECTION A**

Demographic Information

Pseudonym.....

1. Sex.....
2. Age.....
3. Marital status.....
4. Number of years married.....
5. Number of children.....
6. Time since surgery.....
7. Type of employment.....
8. Religion.....
9. Status of Ostomy; permanent/temporary
10. Type of Ostomy.....



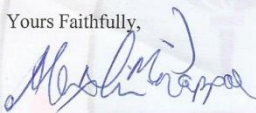
**APPENDIX C**  
**INTERVIEW GUIDE**

**Section B**

<b>GUIDING QUESTIONS</b>	<b>PROBES</b>
1. Can you narrate the events that led to the need for you to have the stoma?	
2. Can you tell me what you knew about stomas before you were scheduled for one?	
3. Tell me about your reaction when you were informed about the ostomy surgery.	
4. Can you tell me what it has been like for you living with an ostomy since you were discharged from hospital?	
5. In what ways has the stoma affected your life?	<ul style="list-style-type: none"> <li>a. Physical</li> <li>b. Psychological</li> <li>c. Social</li> <li>d. Spiritual</li> </ul>
6. Has there been anything particularly difficult for you?	
7. How are you coping with your stoma?	
8. What else would you like to tell me?	

APPENDIX D

COVER LETTER FOR ETHICAL CLEARANCE FROM SCHOOL OF  
NURSING UCC

	<b>UNIVERSITY OF CAPE COAST</b> COLLEGE OF HEALTH AND ALLIED SCIENCES <b>SCHOOL OF NURSING AND MIDWIFERY</b> <b>DEAN'S OFFICE</b>	
Telephone: 233-3321-33342/33372 Telegrams & Cables: University, Cape Coast Email: <a href="mailto:nursing@ucc.edu.gh">nursing@ucc.edu.gh</a>		UNIVERSITY POST OFFICE CAPE COAST, GHANA.
Our Ref: SNM/IVol.1/6 Your Ref:		14 <sup>th</sup> November, 2016
The Chairman Institutional Review Board UCC		
Dear Sir,		
<b>RE APPLICATION FOR ETHICAL CLEARANCE TO CONDUCT A STUDY – SENA AISHA</b>		
We forward herewith the attached application for ethical clearance from the above Post Graduate student of the School of Nursing and Midwifery for your consideration, please.		
Yours Faithfully,  Prof. A. N. M Pappoe DEAN		

APPENDIX E

ETHICAL CLEARANCE LETTER FROM IRB UCC

UNIVERSITY OF CAPE COAST

**INSTITUTIONAL REVIEW BOARD SECRETARIAT**

TEL: 03321-33172/3 / 0207355653/ 0244207814 C/O Directorate of Research, Innovation and Consultancy  
E-MAIL: [irb@ucc.edu.gh](mailto:irb@ucc.edu.gh)  
OUR REF: UCC/IRB/A/2016/52  
YOUR REF:  
OMB NO: 0990-0279  
IORG #: IORG0009096



30<sup>TH</sup> JANUARY 2017

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Ms. Aisha Sena  
School of Health and Allied Health Science  
School of Nursing and Midwifery  
University of Cape Coast

Dear Ms Sena,

**ETHICAL CLEARANCE –ID :( UCCIRB/CHAS/2016/11)**

The University of Cape Coast Institutional Review Board (UCCIRB) has granted **Provisional Approval** for the implementation of your research protocol titled **Lived Experiences of Patients with Ostomies in Accra Metropolis: A Phenomenological Study.**

This approval requires that you submit periodic review of the protocol to the Board and a final full review to the UCCIRB on completion of the research. The UCCIRB may observe or cause to be observed procedures and records of the research during and after implementation.

Please note that any modification of the project must be submitted to the UCCIRB for review and approval before its implementation.

You are also required to report all serious adverse events related to this study to the UCCIRB within seven days verbally and fourteen days in writing.

Always quote the protocol identification number in all future correspondence with us in relation to this protocol.

Yours faithfully,


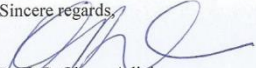
  
Samuel Asiedu Owusu  
Administrator

ADMINISTRATOR  
INSTITUTIONAL REVIEW BOARD  
UNIVERSITY OF CAPE COAST  
Date:.....



## APPENDIX F

### SCIENTIFIC AND TECHNICAL APPROVAL FROM KORLE-BU TEACHING HOSPITAL

<p>In case of reply the number And the date of this Letter should be quoted My Ref. No. <u>KBTH/MS/15/17</u> Your Ref. No. ....</p>	 <p>The logo of Korle Bu Teaching Hospital (KBTH) is circular with the text 'KORLE BU TEACHING HOSPITAL' around the top edge and 'Excellence in Healthcare' around the bottom edge. In the center, there is a caduceus symbol with 'KBTH' written across it and the year '1923' below.</p>	<p><b>KORLE BU TEACHING HOSPITAL</b> P. O. BOX KB 77, KORLE BU, ACCRA.</p> <p>Tel: +233 302 667759/673034-6 Fax: +233 302 667759 Email: <a href="mailto:Info@kbth.gov.gh">Info@kbth.gov.gh</a> <a href="mailto:pr@kbth.gov.gh">pr@kbth.gov.gh</a> Website: <a href="http://www.kbth.gov.gh">www.kbth.gov.gh</a></p>
		<p>7<sup>th</sup> June, 2017</p>
<p>MS. AISHA SENA UNIVERSITY OF CAPE COAST CAPE COAST</p>		
<p><b><u>SCIENTIFIC AND TECHNICAL COMMITTEE APPROVAL</u></b> <b><u>PROTOCOL IDENTIFICATION NUMBER: KBTH-STC 00031/2017</u></b></p>		
<p>The Korle Bu Teaching Hospital Scientific and Technical Committee (KBTH-STC), on 7<sup>th</sup> June, 2017 approved your submitted study protocol.</p>		
<p>TITLE OF PROTOCOL: <b>"The lived experiences of people living with Ostomies in the Accra Metropolis"</b></p>		
<p>PRINCIPAL INVESTIGATOR: Ms. Aisha Sena</p>		
<p>This approval requires that you <b>forward your approved document to Korle Bu Teaching Hospital-Institutional Review Board (KBTH-IRB) for the ethical aspect of the proposal to be assessed before the project can be initiated.</b></p>		
<p>This STC approval is valid till 31<sup>st</sup> September, 2017 You may, however, request extension of the approval period, or renewal as the case may be, should the study extend beyond the stated period.</p>		
<p>Upon completion, you are required to submit a final report on the study to the STC. This is to enable the STC ensure among others that, the project has been implemented as per the approved protocol. You are also required to inform the KBTH-STC and Research Directorate of any publications that may emanate from the research findings.</p>		
<p>Kindly note that, should the need arise, the KBTH-STC or IRB may institute appropriate measures to satisfy itself that study is being conducted according to the highest scientific and ethical standards.</p>		
<p>Please note that any modification to the study protocol without Scientific Technical Committee (STC) approval renders this approval invalid.</p>		
<p>Sincere regards,  Prof. G. Obeng Adjeh Chairman, KBTH-STC</p>		
<p>Cc: The Chairman, KBTH-IRB</p>		

## APPENDIX G

### ETHICAL APPROVAL FROM KORLE-BU TEACHING HOSPITAL

In case of reply the number  
And the date of this  
Letter should be quoted

My Ref. No. KBTH/IRB/17  
Your Ref. No. ....



KORLE BU TEACHING HOSPITAL  
P. O. BOX KB 77,  
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-6  
Fax: +233 302 667759  
Email: [Info@kbth.gov.gh](mailto:Info@kbth.gov.gh)  
[pr@kbth.gov.gh](mailto:pr@kbth.gov.gh)  
Website: [www.kbth.gov.gh](http://www.kbth.gov.gh)

19<sup>th</sup> June, 2017

MS AISHA SENA  
UNIVERSITY OF CAPE COAST  
CAPE COAST

**THE LIVED EXPERIENCES OF PEOPLE LIVING WITH OSTOMIES IN THE ACCRA METROPOLIS**

KBTH – IRB /00031/2017

Investigator: Ms Aisha Sena

19<sup>th</sup> June, 2017, the Korle-Bu Teaching Hospital Institutional Review Board (KBTH IRB) reviewed and granted approval to the study entitled “The Lived Experiences of People Living with Ostomies in the Accra Metropolis”

Please note that the Board requires you to submit a final review report on completion of this study to the KBTH-IRB.

Kindly, note that, any modification/amendment to the approved study protocol without approval from KBTH-IRB renders this certificate invalid.

Please report all serious adverse events related to this study to KBTH-IRB within seven days verbally and fourteen days in writing.

This IRB approval is valid till 30<sup>th</sup> May, 2018. You are to submit annual report for continuing review.

Sincere regards,

OKYERE BOATENG (MR)  
CHAIR (KBTH-IRB)

Cc: The Chief Executive Officer  
Korle Bu Teaching Hospital

The Director of Medical Affairs  
Korle Bu Teaching Hospital

## APPENDIX H

### APPLICATION FOR ETHICAL CLEARANCE

University of Cape Coast  
College of Health and Allied Health Sciences  
School of Nursing and Midwifery  
9<sup>th</sup> November, 2016

Thro;  
The Dean  
School of Nursing and Midwifery  
UCC



The Chairman,  
Institutional Review Board  
University of Cape Coast  
Cape Coast

Dear Sir/Madam,

#### APPLICATION FOR ETHICAL CLEARANCE TO CONDUCT A STUDY

I am a level 850 Master of Nursing student and would be grateful if you would permit me to conduct a study on the topic; *Lived experiences of patients with ostomies in the Accra Metropolis: a phenomenological study.*

Find attached are the necessary documents for ethical clearance.

Yours faithfully,

A handwritten signature in blue ink, appearing to read "Sena Aisha", written over a dotted line.

Sena Aisha

(SN/MNS/15/0022)