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The Lived Experiences of Muslim Stoma Patients' in Cape Town in Relation to their Cultural and Religious Practices

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Declaration

I, Galima Mobara, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole nor any part of it has been, is being or is to be submitted for any other degree in this or any other university.

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Date

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To my husband and children for their support, assistance and encouragement throughout the duration of this study.

This dissertation is dedicated to all Muslim stoma patients in South Africa currently and in the future.

Abstract

Aim of the study

The aim of the study is to explore the lived experiences of Muslim stoma patients in Cape Town, and the effects that these stomas have on their cultural and religious practices. The study intended to explore the challenges that stoma patients experience in their daily lives as well as coping with specific religious rituals.

Background to the study

Muslims follow the religion of Islam, and believe in one God – Allah and follow the teachings of Prophet Muhammad (peace be upon him). It is compulsory for all Muslims to make *Salaah* (prayer) five times a day. Exceptions to this compulsory Muslim practice are children and the mentally ill. Therefore, having a stoma does not qualify one to be excused from making *Salaah*. In order to perform the *Salaah*, it is necessary to perform *Wudu* (ablutions). The passing of any impurities such as urine and/or faeces, including flatus, will nullify the ablution. The problem for the ostomist (stoma patient) is that the impurities flow freely from the body and are unable to be controlled, and therefore would nullify the *Wudu* and *Salaah*. To address this issue, a *Fatwa* (Muslim ruling) has made a special allowance for the ostomist to clean the stoma of all faeces and, if necessary, change or clean the stoma bag before each *Salaah.* It is then considered acceptable for the stoma patient to perform the *Wudu* and *Salaah*.

The literature shows that many stoma patients experience isolation and social deprivation, and discussions around stomas within society were kept very private. Society at large is often unaware of the existence of ostomist and their challenges within their own community.

Methodology

A phenomenological approach was used utilising the interpretive approach. The study sample consisted of seven participants of which three were female and four were male. Their ages ranged between 27 and 72 years old, all residing in Cape Town. Gathering of information continued until the point of information redundancy or saturation.

Information collection and analysis

Two semi-structured, audio recorded conversations were conducted with each participant. Each conversation was 45-60 minutes in duration. Conversations were transcribed and Colaizzi's seven steps of inductive reduction were used to analyse the information.

Conclusion

This study has broken some of the silence surrounding stomas within the Cape Town Muslim community through the voice of the participants. The findings conclude that the participants' narratives of their life experiences with their stomas indicate a fairly normal and positive lifestyle without too many limitations, and confirmed a heightened sense of spirituality. The study contributes new knowledge about the experiences of Muslim stoma patients, and may thus assist healthcare professionals in obtaining a deeper understanding of the challenges faced by Muslim stoma patients. These findings may also assist in the creation of a Muslim stoma support group and the information can be utilised to assist new and other stoma patients and their families. The study will be made available to the *Imaams* (Muslim priest) at mosques and the community to bring about awareness of stomas.

Definition of Terms

Colostomy	A surgical opening from the colon to the body's surface (American Society of Colon and Rectal Surgeons, 1996)[1]
Fatwa	A Islamic religious ruling on a specific topic
Hajj	A compulsory pilgrimage to Mecca conducted at least once in a lifetime by all adult Muslims
Ileostomy	A surgical opening from the ileum to the body surface (American Society of Colon and Rectal Surgeons, 1996)
Imaam	A Muslim priest
Incontinent	Lack of control of urine or faeces
Muslims	Persons who follow the Islamic religion, believing in one God and following the teachings of the Prophet Muhammad
Quran	The Muslim Holy book
Ramadaan	The Muslim month of fasting
Salaah	The five compulsory daily prayers performed by Muslims
Spina bifida	Congenital spinal abnormality resulting in the nerve supply not reaching certain organs, such as the bladder or rectum
Stoma/ostomy	A surgically created opening connecting an internal organ to the surface of the body/skin
Sunnah	Following teachings of the Prophet Muhammad
Ulcerative colitis	Inflammatory bowel disease affecting the large bowel
Urostomy	A surgical opening from the ureters to the body surface (American Society of Colon and Rectal Surgeons, 1996)
Wudu	The compulsory ablution taken before each *Salaah*

[1] See Appendix for attached images

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1. INTRODUCTION

The proverb "cleanliness is next to Godliness" is taken literally and followed strictly by all practicing Muslims in the holistic sense of the phrase. Muslims have very strong cultural, traditional and religious practices (Dangor, 2003). An ostomy created for a Muslim patient thus presents many challenges for the person to practice these strict religious requirements. Once an ostomy is created, urine or bowel contents flow freely and uncontrollably to the surface of the body. An ostomy appliance, generally referred to as a stoma bag, is applied over the opening to collect the contents and may differ in style and size depending on the type of stoma (American Society of Colon and-Rectal Surgeons, ASCR, 1996).

1.1 Personal background of researcher

I am a registered nurse and a married Muslim woman living in Cape Town and have spent the greater part of my professional career assisting in the surgery of patients who have rectal or colon cancer or ulcerative colitis. I am also a volunteer in community health-care work and have encountered a large number of stoma patients who have had different responses from the community when attending religious functions. Many of these patients have experienced that the community are often unaware of what stomas are and the issues resulting from these, such as incontinence. In addition, I am also a member of an Islamic Medical Association.

1.2 Background to the study

Muslims follow the religion of Islam, and believe in one God – Allah and follow the teachings of Prophet Muhammad (peace be upon him). There are approximately 900 000 Muslims in Cape Town (Muslim Judicial Council, 2006). It is compulsory for all Muslims to make *Salaah* five times a day, and to fast from sunrise to sunset during the month of *Ramadaan*; exceptions include children, the aged and those who are mentally and physically ill. In order to perform the *Salaah*, it is necessary to perform *Wudu*. First the body is cleaned with water to rid the body of impurities such as urine, faeces or blood. Then the hands, arms, forehead, face and feet are washed with running water. The passing of any impurities such as faeces

and/or urine, including flatus will nullify the *Wudu*. For Muslim men, the *Salaah* is performed more effectively in a congregation. *Hajj* is performed only by those Muslims who are healthy and can afford the journey to Mecca once during their lifetime.

The critical importance of cleanliness in Islamic practices stems from Chapter 5, Verse 6 of the *Quran* (English translation, by Yusuf Ali), where it states:

"O you who believe! When you rise up for the Prayer, (if you have no ablution) wash your faces and your hands up to (and including) the elbows, and lightly rub your heads (with water), and (wash) your feet up to (and including) the ankles. And if you are in the state of major ritual impurity (requiring total ablution), purify yourselves (by taking a bath). But if you are ill, or on a journey, or if any of you has just satisfied a want of nature, or if you have had contact with women, and can find no water, then betake yourselves to pure earth, passing with it lightly over your face and your hands (and forearms up to and including the elbows). God does not will to impose any hardship upon you, but wills to purify you (of any kind of material and spiritual filth), and to complete His favour upon you, so that you may give thanks (from the heart, and in speech and action by fulfilling His commandments)."

The problem for the ostomist is that the impurities flow freely from the body and therefore are unable to be controlled, and consequently would nullify the *Wudu* and *Salaah*. To address this issue, a *Fatwa* has made a special allowance for the ostomist to clean the stoma of all faeces and, if necessary, change or clean the bag before each *Salaah.* He is then considered clean to perform the *Wudu* and perform his *Salaah* (Burbeck, 2001).

Despite the ruling, many ostimists do not feel clean, and the passing of flatus, which may be offensive, has the possibility to disturb other members in a mosque or those at cultural and religious gatherings. During the fasting month of *Ramadaan*, ileostomies in particular may cause dehydration as a result of the significant amount of fluid lost. Muslims with stomas may feel isolated from cultural and religious activities and face being stigmatised.

1.3 Cape Town Muslims' heritage

Historical research done by Dangor in Cape Town shows that the history of Muslims in Cape Town dates back to the 17th century. They were traditionally referred to as Cape Malays. This is due to their historical heritage from Malaysia, Java, Indonesia, Ceylon, and India. Some were brought as slaves and exiles as far back as 1667. Sheikh Yusuf was banished from Java and exiled to Robben Island by the Dutch East India Company (DEIC). Sheik Yusuf had a broad knowledge of the *Quran* and the Islamic religion (Dangor, 2003).

Slaves were also brought to Cape Town by the DEIC and among them were learned scholars who spread Islam amongst the others slaves (Davids & Da Costa, 1994). Tuan Guru, who was a prince from Tidore, Indonesia was also amongst the exiles brought to Cape Town. As a result, Muslims in Cape Town have diverse cultures and many worked as craftsmen and artisans. Currently, Muslims occupy all social strata in society (Dangor, 2003).

The Islamic Medical Association of South Africa (IMASA) is a recognised organisation and a member of the international mother body. The IMASA is equipped to deal with many Islamic medical issues that require clarity.

1.4 Research question

What are the lived experiences of Muslim stoma patients in Cape Town, in relation to their cultural and religious practices?

1.5 Pre-understandings

Qualitative research embraces the idea of multiple realities. Phenomenology allows the researcher to observe the lived experiences of the participants. These experiences may offer various subjective accounts of the participants' life experiences of a certain phenomenon.

Researchers make certain pre-understandings in qualitative studies and a novice researcher often has pre-understandings of the phenomena which may guide the research methodology to be applied within the research process (Creswell, 2007).

1.5.1 My ontological pre-understandings

Ontology refers to the basic pre-understanding that allows the researcher to describe a particular reality (Creswell, 2007). It comes with the belief that all participants will have their own experience of the phenomena being investigated.

As a Muslim nurse with extensive experience in working with stoma patients, I had certain pre-understandings regarding the life experience of Muslim stoma patients and anticipated a range of different views from both male and female participants.

1.5.2 My epistemological pre-understandings

Epistemology refers to the pre-understandings that underlie knowledge and truth (Creswell, 2007). My understanding is that the participants cannot be removed from their daily social lived spaces. In addition, I anticipated that the participants would allow me as the researcher into these spaces in order for us to collaborate together. Being a Muslim nurse, I bring along knowledge of Muslim religious practices and the phenomena of the experience of Muslim patients with stomas.

1.5.3 My methodological pre-understandings

As a novice researcher, there were many concerns regarding the challenges in utilising a phenomenological approach which required meaningful, in-depth and specific information description and interpretation. I was also concerned about my ability to transcribe this rich information into text. Added to my concern was the real possibility of the subjective and unstructured nature of phenomenology as the research method.

2. LITERATURE REVIEW

When looking at the lived experiences of Muslims with stomas and the relation between this and their cultural and religious practices, it is important to investigate existing literature and research to provide an understanding of the phenomena under investigation, and to learn from these.

Stomas refer to surgical openings from the small or large intestine to the surface of the body, and can be temporary or permanent. Stoma bags are applied over this opening to collect bowel contents (ASCRS, 1996).

One important consideration to note is that as a general point, surgery can be seen to have an effect on patients' lives, in that it often causes a change or alteration in bodily functions. Surgery for cancer resulting in stomas may have a more significant impact than routine surgery. Whilst the outcome of surgery is intended to relieve the body of the ailment or hindrance at hand, the effect that often results in a patient who is incontinent also results in a change in the quality of the patient's life (Persson, Gustavsson, Hellstrom, Lappas & Hulten, 2005).

Society places a significant importance on body image. In a systematic review conducted in the United Kingdom (UK) by Brown and Randle (2005), it was shown that 13,500 people in the UK undergo stoma surgery annually – and for many of these, the public perception pre- and post-surgery sees marked differences. The key perception changes include the stoma bag altering the perceived body shape and associated factors include discharge from the stoma bag resulting in an offensive smell and uncontrollable bowel sounds.

In addition, Muslim stoma patients face public perception of the condition and quality of life issues. This is due to special religious needs, such as *Wudu* and *Salaah*, which is often affected by the constant inconvenience of having to change their stoma bags before prayer times. This inconvenience is reported in a multi-cultural study conducted in the UK by Black (2009) observing various religious groups and their special needs, which highlighted the

importance of nurses being able to understand the cultural practices of minority ethnic groups.

This literature review takes cognisance of the above factors when examining existing research conducted on the quality of life of stoma patients. It also puts an added focus on the religious quality of life of Muslim stoma patients. Additionally, the study delves into the coexistence of religious and traditional stoma counselling. This is first done through exploring literature on the general quality of life issues concerning stoma patients, and also through assessing literature relevant to the environment and nature of stoma patients within the Muslim community at large.

2.1 Quality of life with respect to stomas

Brown and Randle (2005) reported that patients with stomas have a number of physical and psychological challenges. These include depression, stigma of perceived body image, embarrassment, degradation and uncertainty. From a social perspective issues include social isolation, travelling and work limitations. Quality of life also encompasses physical issues such as disfigurement, loss of body function, physical damage, incontinence, odour, clothing restrictions, diet and limitations in sport and leisure. Brown and Randle (2005) in a review of the literature included 56 studies from 1990 onwards, with the majority being qualitative methodologies using phenomenological approaches.

Majola, Ntombela and Zungu (1995), in a study in KwaZulu-Natal, reported that patients frequently struggled to come to terms with their stomas, isolation and the perception of being 'sick' by society often leads to depression. Similarly, Brown and Randle found that emotional and psychological issues often led to patients questioning their ability to lead a normal life post- stoma surgery (Brown & Randle, 2005).

From a social perspective, the physical odours and body changes in stoma patients cause the social isolation and lack of acceptance experienced by the patients. Isolation, often self-imposed due to the societal stigma, results in patients not frequenting places they usually would (Baldwin, Grant, Wendel, Rawl, Schmidt, Ko & Krouse, 2008). Travelling becomes a

problem as patients are often not sure where to dispose their stoma bags, or how many bags they may need. Annells (2006) describes an example of the increase in flatus ballooning in the stoma bags, which resulted in a perceived view of these patients carrying something suspicious hidden underneath their clothing. The impact of these social changes causes lifestyle changes, and often employment problems (Annells, 2006).

From a physical perspective, common issues include leaking bags when they are ill-fitting or skin irritations when bags are too tight (Varma, 2009). This leads to bad odour, which may increase the social stigma and worsen the depression. Many patients need to adjust their diets in order to accommodate food that produces less flatulence and a less offensive smell (Hussein & Fadl, 2001). A number of ileostomy patients produce less solid faeces and often have to re-adjust their diet to make the faeces more solid. Due to this large loss of liquid from the small bowel, fluid balance – the need for the body to balance the amount of fluid lost with the amount taken in – needs to be maintained to avoid dehydration.

2.1.1 Challenges faced by patients

A significant challenge is the adjustment that is needed to make a lifestyle change as a result of having a stoma and stoma bag. Often patients struggle to accept and adapt to the changes in body image and the routine that this involves, which is worsened by the inconvenience in the time patients take to clean themselves as a result of the stomas (Brown & Randle, 2005). Patients need extra time for ablution purposes in preparation for daily prayers as a result of the constant cleansing of the bag and around the stoma site (Hussein & Fadl, 2001). Patients avoid situations such as family functions where they may be surrounded by many people – another example of self-imposed social exclusion.

A Turkish study reported that 83% of the female sample changed their jobs as a result of constant attention required to maintain their stoma bags, as this was something which required, them to be out of the public domain. Stomas require significant dedication from patients to adapt, and to try and maintain some form of normal life, which is not always possible (Kuzu, Topcu, Ucar, Ulukent, Unal, Erverdi, Elthan & Demirci, 2002).

2.1.2 Support structures

Support structures are important in order to improve patients' long-term well-being. It was concluded that where pastors and clergy provide spiritual support to patients and stoma therapists provided health care support, patients were more positive, found greater levels of self-belief and inner peace and felt less helpless (Persson *et al*, 2005; Baldwin *et al,* 2008).

Brown and Randle (2005) also reported that patients receiving sufficient support from friends and family who were included in decision making, exhibited higher levels of happiness and perceptions of their body image.

Majola, Ntombela and Zungu (1995) however, reported that the over-protectiveness and control of families over stoma patients can lead to feelings of being restricted in their activities of daily living.

2.1.3 Effect of the external environment on stoma patients

It has been shown that the environment and economic condition can adversely affect stoma patients and the quality of life they experience. This is shown in rural KwaZulu-Natal (Majola *et al,* 1995) and Pakistan, which were noted to have poor economic conditions in the studies conducted. These poor economic conditions often lead to insufficient stoma bags, or sometimes a complete lack thereof (Khan, Jamal, Rashid, & Ahmad, 2011).

In a recent auto-ethnographic disclosure done on himself in the United States (US), Frohlich (2012) reveals several findings relating to his personal experience with his own stoma. He experienced difficulties in discovering other patients with stomas due to the fact that persons without bowel diseases found it difficult to discuss issues around bowel diseases and bowel movements. It was also not natural for the body's waste products to be collected in a bag outside the body. However, Frohlich emphasises that when surgery saves your life, the human finds ways to cope with the effects (Frohlich, 2012).

Frohlich disclosed issues around his stoma in an on-line video, including pictures of his bare red actual stoma. This led him to meet and research other stoma patients with similar problems leading to several on-line dialogues including stoma patients, their relatives, friends and other interested parties. They shared numerous issues including jargon related to stomas, such as: bags, wafers, pouches and appliances.

Frohlich concluded that, ultimately, all persons with stomas seeks acceptance by friends, colleagues, family and communities. The on-line dialogue also created a space of awareness of stomas with non-stoma persons and highlighted the large numbers of persons with ostomies that existed and the degree of support that they required (Frohlich, 2012).

In another recent postal survey carried out in the UK, the findings indicate how cultural influences affect the psychological adjustments of persons with stomas (Simmons, Maekawa & Smith, 2011). The survey was conducted amongst British nationals and Japanese British nationals. The Japanese participants generally coped with their debilitating diseases by withdrawing from social interaction and generally suppressing their emotions. Thus, the research again emphasises the need for sensitive care counselling programmes to be culture specific. The study also revealed that the Japanese stoma patients experienced greater social isolation for much longer post-surgery compared to their British counterparts. The researchers made a pre-understanding that Asians may view disabilities to have a moral base that is avoidable and self-inflicting. This may increase the stigma towards stoma patients leading to delayed and difficult psychological adjustments (Simmons *et al,* 2011).

In a more recent descriptive, explorative study done in Taiwan, the relationship between spiritual well-being and psychological adjustment amongst stoma patients was explored (Li, Rew & Hwang, 2012). The participants all completed a spiritual well-being and psychological adjustment report. The results confirmed previous findings related to the dramatic psychological and physical impact stomas have on patients. However, the findings also revealed that the participants' cultural background appeared to be linked to their spirituality and coping mechanism and to the significant impact the stomas have on their lifestyle. This research concluded that spirituality is an internal and valuable resource that facilitates psychological well-being and quality of life. Spirituality also promotes a sense of satisfaction

with life itself and facilitates the healing and recovery process amongst patients in general. Frequency of religious practices also promoted psychological coping mechanisms amongst the sick according to the findings in this study. In conclusion, the findings of the study revealed that the participants with strong religious and spiritual affiliations, scored higher on the psychological wellbeing scale which assisted them positively with coping with their stomas (Li *et al*, 2012).

2.2 Stomas in the Muslim world

The assessment of stoma research in the Muslim world is important due to a pre-understanding that Muslim patients who have stomas are affected not only in their daily life, but that their religious duties are compromised as well (Kuzu *et al,* 2002). There are a number of religious rituals that are important for Muslims and a stoma impacts on the person's ability to conduct him or herself in accordance with religious rules. These rituals form part of the five principles of Islam, which can be detailed to be:

1. Belief in the oneness of Allah (God)
2. Performing the *Salaah* (compulsory five daily prayers)
3. Paying *Zakat* (charity) to the destitute and needy
4. Fasting during the month of *Ramadaan*
5. Going on *Hajj* (pilgrimage) if one has the means

2.2.1 *Salaah*

Salaah refers to a series of prayers and prostrations performed five times a day in worship. In order to perform the *Salaah*, one needs *Wudu*. Essentially, *Wudu* is a state of spiritual and physical purity, achieved through the washing of key body parts with pure water. This state of purity is nullified by the passing of flatus, urine and faeces, which stoma patients have no control of; hence the passing of flatus, urine and faeces inhibits the performing of *Salaah*.

However, a *Fatwa* has been passed in reference to the above. Kuzu *et al*, (2002), highlights the details of this *Fatwa* passed by the Egyptian Islamic Institute of Al-Azhar University in

Cairo. Patients with stomas are provided with a legitimate excuse in that their passing of faeces, urine and flatus during *Salaah* does not nullify the *Salaah,* provided that the *Wudu* is renewed before each prayer. This *Fatwa*, as well as Hussein and Fadl (2001), make note of the fact that even though this *Fatwa* is in place, many patients are not aware of this.

In a quality of life study conducted in Egypt on 28 male and female patients with stomas required after cancer surgery, Hussein and Fadl (2001) found that patients felt unworthy of performing their daily prayers in congregation due to a sense of impurity, despite the importance of congregational prayer. In their study, 61% of the patients interviewed did not participate in congregational *Salaah*, due to the leakage of watery faeces causing them to feel impure, whilst 58% indicated that the stoma restricted the time needed to prepare for *Salaah*. Similar findings were reported in the Turkish study conducted by Kuzu *et al,* (2002).

In contrast, a study conducted in Pakistan by Khan *et al, (*2011), where 100 male and female patients with a mean age of 38 years were studied, 80% of the stomas were due to infections, 12% due to traumas and only 8% for cancer. The study revealed that although patients found that soiling of their clothes interfered with their personal hygiene, their religious quality of life was only minimally affected. Many participants continued to perform their *Salaah*, with strict adherence to rituals involved and only a few exhibiting the same patterns as those of the Egyptian patients. This was due to strong religious presence in patient counselling.

In the Turkish study done by Kuzu *et al*, (2002) on patients who had stomas due to carcinoma, the results showed that 67 patients (38%) who always attended congregational prayers at mosques neglected this practice after being given a stoma, whilst a few abandoned the prayers completely. A further significant finding was that those who stopped attending mosque had an increase in social isolation. This lack of attendance of mosque was due to the perceptions of cleanliness and also a lack of knowledge on the *Fatwa* that was decreed.

A study on the effects of colostomy irrigation on Muslim stoma patients was conducted in Turkey by Karadag and Baykara (2009). The findings of this study showed that if patients could be educated on how to empty and fully cleanse their colons, the patients would be able to ensure they were ritually as pure as possible for *Salaah*.

2.2.2 *Hajj*

Hajj is an activity performed at least once in a life-time whereby an adult Muslim is required to visit Mecca in Saudi Arabia and perform certain rituals over a five-day period. *Hajj* requires a state of complete ablution, more so than *Wudu*. Hussein and Fadl (2001), in a study, collected information which showed that 56% of interviewed patients indicated that they were unable to perform the *Hajj* due to their perception that the stoma interfered with their ability to travel. Whilst specific reasons were not described, inference can be made that the key reasons are related to the cleansing of the stoma and disposal of the stoma bags. These findings were contrary to a study done in Iran, where patients found little difficulty in going for *Hajj* as a result of the availability and disposal of stoma bags (Dabirian, Yaghmaei, Rassouli, & Tafreshi, 2011).

2.2.3 Support structures for stoma patients in the Muslim world

The stronger the support structures provided by family, friends and religious leaders, the better the quality of life stoma patients can have. The Pakistan based study of Khan *et al,* (2011) noted that whilst minimally qualified stoma therapists were present in their region, religious leaders played a significant role in stoma counselling. As a result, 49.5% of stoma patients experienced minimal interference in their religious rituals as a result of the guidance provided by the religious leaders. Religious leaders seemed to play a more important role in counselling than doctors, nurses and therapists.

This is in contrast to the Egyptian study of Hussein and Fadl (2001), where minimal religious or health counselling was provided. The study indicated that 61% of stoma patients stopped attending congregational prayers. General quality of life was perceived as being low, due to the lack of both religious and health counselling (66% of patients had some form of physical and psychological impairment). Borwell emphasises the importance of health professionals'

understanding of the multicultural societies they operate in. An example of this is in Muslim religious practice where only the left hand is utilised for cleansing the stoma and the right hand being used for eating. Placement of the stoma bag should be positioned in order to make allowance for the sitting position and prostration made during the *Salaah* (Borwell, 2009).

2.2.4 Improving quality of life in Muslim stoma patients

Kuzu *et al*, (2002) showed that of the 178 patients assessed, sphincter-saving resection was attempted on 51 patients. The study compared the quality of life between those who had sphincters sacrificed during surgery (incontinent) versus those who had sphincter-saving surgeries (continent). The results of the research revealed that the religious quality of life of Muslim stoma patients is negatively impacted upon when they are incontinent, in comparison to those with sphincters and are continent. The research results showed that care should be taken in an attempt to not sacrifice the sphincters, where possible.

Karadag *et al*, (2009) demonstrated that managing the hygiene of stoma patients should be emphasised. Colostomy irrigation should be promoted and patients need to be comprehensively trained on how to conduct this irrigation in order to assist in improving their quality of life. This minimises the uncontrolled gas discharge and noises made by the bowel. Colostomy irrigation can also be practiced before patients attend congregational *Salaah*. This assists in alleviating the odours discharged at prayers, and hence provides the patients with a greater level of comfort and confidence in public.

In a recent comparative 2011 study conducted in Turkey by Celasin, Karakoyun, Yilmax, Elhan, Erkek, and Kuzu, a University of Ankara Life Standard questionnaire was conducted with 93 Muslim patients with colo-rectal carcinoma. The intention of the study was to compare health-related and religious practices of patients who had surgery and were given stomas. The study compared situations where these patients had minimal health counselling and no religious counselling to the current situation where these were made available. The aid of a Muslim religious leader and a stoma therapist was used to aid in this process, providing counselling both pre-and post-operatively.

The findings of the research indicated that patients who were given religious and health counselling had a minimal change in their religious observance and quality of life, whereas previously when they were not provided with counselling, the patients did not fast nor attend congregational prayers. (Celasin *et al*, 2011).

It can be observed that the quality of life of Muslim stoma patients is positively affected when provided with adequate counselling for both their health-related and religious needs. In the above study of Celasin *et al*, a further positive impact was that the patients were advised on the *Fatwa* regarding stomas, thereby enabling them to be informed and aware of the correct procedures to undertake in order to minimise the effect stomas have on their religious observance.

2.3 Understanding the context of qualitative research

Qualitative research is rooted in the naturalistic approach, and concerned with the in-depth study of human phenomena in their natural environment. There may be multiple experiences of realities and the researcher interacts subjectively with the participant (Creswell, 2007).

Qualitative research allows researchers to explore and understand human beings as individuals or as groups of persons with problems. The process involves the collection of information from participants and reflection on it. These reflections are then analysed and interpreted into meaningful themes. During the research process there are continuous interactions between the participants and the researcher. The researcher thus becomes immersed in the phenomena being investigated and becomes the primary instrument in information collection. For this study, the focus was on the participants' life experience with their stoma (Creswell, 2007).

The final presentation reflects the findings and experiences presented or described by the participants. However, in order for this to be meaningful and successful, a relationship of trust needed to be developed between the participants and the researcher.

2.3.1 Phenomenology

Phenomenology can be seen to contain an inherent philosophical component, drawing heavily on phenomenologists such as Husserl, Merleau-Ponty, Heidegger, Van Manen, Giorgi and others (Creswell, 2007). Van Manen explains that phenomenology begins in the original real world of a person's everyday life experience. Munhall notes that phenomenology is in fact not a method of research, but instead is an approach to understand human beings and what their life experiences means to them. Phenomenology describes what participants with similar problems have and do not have in common in their daily lived experience (Van Manen, 1990; Munhall, 1994).

The aim of phenomenology is not to explain human behaviour according to universal laws but according to the individual's subjective experience. Pascal explains that lived experiences of the everyday world can be revealed through the consciousness but may present in many forms. It is through assessing these lived experiences, that the researcher gains deeper understanding in to the meaning of the lived experiences and is able to make sense of them. The researcher therefore sets out to understand the current influence of certain phenomena within the daily lives of the participants (Pascal, 2010).

Van Manen emphasises the importance of these lived experiences being related to the researcher. However, to assign a meaning to these experiences, it is important to find the hidden, richer and significant meanings contained therein. It is also important to gain this information from authentic sources such as the conversations with the participant. The researcher needs to be flexible, due to the fact that in relating these experiences the same type of phenomena often changes from one person to the next. In order to gain an appreciation for these hidden meanings, researchers need to critically listen, understand, and relate to the experience. It is therefore important to engage extensively with the participants in order to fully understand the themes that emerge (Van Manen, 1990).

Phenomenology is becoming increasingly more popular in nursing research as it allows the patient/individuals to describe/share their experiences regarding certain phenomena and

creates an understanding amongst nurses about the patients'/individuals' everyday experiences (Kerrish & Lacey 2006).

Nursing is an art and science concerned with human beings, their health problems and responses to nursing care. The subjective and individual method of phenomenology may be appropriate for the inquiry into nursing research. The research pre-understandings may drive the scientific approach decision that needs to be followed. There are two main phenomenological approaches described in the literature, namely descriptive and interpretive (Lopez & Willis, 2004).

2.3.1.1 Descriptive phenomenology

Descriptive phenomenology arose from the philosophical notions of Husserl on how science should be conducted (Lopez & Willis, 2004). Husserl argued that experience as perceived by human consciousness has intrinsic value and guides scientific study, further noting that human actions are influenced by the perception of what is real. In descriptive phenomenology, it is essential that the researcher sheds all preconceived knowledge or ideas on the subject under study, also known as "bracketing". It is even recommended by Lopez and Willis that the researcher does not conduct a detailed literature review prior to commencing the research. Also, important to note is that the impact of culture and society on the individual's freedom or behaviour is not central in descriptive phenomenology (Lopez & Willis, 2004).

2.3.1.2 Interpretive phenomenology

Interpretive phenomenology, (not to be confused with interpretive phenomenological analysis),[2] arose from Heidegger, a student of Husserl's who challenged the descriptive approach to phenomenology. The key reason for this challenge was Heidegger's view that it is critical to interpret and better understand the lived experiences of participants in order to

[2] Interpretative Phenomenological Analysis (IPA) is used to explore idiographic subjective experiences and social cognitions and is widely used in psychology. IPA theoretical underpinnings stem from Husserl's phenomenology and Heideggerian hermeneutics and symbolic interactionism.

understand the hidden meanings and context contained therein (Lopez & Willis, 2004). Heidegger challenged the descriptive approach of Husserl. Heidegger also stated that in interpretive phenomenology, the critical factor is to understand the relationship that participants have with their life-worlds. Heidegger further states that the concept of "life-world" referred to is due to the impact and influence that the environment can have on one's life, also going further to point out that human beings cannot live in isolation in this world – the relationship that one has with the world defines a person (Lopez & Willis, 2004).

In following this interpretive method of inquiry, there is a degree of interpretive flexibility. The subjective experience of the individual is linked to the social life, culture, work, and relationships with people that the individual possesses. There is no correct or incorrect interpretation in interpretive phenomenology. Human beings are faced with making choices everyday – the freedom that individuals have in the world influences the decisions at their disposal (Lopez & Willis, 2004).

In interpretive phenomenology, the foundation of the findings of the research are therefore based on the interpretations that the researcher derives from the narratives of the participants. These interpretations are examined and can often be challenged by both the researcher and participant. An important pre-understanding in this is that the knowledge and experience of the researcher act as valuable guides to the research process. In accordance with Heidegger, it is impossible to rid the mind of the background and understanding of the researcher during this research process – an idea in contrast with the appropriate bracketing approach presented by Husserl (Lopez & Willis, 2004).

Mackey states that through understanding the interpretive approach it is more likely to reveal depth and diversity within nursing knowledge. The interpretive approach guides the researcher to the appropriate information analysis, thus influencing the diverse discourse and presentation of information. Mackey also recommends that interpretations should start at the point where the researcher engages in the phenomenon, and continues throughout the process. This is reinforced in the reading and listening of the participants' description of the phenomenon, whilst the researcher becomes immersed in the information. Interpretation is also based on prior awareness that is interpreted, but needs to be expressed and revealed (Mackey, 2005).

Mackey goes on to explain Heidegger's concept of the Hermeneutic Circle wherein the interpretation takes the form of a circular process, involving back and forth movement between the description and the interpretation of the experience. The life-world of Heidegger is the process of understanding a phenomenon by moving between the whole and parts of the whole, then back to the whole. The previous and current understanding or pre-understandings are challenged by the on-going dialogue and interpretations and new understandings continuously come into being (Mackey, 2005).

"Interpretive phenomenology can uncover taken for granted, intuitive, and other unrecognised aspects of care" (Chan, 2010:146). Chan also states that even if interpretive phenomenology is new to nursing, its use is recommended. It has the capacity to bring forth the qualitative aspects of the lived experiences of patients thus also incorporating the individuality of patient care.

However, Chan also expresses that Heidegger's philosophical language may need to be made more accessible for nurses to understand and use. This individuality of nursing care will create more empathy in the nursing community and a better response to patient needs. The fact that interpretive phenomenology focuses on the participants' life-world, dialogue between patients and nurses is encouraged. This interpretive approach may also assist nurses to reconnect theory with practice. In addition, Chan refers to the Heideggerian phenomenology as putting focus on humanity sharing its existence with each other and the world in progress (Chan, 2010).

The interpretive approach seemed appropriate for this study as I have been a colo-rectal nurse for many years and have been involved in creating stomas on a large number of patients in the operating room. Finlay states that in following the interpretive phenomenology, the researchers experience, understanding, personal history and knowledge brings them into the research and contributes positively towards the research process (Finlay, 2011).

Having distinguished the difference between the two phenomenological approaches, a phenomenological approach utilising an interpretive stance seemed appropriate for this study. I fully understand that phenomenology is also a philosophy; however, as a novice

researcher it was deemed appropriate at this level and for this study to use a phenomenological approach with an interpretive stance. Therefore there is no philosophical underpinning to the study.

3. RESEARCH DESIGN AND METHODOLOGY

The research methodology is qualitative with the specific method guided by the interpretive phenomenology approach.

3.1 Qualitative research

This qualitative interpretative phenomenological research design allowed myself as the researcher to explore and understand the participants with stomas as individuals. The process involved the collection of information from the participants, which was later reflected upon. The reflected information was interpreted into meaningful themes, whilst I became immersed in the phenomena being investigated. This approach allowed me to find rich, hidden and significant insights into the lives of the participants. These insights form the basis of the discussion provided in the research findings. The interpretative approach was therefore appropriate for this study as I have been a colo-rectal nurse involved with many operations for many years, assisting surgeons in creating stomas on a large number of patients as well as assisting stoma patients within the community.

3.2 Aim of the study

The aim of the study was to explore the lived experience of Muslims with stomas with respect to their cultural and religious practices.

3.2.1 Objectives

- To explore the experiences of Muslims with stomas when they return to their families and their workplace, attend mosque, perform their *Wudu* and *Salaah*, and perform *Hajj.*
- To explore how Muslims with stomas cope with incontinence and other effects of the stoma when trying to meet the religious requirements of a very “clean” body.

3.3 Population and sampling

The study population consists of Muslim men and women in the Cape Metropole who live with a stoma.

3.3.1 Sampling

Good sampling in qualitative research is essential to provide the best results considering the constraints of available resources and the flexibility of this particular research method (Kerrish & Lacey, 2006). The sample selection and size needs to be aligned to the methodology being used. The selected participants need to be available and accessible in order to participate freely in the study (Holloway & Wheeler, 1996). The sampling method of this study is purposeful sampling, which allowed me to invite Muslim stoma patients who could provide rich data.

3.3.2 Sample size

Holloway and Wheeler (1996) recommend a small sample size for a qualitative phenomenological study comprising between six to eight participants. Participants need to share information that will make a meaningful contribution towards the study. In-depth conversations and immersion into the phenomenon means that a large sample size is unnecessary. The sample size of this study included seven participants and information collection continued until the point of information redundancy or information saturation.

3.3.3 Inclusion criteria

The sample criteria should ensure the provision of a rich source of information (Creswell, 2007). The following constituted the criteria for this study:

- Participants are all Muslim
- Participants are all adults
- Participants were able to converse in English

- All participants have a stoma for longer than six months, as at this stage they would have been discharged from hospital, require minimal medical treatment and have established a routine with their stoma
- Participants all reside in Cape Town.

3.3.4 Exclusion criteria

Participants who were unwell or sick at the time of the study were excluded. This refers to patients who were currently still healing from their surgery.

3.4 Study setting

The conversations were all conducted in the participants' home environment, which proved to be most suitable and convenient for all the participants. The rationale for choosing the participants' homes as the setting increased the likelihood that the participants would feel relaxed and at ease in a more familiar setting. It is more appropriate when doing a lived experience study to conduct the research in the natural environment or social context that the participant finds him or herself (Holloway & Wheeler, 1996).

3.5 Information gathering

3.5.1 Gaining access

Participants were recruited using a purposeful sampling method. Due to my long-term involvement and association with stoma patients in the community, participants who were known to me were invited. The participants were informed about their voluntary participation and that the study does not provide any personal and/or therapeutic gain or counselling by the researcher.

3.5.2 The phenomenological conversation

The phenomenological conversation was guided by semi-structured questions as a guideline and was audio recorded. The broad opening question was:

"Please tell me, in your own words, your personal experience with your stoma."

All participants were asked the same initial question; however, the process of the conversation was flexible to allow the participants to express their feelings and opinions in the manner they chose.

Each participant had two conversations for approximately 45 minutes at a time. A transcription of the conversation was completed shortly after the conversation, and before the next conversation occurred.

Field notes were kept to assist myself throughout the research process. This was especially useful for non-verbal communication displayed during conversations. The participants were also encouraged to keep diaries in the period between conversations to capture any explicit information, thoughts or feelings. The participants were encouraged to record any information deemed relevant to the study in the diary, and not on a timed or fixed basis. The diaries were requested to be kept private as a reminder for the participants and to provide further input during the follow up conversations.

3.6 Information unravelling

For this study, Colaizzi's seven steps of inductive reduction were used. Colaizzi points out and encourages researchers to apply these seven steps with flexibility and make the necessary adjustments to allow for rigour.

These steps are:

1. The researcher needs to thoroughly read through the transcribed scripts. By reading through, the researcher obtains an understanding of the meaning of the script by getting a feeling of what was meant by the participant.

2. The researcher needs to extract words and sentences that stand out, or that highlight the phenomena being studied. Following this, the researcher re-writes and summarises the transcript through these highlighted words and sentences.
3. The significant words and sentences are used to formulate meanings.
4. This process is repeated throughout with all the significant statements from all the descriptions narrated with the participant. These are then formulated into clusters of themes. The researcher reads through the original highlighted descriptions to validate these themes. The original transcript can at this point also be rechecked to analyse for any further significant themes.
5. All the significant clusters of themes can be integrated into an exhaustive description of the phenomena being researched.
6. The exhaustive description is at this stage reduced to an essential structure. This then becomes the fundamental structure of the phenomena.
7. In the final stage, the participants are given the opportunity to view the findings and validate them (Colaizzi, 1978).

3.7 Rigour

3.7.1 Five expressions of rigour

De Witt and Ploeg proposed their current framework of findings for expressing rigour in phenomenological research. The following five points are expressions of rigour that they have described and which is applied to this study (De Witt & Ploeg, 2006).

3.7.1.1 Balanced integration

The researcher needs to apply the basic philosophical principles which are suitable to the specific type of research, the findings and the voice of the participants in a balanced manner. For example, *Kader* continued going to mosque as he would have before having a stoma. However, he felt uncomfortable about the fact that he was a young man sitting on a chair and the younger mosque congregants were judgemental about him (Refer to p. 42).

3.7.1.2 Openness

The study needs to be made available to allow openness and access to the process of interpretation. There needs to be an explicit accountability for the described interpretation of the findings. For example, in a diary entry dated 3 March 2013, *Razeen* shares his experience of changing his own stoma bag for the first time (Refer to p. 58).

3.7.1.3 Concreteness

Concreteness involves realistically placing the reader within the experience of the participants' conversation. The examples given need to be recognisable to persons in the real world, allowing them to identify with it. For example, the participants recognised and identified themselves within the themes, and the subject matter becomes a real life experience.

3.7.1.4 Resonance

The expression of the term resonance refers to the explicit effect that the findings have on the reader and participants after experiencing its real life meaning. For example, *Aziza* was very relieved to have broken her own silence for the very first time by being a participant and having her voice heard, but still remain anonymous (Refer to p. 77).

3.7.1.5 Actualisation

The fifth expression of rigour focuses on the fact that even after the interpretation of the phenomenological study is completed, the interpretation of the study's findings may continue for the readers well into the future. The study may be completed, but the interpretation is on-going. This allows for opportunities for further research. For example, *Kader* was keen to compile a booklet of all the personal research he did on the topic of Muslims and their stomas and to distribute it within the community (refer to p.79).

3.7.2 Participant feedback

Bradbury–Jones, Irvine and Sambrook strongly recommend the use of participant feedback as a method to improve rigour in phenomenological research (Bradbury-Jones, Irvine & Sambrook, 2010).

The participants shared the consensus of the interpretations of their conversations. They were in agreement with all of the findings and indicated that there were no exclusions of their experiences. There were no contradictory opinions or dilemmas raised and it can therefore be concluded that the participants were in agreement with the researcher's findings and the feedback received was generally positive

3.8 Ethical considerations

It is a norm in nursing ethics to safeguard and protect patients. Nurses are also guided by their moral duties not to bring any harm to their patients. Ethical considerations need to be kept in mind in all research conducted involving human beings. During the research process participants should not only to be protected from harm, but need to be informed about their rights.

The study was conducted in accordance with the principles of the Helsinki Declaration, to ensure that medical research is subject to ethical standards to protect humans, their health and rights (World Medical Association Declaration of Helsinki, 2008).

3.8.1 Confidentiality

In this study, participants were assured that confidentiality issues will be adhered to, and that they can withdraw from the study at any point, with the consent letter containing a clause for confidentiality.

The participants were allocated a pseudonym that was used throughout the research process. Conversations were only recorded after the initial greeting and establishing of conversation. The participants were informed on their consent forms that their names will

not be included in the research. The participants' confidentiality was respected at all levels of the research, even when having discussions not forming part of the research. The identities of the participants' were not disclosed to anyone besides the principle researcher.

3.8.2 Protection of information

Audio tapes are currently stored in a safe place in an encrypted folder on a computer, with the password known only to myself, for the period of a year. The memory card used in the digital recorder will be reformatted and all data/information erased.

3.8.3 Risk and benefit

It was explained to all participants that in the event of them showing any signs of emotional or psychological distress, they may withdraw from the study, and support in the form of counselling will be provided from the Stoma-therapy Department from where they were affiliated to during their surgery. Additional religious support will be provided from the local Muslim *Imaam* if needed, or from the participant's private practitioner or healthcare provider. Fortunately, this was not necessary.

There was no direct benefit to the participants as a result of participation in the study.

3.8.4 Informed consent and voluntary participation

Written and verbal informed consent was obtained from all participants involved in the research process. The consent came from the participants' free will, whilst also being informed of the nature and purpose of the study. An estimated duration of the length of the research was included in the consent.

During the process of informed consent, the information given to the participant must not influence or affect the spontaneous nature of the research (Holloway & Wheeler, 1996). Participants may withdraw from the research at any stage without any implication to themselves or their family. A copy of the consent form is in **Appendix 2**.

3.9 Significance of the study

It is hoped that the findings of this study will provide information that will enable health professionals to better understand the challenges faced by Muslim stoma patients. The researcher also proposes to circulate a revised version of the findings of the study to mosques in Cape Town in order to increase awareness of the existence of stoma persons within the community.

4. RESEARCH FINDINGS

This chapter presents the four themes that emerged from the analysis of the information gathered from the seven participants. The objective is to give the reader an understanding and insight into the lived experiences of Muslim stoma patients in the Western Cape. The participants' narratives are incorporated as anecdotes to enable the reader to see how the findings were drawn from the information. The narratives can be seen to be reflective of Chapter 5, Verse 6 of the *Quran*, quoted previously.

Additionally, the participants in this study presented three primary reasons for requiring stomas, namely:

1. Spina Bifida: Congenital abnormality of the spinal cord, resulting in a lack of nerve supplies to certain organs.
2. Ulcerative Colitis: Inflammatory bowel disease affecting the large bowel. Surgery to remove the colon is a last resort to ulcerative colitis, after medical therapy has failed. This results in patients requiring a temporary stoma, to allow for the reconnected bowel to heal. The reversal of this temporary stoma may last for many months.
3. Rectal Cancer: Often involves permanent removal of the anus, resulting in patients requiring a permanent stoma.

4.1. Description of themes

Four themes were generated from the individual phenomenological conversations. This set of themes has been named: **'The four S's of stomas'**. In acknowledgement of the participants breaking their silence, the narratives are captured in a different font and colour to highlight the importance of them allowing their 'voice' to be heard. The bold text that is highlighted in the narratives is my own to emphasise meanings.

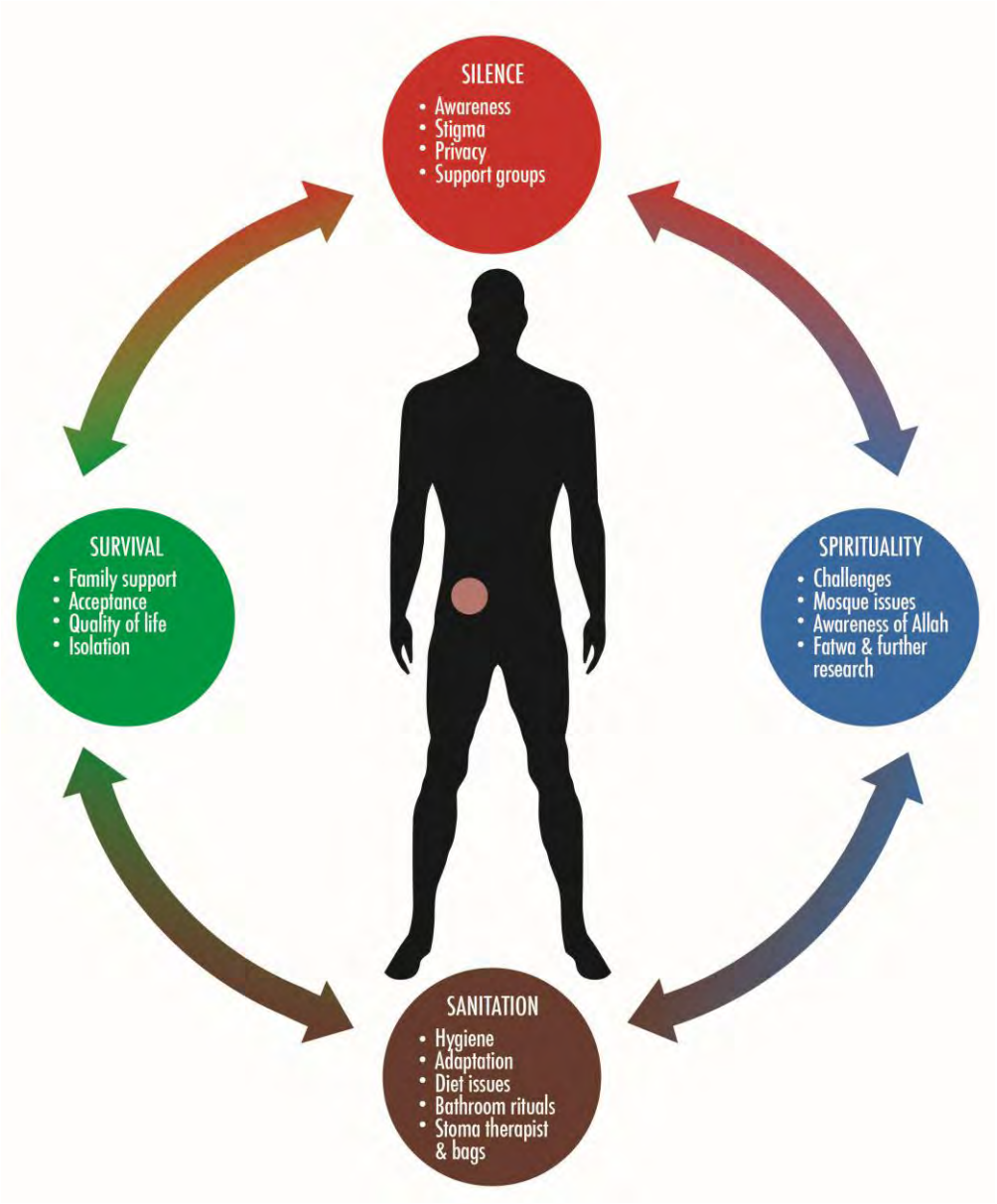

Figure 1: Interlinked Four Themes

Each of the themes depicted in the above image generated various sub-themes. These sub-themes are shown in the below table.

Table 1: Theme and sub-themes

Theme	**Silence**	**Spirituality**	**Sanitation**	**Survival**
Sub-themes	• Awareness • Stigma • Privacy • Support groups	• Challenges • Mosque issues • Awareness of Allah • *Fatwa* and further research	• Hygiene • Adaptation • Diet issues • Bathroom rituals • Stoma therapist and bags	• Family support • Acceptance • Quality of life • Isolation

4.1.1 Theme one: Silence

There appears to be a fear amongst the participants of being rejected should people know that they have a stoma. All of the above sub-themes support the issues of the silence that exists around stomas. This becomes apparent in the theme clusters of 'awareness', 'stigma', 'privacy' and 'support groups' .

Aziza (pseudonym) is the most adamant of all the participants about being silent and secretive about her stoma. Aziza is a 43-year-old married Muslim woman who was born with a Spina Bifida. Due to this congenital abnormality, she was given a urostomy (stoma which drains urine) at birth. After her marriage, she was also diagnosed as being infertile and therefore never had any children.

At the start of our first conversation, Aziza's desperate need for privacy became apparent. She was barely audible, highlighting her fear of voicing herself. I could barely hear her and thus turned up the volume of the digital recorder. Aziza was reassured again of her anonymity and confidentiality.

"I must just stress to you that no one has ever, ever, come to me before you, so I have to make this point that I've never ever thought of the ***silence*** *for a very long time. To me it's always been a* ***given.*** *I have to tell you today: you're the first person that made me think about it so*

*deeply about how **many** of me are out there. And how many of me have the strength and the support that I have had like with my mom and my husband."* Aziza

Aziza tells me that she said a special prayer to get her through this conversation. She is becoming consciously aware of the existence of so many less fortunate stoma patients who may not have the love, protection and support that she has received over the years from a few of her loved ones. Aziza is unaware that this may be the start of lifting the veil off her own silence and reaching out to other stoma patients in the future even in an anonymous manner.

4.1.1.1 Sub-theme: Awareness

In the Muslim community there appears to be a lack of awareness around the existence of stomas, thus creating a perception of exclusion of persons with stomas even amongst mosque congregants. All the participants indicated that bringing about awareness around stomas may make it easier for them to be accepted by society at large. The following anecdotes are some examples experienced by participants indicating this lack of awareness.

Kader

Kader (pseudonym) is a 27-year-old married man with two children. He suffered from ulcerative colitis for approximately four years before having his colon removed and given a stoma in 2011. His stoma will be reversed when he is free of disease. Despite being 27 years old, he is deeply religious and attends mosque for the congregational prayer regularly.

*"I was afraid of people looking at me and thinking what is making this noise … I was afraid that they would **reject** me at the time. Coming in this state to mosque, what people would think or react to the stoma and what the questions would be … pertaining the bag."* Kader

Kader is a confident young man, but regards the opinion of the mosque congregants as very important. Kader needs to be accepted without others being judgmental towards him. It is important for him to continue attending the congregational prayers, but being a sick young

person is not a norm and draws attention to him being different. This disturbs Kader and he is afraid that his stoma would be offensive to the rest of the mosque congregants.

Kader was then asked how he felt about bringing about awareness to the mosque congregates via the *Imaam*. He said:

"It will help the person that has got a stoma and also the person that is looking at that person, he will actually know why you carrying that bag around with you and what you doing with that bag ... then you won't feel as an outcast basically when you going to mosque." Kader

Kader is aware that the *Imaam* is well respected by the congregants and is thus in a position to make the congregants of the mosque aware that having a stoma is an illness and during this time these stoma persons need to uphold their spirituality and not be judged by others who have no knowledge about this physical ailment.

Safia

Another participant is Safia (pseudonym), who also highlights the lack of awareness around stomas. Safia is a 50-year-old divorcee and has one son. She is a primary school teacher who is very passionate about her job. Safia is a very traditional Muslim woman and had severe ulcerative colitis for many years. When her disease became medically untreatable she had surgery where her colon was removed and she was given a temporary stoma.

"When I had this operation, I didn't know what a stoma is. I had this illness all this time and all this treatment, and my doctor actually warned me that our last resort would be to have my colon removed and I'll have to wear a bag, I ... realised that this is the first time I heard about wearing a bag?" Safia

The lack of awareness seems to contribute to the silence around stomas and the cycle is perpetuated when the silence too, results in a lack of awareness. Having a disease that often requires a stoma had no impact on Safia's awareness of stomas until she received one.

Razia

In contrast, persons who were previously exposed to cancer and stomas were more aware of stomas. Razia (pseudonym) is a 52-year-old married woman who had colon cancer and now has a permanent colostomy. She was so aware of the disease and its consequences that she appeared in a magazine article as part of a cancer and stoma awareness programme. She spoke in a relaxed manner with a smile and said:

"*Everyone should know about it. I told them I got a stoma. I tell them I got a Louis Vuitton bag."* Razia

Razia feels strongly about breaking the silence around cancer and stomas to create awareness of its real and serious effects. She talks freely and comfortably about her stoma to friends and even jokes about her stoma bag. Razia sadly says that her mother died of colon cancer and thus she was very aware of this dreaded disease.

Achmat

Achmat (pseudonym) is a 72-old-married man who lives with his wife and shares a house with his married daughter. He has a permanent colostomy after being critically ill following an abdominal aorta aneurysm operation done in 2009, which left his colon ischeamic (no blood supply) after a severe infection.

Achmat is a mature male who feels strongly about bringing an awareness of his illness to others in order to bring about some understanding. He emphasises that having a stoma is just like any other illness and you learn to live with it. You can also go to mosque and make your *Salaah* because you have to.

"*I have no problem with anybody knowing I have a stoma, but you tell the person and he would say* 'nou wat is a stoma' *(*now what is a stoma*). I explain that the colon has been affected that's why I have this bag attached to my body and I have to live with it. I have to sleep with it. I have to make Salaah with it and I suppose when I die they just have to take it off and … end of story."* Achmat

Achmat has a very practical and spiritual approach to accepting the stoma. In his conversation, he emphasises his stoma as a permanent feature in his life. He feels the need to share the reality of his stoma with others to make them aware about his normal spiritual lifestyle with a stoma. Achmat is a regular attendee in the mosque near his home and his opinion about stomas as an elder allows him a privileged voice of respect, which will be well accepted. I felt privileged that Achmat was able to openly discuss this very sensitive and private topic with a stranger and a younger woman.

4.1.1.2 Sub-theme: Stigma

The word stigma denotes something that is culturally disapproved. The fact that stoma patients are incontinent and may be perceived to have a disability may be a contributing factor for it to be stigmatised by some people and more so amongst Muslims. As previously explained, the Muslim religion and all its practices revolve around purity and cleanliness. Having a stoma may be perceived to be impure. The diagnosis of cancer is often kept silent by patients and relatives as it is misunderstood as a death sentence. There is also a perceived link between cancer and it being the reason for getting a stoma. Some experiences of stigmas associated with stomas expressed by the participants are now discussed.

Aziza

Aziza did not want her stoma to be regarded as a type of disability. It was important for her to be treated and challenged in life as any other normal person and she did not want to be marginalised.

"*I also felt that I never wanted to be judged, let alone the stigmatisation. I never wanted sympathy because I wanted to show that I can make it on my own with this condition. Not like a disabled person who is in a motorised wheelchair. So I will row my own boat. So don't feel sorry for me.*" Aziza

Aziza has achieved many academic accolades throughout her life with a stoma and feels strongly about being treated as an independent person. She never wanted her stoma to be

regarded as a ticket to getting special favours and to be considered as being different or unequal. She required no sympathy or pity and worked hard to achieve success in life.

Razeen

Razeen (pseudonym) is a 37-year-old single male who lives with his mother. He has a temporary stoma for a cancer of the rectum operation. At the time of the first conversation he was still receiving chemotherapy and felt very uncomfortable about his stoma. During our conversation, Razeen is very anxious and nervous and his anxiety makes him stutter at times. The conversation takes time as Razeen inhales deeply each time he says the words 'cancer' or 'stoma'.

"*The … cancer is like a stigma around the word … you hear it on the radio, on television and everywhere. I told a friend, I've been off the radar for a while … I had a tumour removed. Obviously when you tell people that then the next question automatically is was it … making hand movement to show that people don't generally like to say the … cancer word and then … I say yes. People automatically associate dying and death with it … their eyes go big … after hearing the cancer part, but their eyes go even bigger when they hear about the bag and its purpose."* Razeen

Despite the shocked response from a very good friend, Razeen confides in him about his stoma. Razeen explains all the details around the function of the bag and receives a huge hug from his friend as an indication of empathy and support. Razeen confides in close friends to ease off the stigma surrounding his stoma and in this manner draws strength from them during a very challenging period in his life. Razeen admits to his discomfort using the terms so closely connected with death. He is still very anxious about whether he has been cured of the cancer.

Safia

Safia is relaxed during our conversation, but coming from a very traditional family, is now smiling while she shares the following with me in a slow, soft voice.

"So you think there's a stigma attached to certain types of illnesses?" I ask her.

"Yes, I think it is a …. community thing and I think the elders brought that along but I don't know if it's just in the Muslim community. Also, when I mentioned to a neighbour about my illness, she said to me, "oh, another neighbour close to me, she's also wearing a bag, but she said oh, you mustn't talk about it."" Safia

Safia believes that the older generation stigmatised certain illnesses and this was not necessarily confined to the Muslims. She now discovers a close neighbour also has a stoma. Safia's neighbour confirms the need to be silent around another neighbour's stoma, which apparently to her may not be spoken of due to the nature of the illness. In contrast to her neighbour, Safia does not keep her stoma a secret.

4.1.1.3 Sub-theme: Privacy

For some of the participants their privacy needed to be maintained to protect themselves against persons who may be judgmental about certain diseases.

Aziza

"*I think I've never really thought about it, what it's doing to me by being* ***silent*** *because … no one's really had a very frank and open discussion about it with me that I should allow others into my life as far as my stoma is concerned … it's* a *private thing. It's like your periods. It's a secret between me and my mom she was protecting me.*" Aziza

The fear of exposure is a pivotal part of Aziza's life. However, she says that participating in the research has turned out to be a relief, letting go of a lifetime of secrecy and silence. She was acquiring a sense of freedom from a secret indoctrinated in her system from birth through her most beloved and supportive mother as a means of protection over the years to come. It seems like a natural process for a mother to protect her child when born with an abnormality like Aziza's. The protection also makes sense when certain diseases are stigmatised by your own community. Although Aziza had a breakthrough with lifting her silence she emphasised her need to remain anonymous.

Safia

In contrast, Safia felt very different to Aziza about her own privacy and stoma.

"I was very open about my illness to my colleagues, and when I discussed it with them the one asked me, now what is going to happen? I said, well, I also don't know much, but I just know that I'll have to wear a bag." Safia

The privacy and silence is not of concern for all stoma patients. Safia realised that colleagues and friends can be of great support during times of need. Safia regarded her openness regarding her stoma as a form of therapy where she gained the support and empathy of those around her. Safia had a temporary stoma and this may contribute to her difference in feelings regarding her stoma. Aziza was born with a stoma and had to adapt to finding her own coping mechanisms to survive. For Aziza the secrecy was essential.

4.1.1.4 Sub-theme: Support groups

There was a strong consensus emphasising the need for a Muslim stoma support group. There were a number of cancer support groups that proved to be very well supported by the patients who were in need of information and general reassurance. The needs of the Muslim stoma patients are unique and the silence that governs the topic makes the required information harder to find. The silence that exists around patients with stomas has also 'hidden' them. There are many queries and unanswered questions for the new stoma patients regarding 'do's and don'ts' around religious activities.

Kader

Kader indicates that special needs existed for stoma patients and the knowledge was not easily available to them.

"*There are a lot of people that have stomas that don't know … they have to do their own research as to what to do when the stoma is there … how to go about their daily prayers and to go on living life … as before. Because of the bag being there … you are conscious of it at all times, you are worried that it's going to leak … I was always doubtful regarding my state of purity until I did my own research as well.*" Kader

The information Kader received from his stoma therapist had some religious guidelines regarding how stoma patients had to go about getting purified in order to make their *Salaah*. Kader was concerned with the inadequacy of detailed information and did his own research to verify his own state of cleanliness for his *Salaah* to be accepted. Kader wanted to make this research information available to other stoma patients.

Razeen

Razeen's intense facial expression holds my attention.

"I went to the end of year oncology … support thingy … and it irritates me a bit is that there's so much hype about breast and prostate cancer and nothing about colo-rectal cancer and I understand that by nature … of the cancer and where it's located … why its taboo and people wouldn't want to talk about it, but I don't feel like it's given enough support particularly in the Muslim context and add stomas to that … Cause you obviously feel you going through the rituals of the religion so as a radio personality I would like to do an on air stoma awareness programme and maybe help start a support group." Razeen

I feel uplifted by Razeen's strong feelings about the absence of a Muslim stoma and rectal support group. He now appears less anxious, but still stutters slightly. Razeen's own diagnosis of rectal cancer has made a huge impact on his very existence and surviving the cancer brings about the need for him to reach out to others in a similar situation. Razeen's community radio work puts him in an influential position with a large audience and is creating a positive effect around his previous struggles with his own anxiety.

4.1.2 Theme two: Spirituality

Muslims believe that Allah will never test them with any burden that is greater than what they can overcome. Generally, when a pious Muslim person is affected by challenges such as a severe illness, their spirituality and belief in Allah makes it easier for them to accept and deal with their illness. However, this is not always easy and for some, it may be difficult and a test of the strength of their belief. They are allowed to be just human and also have their doubts. For others, their spirituality increases once they accept their illness and become

increasingly more aware of their Creator. The challenges faced may bring about uncertainties and they search for answers.

For many Muslim men, attending mosque for congregational prayers is high on their spiritual agenda. Women do not attend mosque for their daily prayers but performs it at home. The theme of spirituality includes the subthemes of spiritual challenges, mosque issues, awareness of Allah and the *Fatwa* and research.

4.1.2.1 Sub-theme: Challenges

The *Salaah* is performed five times a day by all practicing Muslims. It can be done at home or in mosque. The act of *Salaah* involves standing, bending, bowing down and prostrating with the forehead on the ground. Some of the spiritual challenges faced by the participants are now illustrated.

Gasant

Gasant (pseudonym) is a 57 year-old married male who had colon cancer and now has a permanent stoma since 2011. He was a regular in the mosque for the congregational prayers. Gasant was asked how he coped after his surgery with making *Salaah.*

"*After my recovery I could stand, but I still preferred to sit, because I was afraid of going… from standing position into bending down, being afraid that the bag is going to fall off or maybe come loose and excrete faeces out on the side or bottom so I continued sitting … but as the time went along I realised … I could perform the normal prayer … as I usually did.*"
Gasant

It was a challenge for Gasant to do the *Salaah* in its normal position after his surgery, but he never used this as a reason to miss his *Salaah*. He was always scared of having an accident with the stoma bag and was always consciously aware of its potential risk to leak. Gasant's intense faith in Allah was the inspiration and motivation for him to resume making his *Salaah* in its preferred position. He believed that standing and doing the prayers was more spiritual than the perceived easier sitting position that was intended for the old and sick.

Kader

Kader shared a different dilemma with me regarding his conflicting feelings while making his *Salaah*. Kader was a young man, but still very serious about his religious obligations.

*"There was definitely conflict because as we know there is Shaytaan (*Satan*) that are with you at all times and puts you in a state of conflict. Shaytaan plays ... tricks on your mind ... you think that you are impure, and your prayer is not accepted and then you concentrate more on the bag than on your prayer at the time. It seems that the bag is excreting filth but you are still supposed to be in a state of purity."* Kader

Whilst sharing these feelings, with me Kader had a frown on his face and sounded almost fanatical about his state of impurity whilst being incontinent. In his extreme concern about not being sufficiently clean for his *Salaah*, he uses a very harsh word to describe his impure state: filth. This causes Kader to even doubt himself and whether his religious duties are good enough to be accepted by Allah. It was essential for Kader to concentrate one hundred percent on his Creator whilst performing his *Salaah*. Kader is very explicit about his state of purity.

Aziza

Aziza commented about being angry with Allah for putting her through so many trials and tribulations.

"I think maybe just before I got married I was very ... very angry with God, because I realised I am angry and scared at the same time because I didn't know ... it's one thing for a partner to tell you he'll accept you the way you are, but you only know when you live with him. Later I made peace with my God and then it was like a huge burden was lifted." Aziza

Being born with her disease and having her mother protect her all her life made it easier for Aziza to accept her stoma. However, her greatest challenge was sharing her secret with her husband to be. Aziza went through a period of being angry at Allah because she was now faced with a very different and major challenge. There were very few people who knew Aziza's secret and to share it with a husband would be a real test of his commitment to her.

Nevertheless, she finally made her peace with Allah after her husband accepted her unconditionally. This was essentially a start of a new era in her life because her husband would be as committed and protective about her stoma as her mother was throughout her life. Aziza's husband was already in love and committed to her before he even knew that she had a stoma.

4.1.2.2 Sub-theme: Mosque issues

There were various challenges that the male participants faced or perceived when attending mosque. It was important for the men to keep attending mosque, but also to be accepted by the congregation and not frowned upon.

Kader

Immediately after his operation, Kader's physical condition was frail and weak, but he still attended mosque.

"At the beginning I was still in a lot of pain I had stitches so I used to sit on the chairs in mosque where the old people sit. The reason for that was that in Islam, there is no difficulty when praying so the chairs are there for people that have physical ailments. Just recovering from an operation and having a bag, sitting with the old people I felt at an all-time low because they think why he is sitting on that chair if he's young enough to stand. I felt… conscious of young people … the elderly don't judge you. You feel at peace when you sit next to an elderly person, but you don't feel at peace when a younger person is looking at you."
Kader

Kader passionately explained his experience in the mosque. He was still going through the transitional period of getting used to his stoma. Kader was also at the stage where he was struggling with his own physical incapacity and now he was concerned about other younger congregants being judgmental. The chairs at the back of the mosque were generally secured for the aged and the sick. Kader did not want to be identified as sick or disabled, but sitting at the back with the elderly drew attention to him. However, the older men sitting with him on the chairs in the back of the mosque gave him comfort and he kept going to mosque.

Achmat

Achmat had a very unique problem that bothered him for two to three years after he was given his stoma. He was not only a congregant in mosque, but he sometimes took the part of the *Imaam* by leading the congregation prior to having a stoma.

"You see if you leading the Salaah you have to be very careful. If there are fifty or a hundred people standing there, you are responsible for those people's Salaah. So that is why I am very, very cautious in leading Salaah." Achmat

Achmat is a pious and conscientious Muslim. He is very aware of his stoma and his state of purity. Although he felt clean enough (after cleaning his stoma at home and taking *Wudu*) to make his own *Salaah*, he was unsure if he was sufficiently purified to lead a congregation without contaminating their *Salaah*. He was scared that he may be punished by Allah if he nullified their *Salaah*. At times this made him feel guilty about going to mosque because he was not sure how to refuse when asked to lead the *Salaah.* However, he continued going to his local and other mosques.

Razeen

In contrast to the other male participants, Razeen was in a confused state of spirituality.

*"I haven't gone to mosque since the operation and I'm … it's not something I feel very good about. For the first time in my whole life … I never went to mosque on Eid (*Muslim religious holiday*) … because I'm struggling with this fear of dying and … in some way … going to mosque is bringing that up for me psychologically."* Razeen

Razeen's spirituality took a plummet immediately after his stoma surgery. For him, the mosque symbolised such a high state of spirituality, that it reminded him of death. Razeen's fight with cancer and its reminder of death was still a huge factor for him. His unstable psychological and emotional condition made him miss one of the biggest celebrations at mosque, Eid. However, on a later occasion Razeen's spirituality started to change when a very good friend got married and he attended the religious ceremony in mosque with less anxiety.

4.1.2.3 Sub-theme: Awareness of Allah

All participants indicated that their awareness of Allah increased after they were very sick and needed a life-saving operation. It is a belief that illness is a reminder of death and thus brings believers closer to their Creator. The following are some of the anecdotes shared by some of the participants.

Achmat

Achmat was so intense and aware of his doubt in leading the *Salaah* at mosque that he consulted with several *Imaams* in the Western Cape. His piety was intense.

"They all told me that I can lead the Salaah and that it would be my pure intention that counts. They also advised me to inform the congregation of my stoma and then get their general consensus." Achmat

Achmat is currently leading the *Salaah* at his local mosque and claims that this has even brought him closer to Allah. Achmat was so concerned about being spiritually correct that he did his own research on the opinions of the spiritual leaders to give him the necessary guidance and confidence to lead many congregants in their very essential and important religious obligation. Achmat also shared with me that he believed that the more effort that was put into any spiritual deed, the more weight it carried. As Achmat points out, in Islam the intention behind any deed is often more important than the actual deed itself.

Gasant

Most of the participants were extremely grateful for being alive and being given a second chance at life. Thus, they all give praise to Allah for giving them this opportunity at life again. Gasant shares his thankfulness to Allah.

*"To get a second chance like this I am very grateful algamdulillah (*thank God*) that I survived that operation, I survived the kidney scare, I survived the lung scare and obviously had to be*

left behind with the stoma. I am satisfied there is nothing I can do about it. I know Allah knows why and I accept it." Gasant

Gasant's belief in his Creator is so strong that he is absolutely able to accept that what Allah has ordained for a person is with good reason and thus well accepted. He was critically ill and to survive was only through the will and mercy of Allah, who knows why we are put to the test of endurance and ultimately acceptance. The opportunity to continue serving Allah is of utmost importance.

Razia

Razia is just as pure in her belief in what Allah has planned for her.

"I just thought whatever must be must be. We come from Allah and we will go to Allah never mind what illness you have. I just coped … I'm satisfied." Razia

When the doctors diagnosed her with cancer she was shocked. However, she signed the consent form for her operation without a doubt in her mind that this is what Allah willed for her and thus will protect and guide her. She had so much faith in the will of Allah, she immediately consented to get an operation that gave her a permanent stoma, but would save her life.

Kader

Kader struggled with accepting his stoma and with being rejected by society during the first few months after being given a stoma.

"And then I had a turning point … when the religious part kicked in and I didn't care what people think anymore, this is who I am now. I came into this world alone and I'll be leaving this world alone so this is the difficulty that my Creator has put me in and therefore He knows best. After realising this is my life I started becoming more pious. I woke up every morning being grateful for still being … able to serve Him, my Creator." Kader

Kader had a definite move to a much more positive mindset. Kader became more Allah conscious and so did his entire family. For Kader, Allah was the only one that could help him and the only one who he really had to submit to. He had a firm belief that Allah will protect him and guide him and his family in whatever challenges they may face.

Safia

Safia was ill for a long period of time before getting a stoma.

"I did lots of spiritual preparation. I was in contact with my maker all the time. I would get up for the special prayers. Like part of our five daily prayers, there are special prayers to make when you are in need and I did lots of it. Talking to your Creator in your own language was the right thing to do." Safia

Safia's belief in her Creator and her prayers were so powerful that it guided her to make the right decision about having her surgery. Her spirituality took over and Safia did not need to do any difficult preparations to make contact with Allah, but spoke to him with sincerity and in a manner she understood best. The *Salaah* is normally performed in Arabic, but Safia did not only adhere to this rule and knew that Allah would listen to her best in her own sincere way.

4.1.2.4 Sub-theme: Fatwa and further research

A *Fatwa* is a religious undertaking by several spiritual leaders on a specific topic that results in a decision on what is accepted Islamic practice. Five of the participants in this study had heard of the *Fatwa* relating to stomas via the booklet that their stoma therapist handed to them. Two participants had never heard of it, but were guided by relatives and two participant's required additional information and examples of what was said at the time of the Prophet Muhammad (peace be upon him) relating to their own current state of purity.

Gasant

Gasant is friends with many *Imaams* in Cape Town and spoke to several of them regarding his stoma.

"*Imaam Faried (pseudonym) did not know about stomas and so I spoke to one in Bo Kaap and he also did not know about stomas, but was shocked to hear about mine that's why I want to go see him one day and talk to him to do research and he can explain to the community and the mosque people."* Gasant

Gasant experienced the lack of awareness around stomas amongst the religious leaders in Cape Town. Because these *Imaams* were unaware of what a stoma was, they were also unfamiliar with the existence of the *Fatwa* governing stomas. As a form of respect and having confidence in the duties of *Imaams,* Gasant is determined to get an *Imaam* to do some research and become familiar with the rulings around the *Fatwa* and then share the knowledge with the community and stoma patients when required. The Bo-Kaap (suburb above Cape Town Central Business District) is a traditional Muslim area and has the largest concentration of mosques in the Western Cape, and thus a large number of *Imaams* are in that area.

Achmat

Achmat shared details of how he has been investigating and questioning many *Imaams* to get clarity about his leading the *Salaah* with his stoma.

"I spoke to many Imaams around Cape Town to get more clarity about my state of purity with my stoma." Achmat

Achmat needed constant reassurance that he was adequately clean. He also did research since acquiring his stoma and only recently in the past few months felt absolutely certain about his own state of purity in order to lead many congregants confidently. Achmat also learnt many other facts during his research to guide him with 'do's and don'ts' of stomas. He also shares the fact that he takes his *Wudu* at the mosque now instead of at home, immediately before *Salaah*. This shortens his period between taking his *Wudu* and making *Salaah*, keeping him clean for a longer period. Being an older, extremely spiritual person, he always needed absolute clarity and was always guided by his conscience.

Kader

Kader stated that the *Fatwa* was insufficient to satisfy his own personal intense need for clarity regarding his purity. He needed to concentrate better on his *Salaah* and not constantly think about his stoma putting him in an incontinent state. Kader did some very interesting research to satisfy his own need for more knowledge, proof and information.

"I did my own research that dates back to the time of the Prophet Muhammad (peace be upon him) whereby there were females that were in a state of impurity. We know that the menstrual cycle keeps on for about seven days and then after that they need to take a shower to make themselves pure again … but there were cases whereby after the seven days they would still continue bleeding. These females approached the Prophet and asked him what do we do in this case? The Prophet then said that if you … are bleeding after your seven day cycle what you need to do is take your shower and then Wudu and before the next prayer you need to take Wudu again. So there were signs of these types of things dated back to about the fourteenth century back when the Prophet was around so when I read up about this I became more clear." Kader

Kader was very explicit about needing more reassurance regarding his own state of purity in order to perform his prayers. Kader accepted this teaching of the Prophet (peace be upon him) by comparing the females and their irregular menstrual cycles and his own state of impurity with his stoma. He was now more confident that his *Salaah* is valid and will be accepted. This meant a great deal to Kader because the Prophet's teaching is held in high regard and always accepted to be the correct teachings in Islam. Kader finally had peace of mind that when a situation of illness causing a Muslim person to be in an incomplete state of purity, there were allowances made to still continue with their *Salaah* in an accepted manner.

4.1.3 Theme three: Sanitation

Sanitation is a term that covers a broad area from hygiene, to personal purity, and toilet matters. In this theme, sanitation includes sub-themes of hygiene, bathroom time, adaptation to the stoma, dietary issues and the stoma therapist.

4.1.3.1 Sub-theme: Hygiene and purification

In Islam it is essential to be purified both physically and mentally in preparation to perform *Salaah*. The following anecdotes will give some clarity on the participants' hygiene issues. Kader clearly understands the concept of being pure whilst making *Salaah*, but had some doubt about his own state of cleanliness.

*"We learn as Muslims that if you are not in a state of purification your prayers are not accepted ... that is the whole point of taking Wudu ... cleansing yourself to a state of purification, to present yourself to the Creator. I'm trying to say is that if you are NOT in a state of purification then you think that your prayers are not going to be accepted ... and ... then (*sigh*) you become doubtful ... and that affects the sincerity of your prayer at the time."* Kader

Kader expresses the dilemma that he found himself in immediately after getting his stoma. Not only did he want his body to be in a state of purity, but also his mind. Kader is so intense about being pure that he needs to be absolutely and holistically clean to be completely engaged in the process of making his *Salaah*. This helps Kader to devote all his attention to Allah while making his *Salaah* and he believes only then would it be accepted. The intensity of Kader's need to devote himself completely to his Creator is overwhelming, which again highlights the importance of purity in Islam.

Safia

Immediately after Safia was given her stoma, she was concerned about her state of purity and her ability to do her prayers.

"I wasn't aware of the Fatwa, and when I had the op I was thinking, how am I going to do my prayers? Because you have to be clean. If you use the toilet, pass faeces, you had to clean yourself with water and then take Wudu and I thought to myself what was I gonna do now. I then spoke to my Creator: I am not in a very clean state because of wearing this bag, "but accept my prayers" and later I started to feel more comfortable and not abnormal when I stand and do my prayers and before I take my washing, my Wudu, I will empty my bag." Safia

Safia took guidance from her strong faith and her belief in Allah as being most merciful and all forgiving and continued to perform her *Salaah* with confidence. As a matured Muslim woman, Safia accepts that the *Salaah* is compulsory and had to be performed even in adverse conditions. Her initial concern of being incontinent was soon overpowered by her deep-seated spirituality.

Achmat

Every participant related their ritual of cleaning the stoma bag before they purified themselves with *Wudu* in preparation for their *Salaah*. Achmat shared his own concerns of absolute purity with me.

"Before each prayer I would clean the bag and then take Wudu. When you're standing in prayer and you pass wind you have to then break your prayer and go and take Wudu again and then come and join back into the prayer or finish it at a later stage, when you in a state of purity." Achmat

Achmat correctly states that even the act of passing flatus, nullifies the *Wudu*, which is essential for making the *Salaah*. In passing of flatus there is a risk of passing even a micro particle of faeces, which is enough to cause the persons *Wudu* to be nullified and be considered to be in a state of impurity. Achmat takes no risks with his prayers and spends the extra time to re-purify himself.

4.1.3.2 Sub-theme: Adaptation to stoma

Getting used to the stoma bag takes patience and perseverance. Stoma patients need to adapt to a lifestyle where they do not go to the toilet as before. Their urine or faeces are collected in a bag now, and this requires some drastic adjustment of toilet habits. The following are some of the adaptation experiences of the participants.

Safia screws up her face and relays how squeamish she felt about her stoma after her surgery.

"The stoma itself I didn't know what to expect … the first day when the nurse came to … me, she opened it up and said, do you see what you have?, and I didn't want to look at it. I turned my face away and I said to her, I don't want to see and you know she was fine with it and said, no it's fine, you don't need to worry." Safia

Safia was in a state of shock when shown her stoma for the first time. Looking at a newly-made stoma was not something Safia was quite ready for immediately after surgery. Fortunately, she was attended to by a very caring nurse who was patient and empathetic and her caring assisted Safia. This positively helped her adapt and deal with her stoma.

Achmat

The family's support goes beyond moral support and prayers, as they are often the ones who care for the stoma after the patient is discharged from hospital.

Achmat giggles when he relates the following.

*"Well actually … before I didn't remove the stoma bag myself. My daughter and my wife used to do it, but at a later stage with a little bit of help from sister Anne (*pseudonym*) I caught on, on how to do it myself. So I told my wife I will just do it once and if it works I will carry on doing it. Two years ago I started doing it myself."* Achmat

Achmat took a long time to become independent in changing and caring for his stoma and bag, but is now proud to be independent and able to accept and cope with his permanent stoma. The stoma therapist, Anne, successfully counselled and guided Achmat in managing his own stoma in order to regain his independence. He is however very thankful for and proud of the love and support from his family.

Safia

Other family members are supportive, but completely unaware and ignorant as in Safia's case.

"So I said to her: ma, you need anything? I'm going to the bathroom now, I'm gonna empty my bag and it takes a few minutes". So she said: now, what goes into the bag? Is it urine, so I said to her, no ma I don't pass faeces anymore and that is going into the bag?" Safia

Safia's mother was shocked and surprised that her daughter was now passing faeces into a bag. Safia was able to adapt to her new way of relieving herself in the toilet. She was amused by her mother's ignorance, but very proud of her support.

Kader

It seems convenient for Kader to have a small baby to cover up an awkward situation.

"I got that smell and I thought it was my baby, but it wasn't, it was me, and ... I felt embarrassed because I didn't know what to do? I didn't know if anyone around me was conscious of the smell? Or if they thought it was the baby? I rushed to the toilet and changed the bag." Kader

It was easy to get out of his embarrassing situation of a smelly stoma bag and blame it on the baby. Being a young man, Kader was always alert and conscious about his body and was especially concerned about his state of hygiene.

Razeen

For Razeen, the adjustment and changing of the bag was just too challenging for him to do himself.

"The stoma was an adjustment because obviously ... you are still having to go to the toilet like before it's just that you are going in a different way now. My mother still changes it for me every four days. The technicalities and the process ... I still feel a bit uncomfortable ... maybe touching the actual." Razeen

Razeen struggles to speak. He now stutters while he tells me that he is fortunate to have his mother at home to change his bag. He is still anxious and uncomfortable about changing his

own bag. Razeen still cannot say the word stoma and has not really accepted his stoma yet at this stage.

4.1.3.3 Sub-theme: Dietary issues

It is essential for stoma patients to adjust their diets. Foods that cause too much flatus causes their bags to expand too fast and thus may cause it to dislodge and leak. High fiber food may cause an increase in the normal bowel output, which may fill up the stoma bag too fast or cause an irritation to the bowel of mainly ileostomy patients. Following the principle of 'what you take in is what you put out', patients with stomas are restricted to a low fiber food intake and foods causing too much flatus or which can cause bowel obstruction, such as seeds. They are generally educated at hospital about which foods to avoid.

Both Kader and Razeen are aware that they need to avoid too much roughage.

"Okay. Basically it was a major adaption for me because ... having a stoma you are restricted to what you eat. You are conscious at all times of little seeds and pits and skin of the vegetables, because it can cause a blockage in the stoma so, you are limited." Kader

"Avoiding foods that have seeds and pits. Anything that can cause a potential ... blockage or obstruction ... You also need a low residue diet." Razeen

Kader and Razeen explain that they were educated by the stoma therapist at hospital that too much seeds in their diet can cause a bowel obstruction, which would cause them to be ill again. Both men are consciously avoiding any further complications to their health even if it is inconvenient to adhere to the strict dietary conditions.

<u>Achmat</u>

Achmat also relates that food that causes too much flatus must be avoided.

"If I have things that cause lots of winds I … go into the bathroom and then I open my bag on top, just for the wind to escape, and I have to do it in the bathroom because it's very smelly and then I close it properly." Achmat

Achmat has experienced that food such as watermelon, beans or cabbage can cause potential leakage or an accident. He explains that it causes the stoma bag to blow up. If the air is not released, the bag can leak or become dislodged which can soil the clothes or create an embarrassing situation.

4.1.3.4 Sub-theme: Bathroom rituals

All the participants had a very specific ritual with achieving their ultimate satisfaction of being physically pure and clean in order to gain spiritual purification. Of all the participants, Kader was the most intense and precise in following the religion in accordance with the Prophet Muhammad's (peace be upon him) teachings.

Kader

"Having a bag is difficult taking a shower because you afraid that the bag's going to get wet and then come off so you have to put something round it. Now I would normally put a … play bucket that the kids use for building sand castles. I would cover the bag with that and then shower me with my left hand while keeping the bucket on the right hand side with my right hand. So … it would take a bit longer than usual. I never removed the bag because for one reason that … the Prophet always said that when you shower never let dirt or urine or faeces run in that same place, where you cleaning yourself." Kader

Kader was absolutely meticulous about not getting the shower area soiled. He goes further to explain that he cleans his stoma and bag after showering, then washes his hands again when necessary, and takes *Wudu* before performing his *Salaah*. Kader tries to emulate the teachings of the Prophet Muhammed (peace be upon him) as strictly as he can because according to Kader this brings you much closer to your Creator.

Safia

Safia also had to adjust and get used to her stoma bag changing routine.

"Well, in the beginning I timed myself and it was just a bit more than half an hour because I did it in front of the mirror … there are certain steps that you need to follow and oh once I forgot to put on the sealer. But now I'm doing it quite confidently and I spend less time. I also have a routine at school. I have everything close by and you get used to it and learn as you go along. I go into the bathroom with my wet wipes and with my own towel, and I see that I'm clean when I come out there. I don't want to feel uncomfortable." Safia

Safia has adapted her bathing ritual to fit in with her lifestyle and has accepted her stoma to be part of her life now. Being a teacher and sharing a bathroom with many others for a major part of her day, Safia has also adapted to her workplace and has a sustainable routine for emptying and cleaning her stoma bag. Her state of hygiene was a priority in her life as she also comes into close contact with many children. It is also important that there is never an offensive smell coming from her stoma bag.

Razia

Razia has a different shower ritual to Kader.

"I get into the shower and take off the bag to do the cleaning, wash it while I stand under the shower and oh yes, I taught myself to do it early morning. I don't eat anything then it's empty, right, so then I don't have any spills while I'm doing it." Razia

Unlike Kader, Razia feels more comfortable and has no problem with taking her stoma bag off in the shower. But, like Kader, she does not want to spill stoma contents in the shower. She has learnt a routine of having her stoma bag empty in the early morning by not eating anything before having a shower.

Razeen

Although Razeen's mother changes his bag for him, he is able to empty it himself when necessary. He explains his special ritual:

*"I take the bag and fold the toilet paper in half like that (*demonstrates*), but you then press it from the bottom up to the top so that whatever else is left in there … any residue comes out. And then I have four or five paper towels with me, in case it starts to work so that I can catch whatever come out not to touch my body … because I have already had a shower."* Razeen

Razeen is meticulous in making sure the stoma bag is empty of its contents and that the faeces do not touch his clean body and contaminate him again. He has a ritual of ensuring that the offensive content from the stoma bag does not come into contact with his skin. Whilst talking, Razeen is still uncomfortable in using the term stoma. However, he was able to empty the bag, but took many months before he changed the bag himself.

4.1.3.5 Sub-theme: Stoma therapist and stoma bag

All of the participants in this study had access to a stoma therapist and received their initial stoma care in hospital soon after their surgery. The following anecdotes are some of the stories related to the participants' experiences with their stoma therapists and handling their stoma bags.

"The stoma nurse said I must start doing it myself, but I was not ready yet, and they were very patient … but later I went into the bathroom and there was no emotion at all. I did it myself and I was actually proud of myself when I did it and used a little jug, because they had to check I think the consistency." Safia

Safia appears to have had the necessary guidance from her stoma therapist without much problem. Safia took a while, but with the necessary guidance and empathy the process of taking care of her own stoma bag became a positive experience. Safia demonstrated that support from the stoma therapist was essential.

Achmat

Achmat shared the same positive experience with his stoma therapist as Safia.

"Sister Anne always offers me advice, how to do this, how to do that. When I had a rash around my stoma she gave me another bag to put on, you just clip it on and off again without removing the glue part, that was very helpful. And at a later stage she showed me how to put on something else over the bag, to protect the bag when it leaks so it doesn't go onto your clothes. The regular ones cost 800 Rand a box, which is 30 Rand to 40 Rand a bag so it's very expensive to replace. If the bag is really full I change it immediately whether it is twice a day or in the in the evenings, but if it's not so full I don't worry." Achmat

Achmat has confidence in his stoma therapist and consults with her when he experiences stoma related problems. However, Achmat only uses disposable bags, but has made that expensive choice to suit his intolerance to a re-usable bag. His obsession with being absolutely free of any impurity when performing *Salaah* has left Achmat with the decision to never empty and reuse the same bag again. Achmat is the only participant who disposes of his bag when it is full on a daily basis, unlike the other participants who will use the same bag for two to three days.

Razeen

All stoma patients learn to carry emergency or spare stoma bags in case of a leak or accident with the bag. Sometimes the leak requires more than just a change of bag, a shower seems more appropriate as Razeen explains.

*"It was a really hot day ... I remember it being twenty nine degrees (*Celsius*) so being someone that... sweats a lot the bag basically came loose and whilst driving I got the smell and the bag leaked on the bottom section and wet my clothing ...and I was forced to go home to get the bag changed and then as well take a shower."* Razeen

Razeen depended on his mother to change his bag until very recently. When he did have an accident with a leaking bag, even having a spare bag did not help and thus he went home to

get help in changing his bag. For Razeen this was a rather traumatic experience and he was fortunate to be in a situation where he could return home and also have a shower.

Aziza

"I have a spare bag with me at all times. When my urine bag is full I just go to the toilet and empty it. Once my bag leaked and my husband and I had to rush home. I just ran into the shower because you know, urine … smells very strong. I was very embarrassed." Aziza.

Aziza is always meticulous about having a spare bag, but accidents do happen. Aziza experienced many of these accidents throughout her life with her stoma. She also indicates that the bad smell of urine can be worse than faeces.

Most of the participants received good support and guidance from their stoma therapist on general stoma-related issues. However, some of them indicated the need for the availability of more culture-specific trained therapists who could give more guidance on religious and culturally-related problems.

An excited Razeen informs me on 3 March 2013 that he finally changed his own bag and it took only half an hour.

4.1.4 Theme four: Survival

Being diagnosed with a life threatening disease such as cancer or chronic inflammatory bowel disease can be devastating to a patient. This devastation is worsened by being told that they will now require a stoma. To survive the impact that this diagnosis will have on the quality of life, it is important to accept the situation in order to cope. However, family support is a crucial factor in accepting and coping to survive this devastating illness. It also helps to prevent or minimise depression, emotional trauma, and isolation. Therefore the survival theme revolves around the sub-themes of family support, acceptance, quality of life, and isolation.

4.1.4.1 Sub-theme: Family and friends' support

The support of loved ones includes close family and friends of the stoma patient. All of the participants in the study received a great amount of support throughout their illness. For some, the support meant that it was easier to accept that the surgery was lifesaving and the stoma was absolutely necessary. A few anecdotes of support structures received by some of the participants are included below.

Safia

"*Monday I had the op and I was a bit emotional when the elders, my Dad's sisters (my dad passed on) came to see me the Saturday and then I had my first outburst* [of tears] … *and I* [stutters] … *because I loved my father so much that they actually represented him. And that was my first and my last outburst and … I accepted it.*" Safia

Safia is a traditional Muslim woman who honored and respected the opinion and guidance from the senior members of her family. It meant a great deal to her when they visited her in hospital and it was easier to accept when the doctor told her that the surgery would save her life, but she will have a stoma. Safia's emotional turmoil with her disease was shared with those who cared and it had a positive effect. The power of love from her father's family was very meaningful.

Kader

Being a young person makes it more difficult to accept a life-threatening disease especially if you have dependents like a spouse and two children to take care of.

"I honestly can't say if I did not have their support, I don't know what I would have done, because there was no other support by any religious leader whereby they could help me and tell me: Look we've had a case like this before we know how you feeling at the time, so the family and in-laws basically stepped into that place of being there for me, guiding me, helping me through the times of getting this bag." Kader

Kader was very confident throughout our conversation, but now appears shaken with emotion and almost tearful. I offered Kader a break from the conversation at this time, but he continued. His speech becomes softer as he tells me with disappointment that there was minimal support from his *Imaam*, who knew nothing about stomas. Kader is very proud of the unconditional support of his family who is his lifeline during this very difficult time in his life. Again, as with Safia, the support and prayers of the elders in the community were hugely respected.

Aziza

Due to her insistence on privacy and silence, Aziza's stoma is known only to a very few people and as a result she is dependent on their support, but not sympathy.

*"He's [*her husband*] been amazingly supportive ... he doesn't emotionalise it. He doesn't make it soppy ... he knows that I don't want the sympathy part*." Aziza

For Aziza, her husband's support is crucial, but it is important for her to remain independent and not be treated like an invalid or disabled person.

Razia

However, two of the participants became completely dependent on their loved ones for support both emotionally and physically.

"*Oh they're so cute. They're five years old and then to my husband, they say, Pa! I'm gonna be the doctor. Then the one want to put the powder and the spray on ... so they want to be helpful*." Razia

Razia has her stoma now for four years and is a housewife. She never changes her own stoma bag. Her husband changes her bag for her all the time, and is now even getting the grandchildren involved. She smiles and claims to have the most loving family. Razia is prompted further and ask her if she has ever changed her bag. She replies with a smile, *"only in emergencies*."

Razeen

Like Razia, Razeen is still dependent on his mother to change his stoma bag.

"I still have not ... attempted changing it myself. I've been very blessed that my mom is helping me to change it and it's coincidental that I am living at home now ... a very good place to be, the support and physical help." Razeen

Razeen is unmarried and has been living with his parents since he has been sick. He is very proud of the fact that his mom is changing his bag because he is unprepared to do it himself. He has expressed that he will try, but now is too soon. Razeen's mother is the pivotal support person in his life currently and he almost takes advantage of her kindness. He also enjoys the support of close friends.

"My one friend tells me when he goes to the toilet he thinks of me, about how lucky he is that he's able to go normally. I don't go like that anymore." Razeen

Razeen struggles to cope with his cancer and stoma, and requires all the support that he can get. He more recently showed a close friend his stoma bag and really sounds more positive about his condition. This contact with a very close friend was a few months post-surgery.

4.1.4.2 Sub-theme: Acceptance

It was imperative to accept their stoma in order to survive. The participants share details of their struggles to accept and cope with their stomas in order to continue with their lives with their families and within the community.

Aziza

To those born with abnormalities, like Aziza, there was no choice, but to accept the situation because there were no other options.

"In fact, death knocked on my door the day I was born. I've had nine operations in total. My stoma affected the rest of my body." Aziza

Being born with a spinal defect, to survive, Aziza was given a stoma at birth. The journey was not easy, but with a very dedicated and supportive mother and later her husband, she survived. She is realistic about her close encounters with death and is thankful to be alive. Aziza gives credit to the two most important people in her life: her mother and her husband. Having a defect since birth, Aziza's physical condition is far removed from normal, but she does not allow it to negatively impact on her life. It certainly helps that she does not remember the suffering she may have encountered immediately after birth.

Razia

For the other participants, they were given a lifeline after a serious illness, the stoma was something that they had to accept and deal with.

"They say cancer there is nothing you can do about it so you have to just accept and have the operation. When they took it away (the cancer) I was actually prepared for the stoma, but I was very sick. I didn't really care what's going to happen to my body ... In my mind they must do what they want to as long as the cancer gets cut out I wasn't really worried what a stoma is gonna do in my life." Razia

Razia was too ill in hospital to refuse the operation and knew that this was her only chance at survival. She accepted the fact that she will have a stoma, but the dreaded cancer would be gone. Razia made the choice by herself to have the surgery without consulting her husband. She had lost her mother to cancer and she is aware of her own mourning at the time and did not want her family to go through the same experience. Being given the opportunity to have this life saving operation, she took it without any fear.

Kader

Kader was faced with a similar situation as Razia. He has a family who loved him dearly. In a very emotional state he relays that the doctors gave him no choice other than to have the life-saving operation. Razia and Kader were given the option of ending the conversation if it became too emotional at this stage, but they both opted to continue.

"*Look, there is … no light at the end of the tunnel, I had to make a decision for them to remove the colon and … get a bag and it was frightening because I still had to … try and cope to start living a life with the bag. Basically I took it day by day, it was difficult because … having something that wasn't there before*." Kader

Kader was scared, but he knew that he had only one chance of survival by getting a stoma. Once the stoma was there, Kader made a conscious choice to accept it taking it one step at a time. His family provided the strongest motivating force in accepting the stoma. Kader was constantly reassured of the unconditional support of his family and they became even more united as a family structure.

Razeen

Razeen initially struggled to accept his cancer and stoma. He explained how positive his therapy was with a psychologist where he learnt to accept his stoma, and this helped relieve the initial anxiety and anger with having cancer.

"I love and accept myself … even though reality is that I was diagnosed with rectal cancer I love and accept myself … my body is healing itself from the cancer. I actually do think I can eventually accept it because there are a lot advantages and positives. A friend called his stoma bag Julius Malema [a controversial and vocal politician in South Africa], *full of hot air and a few other smelly things."* Razeen

Razeen is now even joking about his stoma. He is starting to accept it finally and is ready to cope with a new adjustment to his daily lifestyle. Razeen had a positive response to his therapy and made an impression when he admitted that he may be able to survive living with a stoma permanently if necessary.

Summary

The participants clearly demonstrated that they initially required a combination of psychological support from therapists as well as emotional and physical support from friends and family. Coping became easier for the participants once they had been through the process and accepted their condition.

4.1.4.3 Sub-theme: Quality of life

Having a stoma is described as a frightening experience and has a huge impact on the patient's body image. It is something new and different and requires adapting to a new lifestyle. Some participants find it more difficult than others to adjust and the impact on the quality of life varies. These issues vary from wearing different clothes to allow for a stoma bag, to travelling issues and physical health constraints.

Aziza

Aziza has a urostomy (stoma draining urine) and thus needs to empty her bag every one-and-a-half to two hours.

"When I go on a long drive I drink less, but I try to make a stop at every toilet. I would insist. Pitstop. Because I know it's going to burst when it's full. There's only so much it can take. It hasn't been a straight road because of all the challenges. My bag leaked at a wedding, and I used to be on campus and the bag would burst and then I have a leak and I would silently think that I'm probably smelling or something." Aziza

Aziza is mostly positive about her achievements in life, but is very conscious about her urine bag leakages and tells me that urine smells worse than faeces. Her life is controlled by the limited capacity of her urine bag and her lifestyle is adapted accordingly, but it does not reflect any social deprivation. Aziza is certainly coping with the only lifestyle she knows.

Achmat

Achmat shares his travelling experiences with me.

"My wife and I decided to go Umra, visiting Saudi Arabia on a spiritual trip and after consulting with Sister Anne (pseudonym) I got my extra stoma bags and proceeded. I went to Cairo, Medina, Makkah, and Israel. Even going through customs it didn't affect us." Achmat

Achmat explains that this journey was the most spiritual uplifting time in his life since getting a stoma. The travel was easy and he had no problem with disposing of his stoma bags or getting through customs with it.

Safia

Both Safia and Razia were experiencing a better quality of life with their stomas. It was a more controlled way of emptying their bowels than the uncontrolled incontinence suffered previously.

"I had no quality of life. I didn't go anywhere … I had to go to the loo about 12 times a day with diarrhoea. At one stage I was in the supermarket, I had to leave my trolley right there. I had to rush. I had lots of accidents, not getting to the loo on time." Safia

Razia

Razia shared a similar story with me.

"I'm coping quite fine, because without the stoma my stomach would have been running 20 times a day. So with the stoma it's in control and you can just empty it when necessary, because your bottom's become raw when you don't have a stoma." Razia

Safia and Razia shared their stories of uncontrolled incontinence before their surgery. Their illness left them with several uncontrolled bouts of diarrhoea which left them mainly housebound. The diarrhoea also had a detrimental effect on sensitive areas of their bodies. In this context, the stoma brought much relief to both Razia and Safia.

Gasant

Gasant was questioned about any changes in his dress code.

"I changed my dress style … because of the stoma I'm wearing a thobe [similar to a dress]. *People wear it in the Middle East, but I'm wearing it now every day because … it is not tight, it's free flowing and you just change it every day like you change your shirt. It's more comfortable wearing this than having a belt around your body or a tight thing."* Gasant

Gasant's transition of garment change was appropriate and he felt very comfortable and pious with his new style of dressing. He changed to a traditional Arab garb, which suited him as a more religious man and his comfort took priority. Gasant is very conscious of his general hygiene and the need to wear a clean *thobe* at all times.

Summary

It can be concluded that there were few and only minor materialistic quality of life sacrifices that were made by the participants in order to survive their stomas' impacts.

4.1.4.4 Sub-theme: Isolation

The Muslim community of Cape Town, as previously explained, is very closely intertwined. This means that there is always an invitation to attend some or other religious or cultural social event. The stoma may have had an impact on the participants' life, but certainly has not impacted on their social lifestyle.

Razeen

Razeen was the only participant who delayed socialising due to his anxiety regarding his stoma.

"Actually, I only started going out the last two weeks. The first few months after the operation I was scared to go out because I was in shock about this whole thing and struggling with a lot of anxiety and the doctor's given me some Xanor [tranquilizer], *but I went to a wedding recently and I was okay."* Razeen

When Razeen's physical and psychological condition improved, he started to socialise. He is smiling while proudly explaining the effort he made to dress up to attend a wedding. He attended both the religious service in the mosque and the reception dinner. Initially, Razeen's inability to accept his stoma led to much anxiety in his life, but this has been treated successfully with therapy and medication. All of the other participants felt completely comfortable about socialising and attending different social and religious events.

Safia

Safia has not missed out on any social activities after healing from her surgery. She is socially very active and socialises with close friends.

"I'm very open about my stoma, last week I met with a few colleagues and we were eating watermelon and I heard some noises and they were actually laughing. They were saying "oh your husband is making a noise there." I don't feel embarrassed about it. I've been to theatre on Saturday night I had no problem." Safia

Safia has not kept her stoma a secret from her colleagues and friends. She feels very comfortable with her stoma and even shares a joke with friends about it. She experiences no problem in attending any social function and proudly informs me that she attends many different cultural and social events.

Aziza

Despite being very secretive about her stoma, this does not stop Aziza from living a considerably normal social lifestyle and her secret remains well hidden.

"So any visit I make, I make sure I go to the toilet. And if I go to shows or theatre or cinemas, my husband knows it's a toilet stop before and after. You must remember a movie is just about two hours." Aziza

Aziza's husband understands all her limitations and restrictions around her stoma. He thus makes allowances for her toilet needs to empty her urine bag so that they may continue socialising. Aziza is very aware of the limitations and capacity of her urine bag, but this does not restrict her social activities.

Summary

None of the participants in this study have reflected any indication of social deprivation or isolation as a result of their stoma. Their ability to accept and cope with the assistance of family support has allowed them to continue their survival with a stoma. The life experiences

of these stoma participants indicate that the survival theme was better managed through the assistance of a closely knit Muslim community.

5. DISCUSSION

This chapter will be a reflection of the experiences and findings of this study. It will address the issues identified in the findings and their relevance to the current literature. In addition, this chapter highlights the limitations and strengths of the study as well as the effects of the study on the researcher and participants. Recommendations for further research will be discussed.

5.1 Significance of the methodology

In accordance with the principles of interpretive phenomenological methods as described by Heidegger (Lopez & Willis, 2004); the researcher is allowed to bring her personal experience and knowledge into the field of the research process. As such, as the researcher I gained a deeper understanding into the daily lives of all seven participants and what impact their stomas have on their lives. My personal experience, knowledge and understanding of the Muslim religion, Islam, was a significantly enabling factor throughout the research process. Having extensive experience as an operating room nurse and assisting with many operations that required the patient having a stoma provided me with a good understanding of the underlying pathology of this condition.

5.2. General discussion on findings

The four themes and related sub-themes that emerged from the analysis are discussed and cross- referenced with other findings identified in the literature review.

5.2.1. Silence

The Muslim community in Cape Town is a very close knit community who are often connected through marriage, business or geographical location. During the years of apartheid in South Africa, 1960-1994, the Muslim community existed and lived mainly within the so called 'coloured' areas and often chose their place of abode near to where a mosque was situated. This may be a significant reason why factors around stigmatised issues were

kept silent because it would be easy to spread amongst a very closely-knit community. The dreaded death outcome surrounding the diagnosis of cancer was generally not open for public discussion. Having a stoma was often associated with cancer or was simply a completely unknown illness.

The findings related to the theme of 'silence' are to some degree consistent with the findings of Frohlich's (2012) auto-ethnography study. Dennis Owen Frohlich was an American citizen who had ulcerative colitis and had surgery to remove his entire colon and had a stoma for nine months. Frohlich reveals that persons who have newly-acquired stomas do not easily find others who have stomas because it is not a topic readily disclosed or discussed. He explains that to have your intestine coming out of your abdomen and collecting faeces in a bag is very unnatural. Individuals also do not find it comfortable to talk to others about their bowel habits and in comparison, none of the participants in this study had heard of a stoma or its implications until they required one. Frolich was introduced to the word 'stoma' only when requiring one himself during an emergency operation. It appears that the silence around stomas is not unique to Muslims only, but also common to first world citizens of the United States, like Frohlich.

Frohlich also states that his online video stories, which revealed his own, bare, red stoma was a remarkable success since it assisted and reached out to other silent stoma patients. *Safia* has been trying unsuccessfully for months to find Muslim stoma patients on-line. The response has been poor although she has had many online discussions with non-Muslims; male and female and even children, who shared many informative stories with her.

Aziza revealed her feelings of relief and freedom in being allowed to participate in this study and being given a meaningful opportunity to break her lifelong silence on her stoma (she still wishes to remain anonymous).

All of the participants who were part of this study felt that their voices may contribute to a society that has a veil of silence, ignorance and stigma concerning this particular topic. At the end of the second round of conversations all the participants had come into contact or

heard of other Muslim stoma patients within the community. This is a significant indication of the fact that there are a known number of stoma patients within the community.

One of the main objectives of the outcomes of this particular study would be to assist with breaking this silence through bringing about awareness amongst the community regarding the existence of stomas.

5.2.2 Spirituality

In a descriptive, explorative Taiwanese study done by Li *et al*, the findings reported that there was a definite relationship between spiritual well-being and the psychological adjustment of persons with cancer and a stoma (Li *et al*, 2012). The findings in this study have a number of similarities with the findings of Li *et al*, in that the participants, who were very spiritual and experienced spiritual wellbeing, found it easier to accept their stoma and thus found it significantly easier to cope and move on with their daily lifestyle. The participants, as Muslims, related their spirituality to what Allah has planned for their life as inevitable and therefore acceptable.

The *Quality of Life Study* conducted in Egypt on 28 patients with stomas, revealed that 61% of the patients felt unworthy of making *Salaah* in congregation due to their state of impurity, (Hussein & Fadl, 2001). This is in contrast to this study in that all of the male participants, except *Razeen* who took a longer time to return to mosque, continued to do their daily prayers in congregation. It also appears from the findings that the participants' own spirituality and those they were closely associated with, had a positive influence on them. For *Razeen*, his mother's spirituality had an overwhelming effect on his wellbeing and was the catalyst for rediscovering his own spirituality, and developing a more positive attitude in acceptance of his stoma.

Kuzu *et al*, described some compromised religious duties in a study done in Turkey (Kuzu *et al*, 2002). These compromises were attributed to various reasons such as: patients unable to accept their own state of impurity, inability to conduct the prayers in accordance with religious rules and general feelings of unworthiness (Kuzu *et al*, 2002). This was inconsistent

with the participants in this study who generally remained spiritual and some became even more aware of their religious duties and their commitment to their Creator. It is for this reason that the *Fatwa* was initially established to clarify the rulings for Muslims who have stomas and to describe what the limitations are, as well as providing guidelines for prayers, attending mosque and other religious activities. However, all participants in this study revealed that the guidelines on the *Fatwa* that was given to them via their stoma therapist appeared to be insufficient and lacking detail for more intense religious practices and guidelines.

Kader revealed that going to mosque was initially uncomfortable due to his physical impairment, which meant he needed to sit on a chair. Generally, in mosque the aged and sick sit on chairs which are strategically placed near the back of the mosque. When a young man sits on a chair near the back, the assumption is that he has a physical problem. However, for *Kader* his spirituality exceeded this uncomfortable position and as soon as he started to accept his stoma, he had no issue with attending the congregational prayers and sitting in the back row on the chairs with the old men.

Achmat was the only one who performed the lesser pilgrimage to Mecca (*Umrah*, a religious journey lasting about two to three weeks) and was not inconvenienced at all by his stoma during his travels or when performing the special religious rituals. *Hajj* is the major pilgrimage and it involves many more religious rituals. *Achmat* expressed this experience to be the highlight of his spiritual life, since being critically ill and requiring a stoma. This is inconsistent with the finding of Annels, who concluded that stoma patients found it difficult to travel (Annels, 2006).

5.2.3. Sanitation

In being consistent with the strict and almost fastidious Islamic teachings and practices around hygiene, the theme of sanitation was important. All the practices and rituals that a Muslim is required to perform revolve around how clean, and in what state of purity the person is in. Sanitation was thus a priority on the agenda: all the participants in this study emphasised the cleansing rituals and concerns pertaining to their stomas. As discussed

previously in this study, it is obligatory for every Muslim man, woman or child to clean themselves with running water after urinating or defecating. The body needs to be cleansed of all impurities at all times. It is for this reason that you will find in all the toilets in Muslim homes around the world a bidet, a bottle, and a jug or toilet hose to cleanse the private parts after using the toilet. Generally in the Western Cape there is a water bottle in the toilet for this purpose. It is thus completely understandable the dilemma of impurity that the stoma patients suddenly faces because they are now incontinent of urine or faeces.

The findings concerning dietary constraints as described by Varma are consistent with the findings in this study. In order to reduce the amount of offensive odour and excessive flatus passed and the possibility of dislodging the stoma bag, stoma patients generally were required to adjust their diets to avoid certain foods such as beans, cabbage, watermelon and excessive fibre (Varma, 2009). Some of the participants who have more established stomas also controlled and formulated their meal times around their prayer and ablution times to avoid excess flatus passed during these times.

Brown and Randle as well as Hussein and Fadl discussed in detail their findings concerning sanitation of their stoma participants. In both studies the researchers revealed that stoma patients spend a lot of time cleaning their bags and their bodies around the stoma site. As a result they are inconvenienced by the time it takes for preparing to take *Wudu* in order to perform *Salaah* (Hussein & Fadl, 2001; Brown & Randle, 2005). This is consistent with the findings in this research. During the conversations, all seven participants in the study articulated in great detail their own set of rituals that they used during their ablutions. Much of the time spent during the first interview with each participant emphasised the manner in which they purified themselves in order to be sufficiently clean to make their *Wudu* and *Salaah*. They were constantly anxious about their state of purity and the extra time required for ablution and cleansing the body of all impurities did not restrict the participants from making their *Salaah* and thanking their Creator for giving them another chance at life. The participants were as consistent in their performance of *Salaah* as before having a stoma.

5.2.4. Survival

A good support structure is essential for the survival of these stoma patients. Some of the participants in this research indicated that the severe form of disease leading up to the surgery that required them to have a stoma was like swopping a death sentence for a stoma bag because they had no choice.

Majola *et al,* in the KwaZulu-Natal study, reported that stoma patients often struggled to come to terms with their stomas. The patients became socially isolated and this led to depression (Majola *et al*, 1995). Brown and Randle supported this with their findings by explaining that stoma patients often struggled to lead a normal life as a result of severe psychological and emotional issues (Brown and Randle, 2005).

In the study done by Baldwin *et al,* they reported that due to lack of acceptance experienced by stoma patients, they became socially isolated. The physical odours and body changes associated with their stomas often lead them to a life of self-imposed social isolation and perceived societal stigma (Baldwin *et al*, 2008).

The seven participants in this study clearly stated that they had received enormous support and commitment from close relatives and friends. For those who were married, it was their spouse and children's support that became their lifeline to acceptance and coping. For the unmarried participant it was his parents' commitment and understanding that led to his acceptance of the situation.

Kader and *Razeen* were two young males who struggled initially to cope with their stomas. *Razeen* took much longer to settle into coping with and accepting his stoma and the survival issue was a slower process. His emotional strain was associated with the fact that he was diagnosed with cancer that required surgery and further treatment of chemotherapy. However, the strong support *Razeen* received from his mother (he was unmarried) opened the door to survival by slowly and finally coming to terms with his cancer and his stoma. *Razeen's* social isolation was limited to a few months and he even re-established a relationship with a past girlfriend.

In a Turkish study done by Kuzu *et al*, most of the older men socialised and made friends by attending mosque. Therefore, the older patients with stomas became uncomfortable and felt unworthy of attending mosque, which left them completely isolated because all their friends were mosque friends (Kuzu *et al*, 2002).This was inconsistent with the findings of this study because the male participants still attended the congregational prayers at mosque. This may be to a lesser degree than previously due to the physical constraints of their illness in the early months after getting their stomas. This attendance appeared to have improved as they became more adapted to their stoma. However, the research in the ethnographic study by Frolich reinforces the importance of stoma support groups, but in the US they are lacking and the nearest stoma support group was three hours away from where he lived (Frolich, 2012). This finding is consistent with the findings in this study where the seven participants indicated the need for a Muslim stoma support group. This will allow stoma patients to feel free to discuss problematic issues which they may experience and due to the silence issue, not find a safe space to openly discuss their private issues.

My Diary Entry, 15 March 2013:

"Safia told me today that she passed her Honours Degree in Education and she was very proud to have achieved this despite her illness over the last year."

5.3. Challenges of this study

5.3.1. Weaknesses

The limitations of this study were that all seven participants came from middle class homes with a similar socio-economic profile. They all have access to electricity, running clean water and indoor bathrooms with toilet facilities. A comparative study where none of these facilities exist may result in very different findings.

The silence factor may have set limitations in enabling me to access a larger and more diverse cohort of participants. Another limitation may be the difficulty to adhere to the word limit of this study due to the many very interesting and meaningful anecdotes that needed to be included. I just exceeded the stipulated word count of 25 000 by 1000 words.

5.3.2. Strengths

My extensive experience as an operating room nurse working with a dedicated colo-rectal surgeon provided a deep insight into the world of patients requiring stomas. As a result of this understanding and familiarity with colo-rectal diseases, I was well accepted by all participants.

My professional status as a nurse, gender and age had created a trusting environment for the participants during the interview process. My own spirituality, community involvement and understanding of Islam and its rituals was a positive factor. My passion surrounding the topic being researched gave me an enormous amount of strength. This proved to be a strong driving force in continuing the task of analysing the data during stressful periods.

The continuous support of my supervisor and her belief in me gave me the strength to continue with this topic that I felt so passionate about.

5.4. Effect on the participants

None of the seven participants interviewed suffered or displayed any negative repercussions from being part of the research process. There was no need to refer any one of them for counselling to their local general practitioner, psychologist, stoma therapist or *Imaam*. The participants welcomed me into their homes as this was found to be the most suitable place for the conversations. They were very accommodating around my busy schedule as a full time employee, mother and part-time student. Before commencing the conversations, in accordance with the requirements and ethical commitments of my proposal, I explained to each participant that I was unable to be their counsellor; however, the conversation in itself appeared to have a distinctly positive effect on certain participants, such as *Aziza* and *Kader*.

Aziza put a significant amount of trust and faith in me not only as the researcher, but also as a person. She acknowledged that she felt relieved to 'bare her soul' about her congenital condition. Although *Aziza* was relieved to break her silence for the first time, she was adamant about maintaining her privacy during this study. She was constantly reassured of

this by me. I was the first stranger she had ever spoken to about her physical condition. The extent of faith and trust in me was such that she made a special request for me to be in attendance at her death washing ritual if she died before me. *Aziza* declared that even at her death she wanted to keep her condition a secret, private and silent.

Razeen also displayed an enormous amount of confidence in me as the researcher. During his first interview he emphasised his troubled state of spirituality which he was unhappy about, but was not yet ready to address. During his second conversation several weeks later, he was very excited and displayed a new perspective towards his spirituality and attributed it to myself and to his mother. *Razeen* returned to performing almost all of his daily prayers and was slowly, but confidently moving into a spiritual space.

After the initial conversation, *Kader,* who was the youngest participant, displayed a sincere interest in doing some constructive research to interpret and confirm certain religious aspects surrounding his stoma and spirituality. His state of purity or lack thereof became a driving factor in his research. As *Kader* wanted to know more than what the *Fatwa* stated, he went to great lengths to research supportive Islamic literature to make himself more comfortable concerning his sanitary preparations for the rituals of the *Wudu* and *Salaah*. He was acutely concerned about being and feeling completely purified during his *Salaah* in order for his prayers to be accepted by Allah. He was keen to produce a compilation of his findings which could be made available to stoma patients.

Generally, there was a positive feeling amongst all the participants for making a contribution towards a relevant study pertaining to their daily lives as persons with stomas.

5.5. Effect of research on the researcher

As a Muslim woman undertaking this study, I took extreme care in my choice of words in describing certain phenomena and explaining some religious principles. I needed to retain a well-balanced professional, open-minded approach and not appear to produce a stereotyped view on Islam. This study and the world of the participants had a definite spiritual impact on me. Over the time period of the study, I have certainly become

increasingly more aware about life's challenges, specifically taking for granted matters such as answering to the call of nature. A visit to the toilet is normal for most persons, but very different for a stoma patient.

The impact on me being engaged in the lives of this group of participants was very positive. Realising their strengths, spirituality and capacity for survival during very challenging times motivated me to take a closer look at myself as an 'individual' within a family and a community. Being part of 'their' community allowed me to see, understand and appreciate my own strengths and good health and show appreciation for it. I am forever thankful to my creator, Allah, for my own health and that of my loved ones. My own spirituality has escalated, and with that escalation came the need to do more for those around me who are more challenged with their health.

I am grateful for the opportunity to undertake this study in the capacity of a part-time student and be simultaneously committed to several other demands in life. It has given me an overwhelming feeling of stimulation and joy not only to do this study, but to hopefully be able to use its findings within the Muslim community at large as an awareness and informative tool.

As a professional nurse I have been exposed to a large number of Muslim stoma patients who silently exist within the community. Unfortunately, although this study was limited to only seven participants, there is evidence of the existence of many more stoma patients within the small Western Cape Muslim and non-Muslim communities. The awareness of the existence of so many Muslim stoma patients within the community has provoked my thoughts to redirect my personal professional capacity. I do not intend to embark on a career as a Muslim stoma-therapist, but certainly some form of guidance and counselling is appealing.

5.6. Recommendations for further research/intervention

The findings of this study reflect the life experiences of the seven participants. I am of the opinion that the findings are a fair representation of most of the Muslim stoma patients in the Western Cape.

The participants from this study indicated a keen interest in initiating a Muslim stoma support group. They also indicated the need for a more detailed 'Patient Information Booklet' that provides specific guidance on the religious *'do's* and *don'ts*' for Muslim persons with stomas. The *Fatwa* from the Al-Azhar University in Cairo, Egypt is mentioned briefly only in the general stoma information booklet given out by the stoma therapist. *Kader* was keen to initiate this with the assistance of some senior religious leaders in the Western Cape to make the information booklet more relevant and detailed. He has already done a large amount of research pertaining to stomas and the Muslim patient.

There appears to be a need for more cultural-specific stoma therapy training. The participants in this study received stoma counselling before, during and after their surgery. However, the participants expressed the need for more understanding and guidance on how to care for their stomas particularly, in relation to their purification preparation for performing their religious obligations.

To introduce the findings of this research in a condensed form to the Muslim community and the religious leaders of the Western Cape would be a great achievement. For the seven participants' and me, it would be a positive contribution to other stoma patient's to highlight the possibilities of a normal lifestyle for a Muslim with a stoma. This awareness may be the start of the lifting of the veil of silence for Muslim individuals with stomas.

6. CONCLUSION

In Islam, we accept that we are going to die and that there is a 'Life after Death', which in the *Quran* is described to be forever and better than the existing one, if you truly obey and believe in Allah. However, when faced with a life-threatening disease and the reality of death, it can be extremely terrifying and confusing which may impact on one's state of spirituality. Fortunately, the basic belief system and spiritual strength of most Muslim patients and their loved ones is what draws them back to believing in and serving their creator, Allah. The support of their loved ones seems to be the single most important factor during this very uncertain and confrontational period. Facing the uncertainty of impending death is in itself an enormous challenge and the overwhelming feeling of potential rejection by the community due to having a stoma may seem even more threatening.

The Muslim community is unique to society at large because nearly all their religious obligations are intertwined with their state of purity. This purity does not only refer to the body, but also to the clothes and physical surroundings. Even the smallest drop of impurity can nullify the *Wudu* and *Salaah*. During the *Salaah* shoes are removed, special clothes are worn and special prayer mats are laid out. Under these extreme conditions of purity, how do stoma patients cope with a bag filled with urine or faeces attached to their bodies? Conversely, the religion of Islam is very understanding. Allah is most forgiving and most merciful and would surely understand and accept the full impact of all illnesses.

Having a stoma is not purely about disease intervention, it also has an enormous impact on the holistic being of any human. It is the moving away from 'normal' to a completely 'abnormal' way of ridding of your body's waste products. From sitting on a toilet to pass urine or faeces, to collecting the waste in a plastic bag on the surface of the body may be completely unheard of for some persons. Being given a stoma often entails dealing with a life-threatening disease and then for some, also having to face the stigma of 'cancer', 'tumour', 'chemotherapy', 'radiation therapy' and then a 'stoma' is very daunting.

The close-knit Muslim community in Cape Town was definitely a symbol of families and loved ones caring for one another. The community is very united and supportive during difficult times. However, the issue of silence was still dominant within the community, so for many, the support came from immediate family and close friends where there was no silence amongst them.

This study has broken some of the silence surrounding stomas within the Cape Town Muslim community through the voice of the participants. Bringing about awareness within the community will certainly assist stoma patients in feeling more accepted and better understood. They may then be accepted as having a disease and not perceived as being 'punished', 'disabled' or 'dirty'. This awareness may result in the broader community being less judgemental on matters that pertain to the general politics around the body's function when medical or surgical intervention is warranted.

The participants' narratives of their life experiences with their stomas have indicated a fairly normal and positive lifestyle without too many limitations, and confirmed a heightened sense of spirituality. This is very important as the Muslim community in Cape Town take their religious requirements in a serious manner.

The findings of this study contributes new knowledge about the experiences of Muslim stoma patients, and may thus assist healthcare professionals in obtaining a deeper understanding of the challenges faced by Muslim stoma patients. These findings may also assist in the creation of a Muslim stoma support group and the information can be utilised to assist new and other stoma patients and their families. The study will be made available to the *Imaams* (Muslim priest) at mosques and the community to bring about awareness of stomas.

A study such as this may assist society at large to live and cope with life and not be despondent/ disillusioned when life deviates from its 'normal' course. Most people are taught to be kind to others and certainly should receive this kindness in return. It is essential to practice what we preach and embody kindness in our daily lives.

REFERENCES

American Society of Colon and Rectal Surgeons, 1996. *Ostomy.* American Society of Colon and Rectal Surgeons.

Annells, M. 2006. The experience of flatus incontinence from a bowel ostomy: a hermeneutic phenomenology. *Journal of Wound, Ostomy and Continence Nursing*, 33(5): 518-524.

Baldwin, C.M., Grant, M., Wendel, C., Rawl, S., Schmidt, C.M., Ko, C, & Krouse, R.S. 2008. Influence of intestinal stoma on spiritual quality of life of U.S. veterans. *Journal of Holistic Nursing*, 26(3):185-194.

Borwell, B. 2009. Rehabilitation and stoma care: addressing the psychological needs. *British Journal of Nursing,* 18(4): 20-25.

Black, P. 2009. Cultural and religious beliefs in stoma care nursing. *British Journal of Nursing*, 18(13): 790-793.

Bradbury-Jones, C., Irvine, F. & Sambrook, S. 2010. Phenomenology and participant feedback: convention or contention. *Nurse Researcher*, 17(2): 25-33.

Brown, H. & Randle, J. 2005. Living with a stoma: a review of the literature. *Journal of Clinical Nursing*, 14: 74-81.

Burbeck, J.W. 2001. Fatwa about preparation of prayer for Muslim osttomates. *World Council for Enterstomal Therapist,* 21(1):32.

Celasin, H., Karakoyun, S., Yilmaz, S., Elhjanii, A.H., Erkek, B., Kuzu, M.A. 2011. Quality of life measures in Islamic rectal carcinoma patients receiving counselling. *Colorectal Disease*, 13: 170-175.

Chan, G. 2010. *Interpretive phenomenology in health care research*. Indianapolis: Sigma Theta Tau International.

Colaizzi, P. 1978. *Existential phenomenological alternatives for psycology*. In Psycological research as a phenomenologist views it. Valle, R. & King, M., eds. New York: Oxford University Press. 48-71.

Cresswell, J.W. 2007. *Qualitative inquiry research design: choosing among five approaches*. 2nd ed. London: Sage Publications

Dabirian, A., Yaghmaei., F., Rassouli., M., Tafreshi., M.Z. 2011. Quality of life in ostomy patients: a qualitative study. *Patient Preference and Adherence*, 5:1-5.

Dangor, S.E. 2003. The establishment and consolidation of Islam in South Africa: from the Dutch colonisation of the cape to present. *Historia*, 43:203-220.

Davids, A., & Dacosta, Y., 1994. *Pages from Cape Muslim History*. Cape Town: Shuter and Shooter.

De Witt, L. & Ploeg, J. 2006. Critical appraisal of rigour in interpretive phenomenological nursing research. *Journal of Advanced Nursing*, 55(2): 215-229.

Finlay, L. 2011. *Phenomenology for therapists: researching the lived world*. United Kingdom: Wiley-Blackwell Publishers.

Frohlich, D. O. 2012. Self-disclosing my ostomy to the dominant culture. *J Wound Ostomy Continence Nurs.,* 39(6): 627-631.

Holloway, I. 2008. *A-Z of qualitative research in healthcare*. United Kingdom: Blackwell Publishers.

Hussein, A.M. & Fadl, S.A. 2001. Quality of life in Egyptian stoma patients. *Egyptian Journal of Surgery,* 20(3): 598-607.

Karadag, A. & Baykara, Z.G. 2009. Colostomy irrigation: an important issue for Muslim Individuals. Asian Pacific Journal of Cancer Prevention, 10:1189-1190.

Kerrish, K. & Lacey, A. 2006. *The research process in nursing.* 5th ed. Oxford: Blackwell Publishing.

Khan. M.A., Jamal, S., Rashid, R., & Ahmad., N. 2011. Quality of life assessment in patients with stoma in Muslim population. *Pakistan Institute of medical Studies*, 7(4): 222-227.

Klipper, H.C. 2008. Writing a qualitative research proposal. *Curationis,* 31(4): 62-72.

Kuzu, M.A., Topcu, O., Ucar, K., Ulukent, S., Unal., E., Erverdi, N., Elhan, A., Demicirci., S. 2002. Effect of sphincter-sacrificing surgery for rectal carcinoma on quality of life in Muslim patients. *Dis Colon Rectum*, 45(10): 1359-1366.

Kvale, S. 1996. *An introduction to qualitative research interviewing*. London: Sage Publications.

Li, C., Rew L. & Hwang, S. 2012. The relationship between spiritual well-being and psychosocial adjustment in Taiwanese patients with colorectal cancer and a colostomy. *Journal ofs Wound Ostomy Continence Nursing.,* 39(2): 161-169.

Lopez, K.A. & Willis, D.G. 2004. Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. *Qualitative Health Research*, 14(5): 726-735.

Mackey, S. 2005. Phenomenological nursing research: methodological insights derived from Heidegger's interpretative phenomenology. *International Journal of Nursing Studies*, 42: 179-186.

Majola, S.G., Ntombela, B.B. & Zungu, B.M. 1995. A study of the attitudes of colostomy patients towards a stoma. *Curationis,*18(1): 49.

Munhall, P.L. 1994*. Revisioning phenomenology: nursing and health science research*. New York: National league for nursing press.

Pascal, J. 2010. Phenomenology as a research method for social work contexts: understanding the lived experience of cancer survival. *New Scholarship in the Human Services*, 9(2): 2-23.

Persson, E., Gustavsson, B., Hellstrom, A.L., Lappas, G., Hulten, L. 2005. Ostomy patients' perceptions of quality care. *Journal of Advanced Nursing*, 49(1): 51-58.

Silverman, D. 2006. *Interpretive qualitative information*. 3rd ed. London: Sage publications.

Simmons, K., Maekawa, A. & Smith, J. 2011. Culture and psychological function in British and Japanese people with an Ostomy. *Journal of Wound Ostomy Continence Nursing*., 38(4): 421-423.

Van Manen, M. 1990. *Researching lived experience.* Human Science for Action Sensitive Pedagogy. New York: State University of New York Press.

Varma, S. 2009. A healthy lifestyle for the ostomist in relation to exercise. *British Journal of Nursing*, 18(17): 18-22.

World Medical Association. 2008. *WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects*. [Online]. Available: http://www.wma.net/en/30publications/10policies/b3/ [2012, May, 24].

APPENDIX 1: ETHICS APPROVAL

FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Faculty of Health Sciences Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: sumayah.ariefdien@uct.ac.za

06 December 2012

HREC REF: 546/2012
Mrs G Mobara
c/o Ms N Fouche
Department of Nursing & Midwifery
F-45
OMB

Dear Mrs Mobara

PROJECT TITLE: THE LIVED EXPERIENCE OF MUSLIM STOMA PATIENTS IN CAPE TOWN, IN RELATION TO THEIR RELIGIOUS AND CULTURAL PRACTICES

Thank you for addressing the issues raised by the Human Research Ethics Committee.

It is a pleasure to inform you that the HREC has **formally approved** the above mentioned study.

Approval is granted for one year till the 28 December 2013.

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form, if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA),

sAriefdien

Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

APPENDIX 2: PARTICIPANT CONSENT FORM

PARTICIPANT CONSENT FORM

Nurse researcher: Galima Mobara

Student number: MBRGAL001

Address: 22 Lacre Road, Lansdowne, Cape Town, 7780

Home telephone number: +27217977926

Mobile phone number: +27825639629

University Particulars: Division of Nursing and Midwifery, School of Health and Rehabilitation Sciences, University of Cape Town, Anzio Road Observatory, Cape Town, 7925

University telephone number: +27214066672

Supervisor: Nicki Fouche

Chairperson of Human Resource Ethics Committee: Prof. M Blockman, E.52 Old Main Building, Groote Schuur Hospital

Contact number: 0214066492

Dear Participant

As-Salāmu `Alaykum

م. سلام عليك

The following information is provided for you to decide and to give consent to participate in this study. All participation is voluntary and you are free to decide not to participate or withdraw at any time in the research process. You may ask any questions pertaining to the study and it will be answered as best as possible.

I am a nursing student doing a Master's Degree, doing a qualitative study on the following topic:

"What are the lived experiences of Muslims stoma patients in Cape Town in relation to their cultural and religious practices?"

The outcome of this study may add value to the care, preparation, and empathy provided to Muslim stoma patients, and the results of the study will be shared with other healthcare professionals to assist them in understanding the challenges experienced by Muslim stoma patients. In addition, the results will also be shared with some of the *Imaams* of the local mosques in Cape Town in order that they may understand and assist where necessary to give religious advice, guidance or counselling to stoma patients and the community.

I intend to conduct conversations comprising of a set of informal questions with all participants. I propose that there will be two audio-recorded conversations conducted per participant, each consisting of 45-60 minutes, with a diary kept by participants between the periods of the two conversations occurring. The diary is intended to record any relevant thoughts or feelings with regards to the study, and will be a private logbook seen only by the participant.

The intention is to not expose any of the participants to any harm or risk. It is important to note however that minimal potential risks may exist. One of the potential risks may be emotional disruption as a result of the participant relating their life experiences. A second potential risk is that the revealing of the possible impact of the stoma on the participants' religious practices may lead to feelings of guilt. The conversation itself will not form part of a counselling session between participant and researcher. Where necessary, and if any participant requires emotional support during the process of this study, they will be referred to obtain the necessary counselling from their local stoma therapist, *Imaam* or General Practitioner. Whilst there are some minimal potential of risks involved in this study, it is the opinion of the researcher that these risks are outweighed by the benefits to the participants. These benefits include being part of a community programme for the Muslims in Cape Town, resulting in increased community awareness with regards to stomas, and what it means for the community at large. This has the potential to lead to a renewal of understanding and thus minimising the societal stigma attached to having a stoma. This awareness will also aid other stoma patients. Additionally, the opportunity for participants to share their life experience, and have it related to, may have a positive impact on their emotional well-being.

I will share the analysed information with you to ascertain credibility, as well as the final findings of the research. Your confidentiality will be respected, and your identity will be kept

private and not used in the research; pseudonyms will be used to protect your names from anybody.

Ethics approval has been obtained from the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town.

All information obtained from the conversations will be kept confidential and secure, on a computer with password protection, with the password known only to the researcher, for the period of one year.

The researcher or supervisor can be contacted at the details provided above, and is encouraged to ask any relevant questions prior to signing the consent form.

Please note that there will be no payments or therapeutic gain provided to participants for their input in this research, and that participants may withdraw from the study at any point without any consequence.

Please sign your consent with full knowledge of the nature of the research.

Signed:

_____	_____
Participant	Date and place
_____	_____
Researcher	Date and place

Do not hesitate to contact me at any time to ask any questions or raise any queries.

APPENDIX 3: CONVERSATION GUIDELINE

(Example of initial set of open-ended questions to be probed)

1. Main question:

   Tell me, in your own words, your personal experience with your stoma.
2. How would you describe the specific effect of the stoma on your daily lifestyle?
3. Please describe how it has affected your religious obligations?
4. Please tell me in your own words the impact the stoma has had on your hygiene?
5. What do you not like about your stoma?

APPENDIX 4: IMAGES

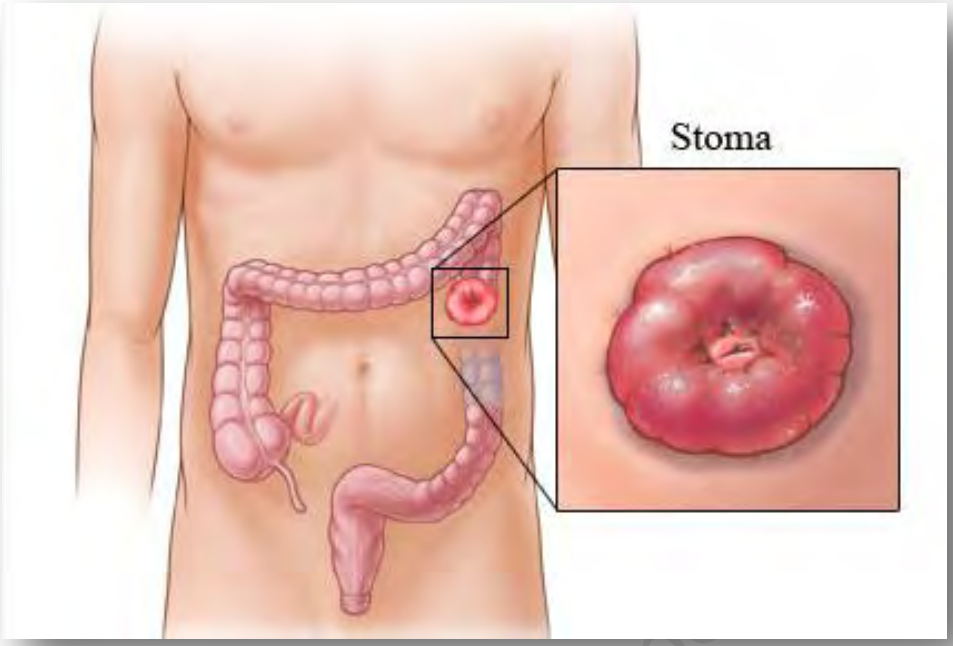

Figure 1: Stoma

Figure 2: Creation of Colostomy

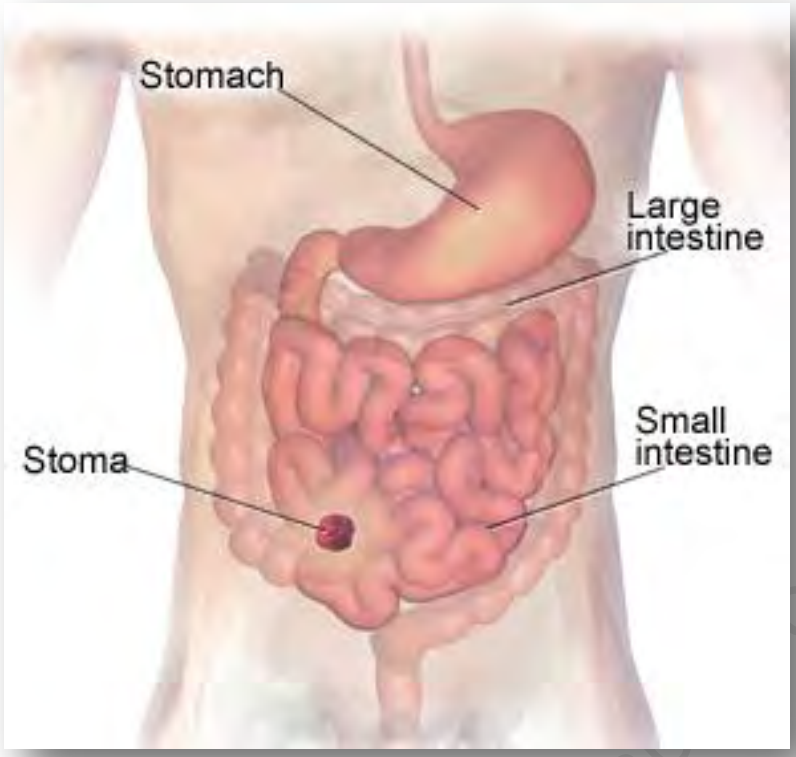

Figure3: Ileostomy

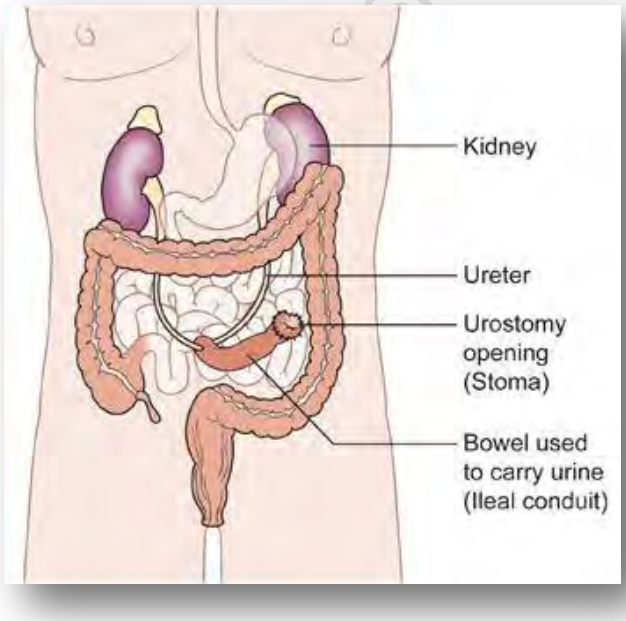

Figure4: Urostomy

All images are taken from:

- http://www.stfranciscare.org/saintfrancisdoctors/cancercenter/nci/CancerSummary.aspx?id=CDR62954.xml
- http://www.cancerresearchuk.org/cancer-help/type/bladder-cancer/treatment/invasive/surgery/types-of-surgery-for-invasive-bladder-cancer
- http://www.orvosok.hu/orvosiszotar/kolosztoma-257/