

**LIVING UNDER THE THREAT OF EBOLA:  
A PHENOMENOLOGICAL STUDY**

by

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**UNIVERSITY OF SOUTH AFRICA**

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**January 30, 2014**

Student Number: 351 - 438 - 00

**DECLARATION**

I declare that **“LIVING UNDER THE THREAT OF EBOLA: A PHENOMENOLOGICAL STUDY”** is my own work and all the sources that I have used or quoted have been indicated and acknowledged by means of complete referencing and that this work has not been submitted before for any other degree at any other institution.



.....  
**Amandu Gerald Matua**

*January 30, 2014*

.....  
**Date**

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**LIVING UNDER THE THREAT OF EBOLA: A PHENOMENOLOGICAL STUDY****STUDENT NUMBER:** 351- 438- 00**STUDENT NAME:** AMANDU GERALD MATUA**DEGREE:** DOCTOR OF LITERATURE AND PHILOSOPHY**DEPARTMENT:** HEALTH STUDIES, UNIVERSITY OF SOUTH AFRICA**SUPERVISOR:** PROF. DIRK MOSTERT VAN DER WAL**ABSTRACT**

This study articulates the phenomenon of living under a constant threat of Ebola haemorrhagic fever, including what people's reactions towards individuals and families affected by the illness symbolizes as well as the meanings ascribed to Ebola. The study was conducted in Kibale district in Midwestern Uganda to aid understanding of the human aspects of Ebola which has continued to result in widespread fear and anxiety, thereby creating challenges for affected individuals, families and health care professionals.

A phenomenological inquiry was undertaken using Wertz's (1983, 2005, 2011) empirical psychological reflection approach for data analysis, after utilizing purposive, convenience and criterion sampling techniques to select twelve (12) adult survivors and caregivers who anticipated, experienced and survived the outbreak and were in good health and also willing to take part in the study.

Data were generated using in-depth qualitative interviews and the interviews continued until data redundancy was reached. The interview proceedings were digitally audio-recorded in addition to taking field notes and these were transcribed verbatim. Data analysis occurred at idiographic and nomothetic levels according to the principles of Wertz's empirical psychological reflection.

Thematic analysis of the research data revealed seven (7) themes, namely:

- Living under constant threat of Ebola
- Nature of Ebola experience: unique and general meanings
- Surviving Ebola: physical, psychological, social, spiritual and economic implications on survivors
- Caring for Ebola patients: social and psychological implications
- Public reaction toward persons affected by Ebola
- Social-cultural beliefs and practices related to Ebola
- Coping with and living in the aftermath of Ebola outbreaks

Adaptation emerged as the single most encompassing and accommodating concept that united the various themes, categories and sub-categories. It further grounded survivors', caregivers' and community's experience of anticipating, experiencing and coping with challenges associated with Ebola.

The findings add substantial knowledge about how survivors and caregivers experience Ebola outbreaks. Important recommendations are made and guidelines that may be used to increase survivors', caregivers' as well as the community's resilience to challenges of future Ebola outbreaks are suggested.

### **KEY WORDS**

Ebola, threat, phenomenology, lived experience, survivors, family caregivers, fear, stigma, ostracism, coping, adaptation, resilience, Kibale, Uganda.

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**LIST OF ACRONYMS AND ABBREVIATIONS**

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<b>AFINET:</b>	Africa Epidemic Network
<b>AIDS:</b>	Acquired Immunodeficiency Syndrome
<b>BEBOV:</b>	Bundibugyo Ebolavirus
<b>BSL-4:</b>	Biosafety level- 4
<b>CDC:</b>	Centre for Disease Control and Prevention
<b>CEMI:</b>	Cultural Explanatory Model of Illness
<b>CIDRAP:</b>	Centre for Infectious Disease Research and Policy,
<b>CIEBOV</b>	Cote d'Ivoire Ebolavirus
<b>DRC:</b>	Democratic Republic of the Congo
<b>DSM-IV:</b>	Diagnostic and Statistical Manual of Mental Disorders-IV
<b>ELISA:</b>	Enzyme-linked immunosorbent Assay
<b>EPR:</b>	Empirical Psychological Reflection
<b>FBO:</b>	Faith Based Organisations
<b>GPS:</b>	General Psychological Structure
<b>H5N1:</b>	Influenza A virus- causes illness in humans and other animals
<b>HIV:</b>	Human Immunodeficiency Virus
<b>ICRC:</b>	International Society of Red Cross and Red Crescent Societies
<b>IFA:</b>	Immunofluorescence Assay
<b>IPA:</b>	Interpretative Phenomenological Analysis
<b>IPD:</b>	Individual Phenomenal Description
<b>IPS:</b>	Individual Psychological Structure
<b>KDLG:</b>	Kibale District Local Government
<b>LT:</b>	Labelling theory

**LIST OF ACRONYMS AND ABBREVIATIONS**

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<b>MPEG:</b>	Moving Picture Experts Group
<b>MSF:</b>	Médecins Sans Frontières
<b>NGOs:</b>	Non-Governmental Organisations
<b>PTSD:</b>	Post-Traumatic Stress Disorder
<b>RAM:</b>	Roy's Adaptation Model
<b>RDC:</b>	Resident District Commissioner
<b>REBOV</b>	Reston Ebolavirus
<b>ROC:</b>	Republic of Congo
<b>RT- PCR:</b>	Reverse transcription-polymerase chain reaction
<b>SARS:</b>	Severe Acute Respiratory Syndrome, a Corona virus disease
<b>SEBOV</b>	Sudan Ebolavirus
<b>SIT:</b>	Social identity theory
<b>TAFV:</b>	Tai Forest Virus
<b>UBOS</b>	Uganda Bureau of Statistics
<b>UNCST:</b>	Uganda National Council for Science and Technology
<b>UNICEF:</b>	United Nations Children's Fund
<b>UNISA:</b>	University of South Africa
<b>URCS:</b>	Uganda Red Cross Society
<b>UTODA:</b>	Uganda Taxi Operators and Drivers Association
<b>UVRI:</b>	Uganda Virus Research Institute
<b>WHO:</b>	World Health Organization
<b>ZEBOV</b>	Zaire Ebolavirus

## CHAPTER 1

### BACKGROUND AND ORIENTATON TO THE STUDY

*“Our clothes were burned, and our children kept away from us, our families shunned us and were very afraid of us. My children would not shake my hand and told me not to ride my bike home from hospital because it might carry Ebola” (Nurse, Gulu Referral Hospital 2001).*

#### 1.1. INTRODUCTION

This phenomenological study was conducted to articulate how the public experiences the phenomenon of living under a constant threat of Ebola haemorrhagic fever, hereafter, referred to as ‘Ebola’, that is, how they perceive it and what their reactions towards persons affected by the illness symbolise. The study explicates the public’s perception and the meanings they ascribe to the disease. The present study was conducted in Kibale district in South Western Uganda (refer to figure 1.1), where one of the latest Ebola outbreaks occurred (World Health Organisation, WHO 2012a:1-2).

The main motivation to articulate perceptions about the illness stems from widespread ostracism and stigma experienced by individuals infected or believed to be infected by Ebola during and after outbreaks. Incidences of antisocial campaigns targeting these populations, evidenced in literature (Hewlett & Amola 2003:1242; Center for Disease Control and Prevention, CDC 2011:1-2) and in main stream media (Mugisa, Businge, Mugisha, Kisakye, Nzinjah & Thawite 2007:3-4; New Vision 2012a:3-4) indicate that Ebola patients, their close family members and family caregivers are subjected to dehumanising acts of social rejection and stigmatisation.

Articulating such lived experiences generates information that may be used to explain people’s reactions during outbreaks and is also useful in enabling caregivers and policy makers to better prepare the population for future outbreaks. Ni Chonghaile (2012:2) concurs that addressing such real life experiences reinforces community health education campaigns, which serves to reduce the widespread fear, panic, and hysteria that characterises Ebola epidemics in the Great Lakes region and globally.

## 1.2. BACKGROUND TO THE STUDY

This section orients the reader to the main issues underpinning the study, in this case issues related to Ebola outbreaks in the recent past. This clarification aims to facilitate better understanding of the public's perception and beliefs related to what Ebola means to them. The geographic and demographic details of the study area are discussed followed by highlights of cultural beliefs and practices associated with serious illness in the Sub-Saharan region in order to contextualise the study. In addition, the nature of Ebola infection is presented followed by highlights of Ebola epidemics in Uganda. The section concludes with discussions on current epidemic control practices and reported psycho-social implications of recent Ebola outbreaks.

### 1.2.1. Geographic and demographic details of Kibale District

Kibale district is located in South Western Uganda, approximately 215 Km, by road, west of Kampala, Uganda's capital and largest city (refer to figure 1.1).



**Figure 1.1. Map of Uganda showing Kibale District.**

(Source: <http://www.ugandamission.net/>. Accessed: 9<sup>th</sup> August 2012).

Politically, the district is part of the Bunyoro Kingdom, one of the ancient traditional monarchies in Uganda. It is bordered by Hoima district to the north, Kyankwanzi district to the northeast, Mubende district to the east, Kyegegwa district to the southeast, Kyenjonjo district and Kabarole district to the southwest and Ntoroko and Lake Albert to the west. It has a tropical climate, characterised by regular rainfall and dense plant and forest cover. The district population is 613,200, comprising 300,500 males and 312,700 females (Kibale District Local Government, KDLG, 2012:1-2).

In economic terms, the Uganda Bureau of Statistics (UBOS) (2006:3-4) records indicate that agriculture is the mainstay consisting mainly of subsistence production of food and cash crops. The food crops grown include bananas, cassava, beans, groundnuts, sweet potatoes, tomatoes, onions, cabbages, Irish potatoes, finger millet, upland rice, cow peas and simsim; while the major cash crops are brewing bananas, coffee, cotton, tea, cocoa as well as tobacco (UBOS 2006:3-4; KDLG 2012:1-2).

The district is predominantly rural with an average population density of 145 persons per square kilometre, with just about 1% of inhabitants living in urban settlements. This implies that majority of the population depends heavily on the forest and forest animals for food, thus implying a regular human-animal interaction. This is a significant statement because human-animal contact has been linked to introduction of Ebola and Marburg infections to human populations from animal natural reservoirs in past outbreaks in Uganda, Democratic Republic of the Congo, DRC and Republic of Congo, RoC (CDC 2008:1-2; Leroy, Gonzalez & Baize 2011:969; WHO 2012b:1).

### **1.2.2. Cultural classification, beliefs and practices related to human disease**

In most parts of Africa south of the Sahara, such as Uganda, where this study was conducted, the concept of disease and illness is frequently associated with the world of spirits. In their classical article, Appiah and Gates (1999:1-2) report that these spirits which are believed to be either 'good' or 'bad' impact humans in both 'good' and 'bad' ways. The 'good' spirits are believed to offer protection against harm, misfortune or disease, while 'bad' spirits cause disease, misfortune or suffering. This belief system is structured around the notion that 'protection' from the spirits is

directed at individuals who respect social, cultural and religious rituals and practices. This implies that individuals and families who 'abandon' these practices, risk being deserted by 'good' spirits, leaving them 'exposed' to the 'bad' spirits. In the broader sense, this means that individuals and families who fail to adhere to the "must dos" risk being branded and ostracised in the event of calamities. This then results in alienation of affected persons and their families, reinforced by the belief that they are "paying for their sins" as witnessed during recent Ebola epidemics (Mason 2008:1-3).

In the recent past, such alienation triggered by disease outbreaks played out as strict socio-cultural sanctioning during the 2000/2001 Ebola outbreak among the Acholi people of Northern Uganda. Al Safi (2005:1-4) and Hewlett and Amola (2003:1243) report that when the locals classified the Ebola outbreak as '*gemo*', meaning "a killer epidemic", a very stringent form of social sanctioning was applied to affected persons. Al Safi (2005:1-4) explains that this social classification and sanctioning that ensued, compelled affected families to isolate persons suspected to be suffering from Ebola in houses at least 100m from all other houses, barred visitors to them except the elderly who cared for them. The sanctioning also required clear identification of the house of the sick and restricted free movement of people. The protocol further forbade dancing, sexual relations and eating meat from animals that died of unknown causes, and eating food prepared outside one's homes. Hewlett and Amola (2003:1242) add that the protocol obliged survivors to remain in isolation for four weeks before moving freely in the villages, and whenever death occurred, burial occurred at the edge of the village, conducted by survivors of previous '*gemo*' or those who have cared for the sick without becoming ill (Hewlett & Amola 2003:1242).

These culturally motivated beliefs and practices regarding human disease resurfaced in Uganda during the 2007 Ebola Bundibugyo outbreak, where incidences of social sanctioning were reported once again. As this epidemic spread, Mugisa, Businge, Mugisha, Kisakye, Nzinjah and Thawite (2007:3-4) document numerous incidences of socio-cultural sanctioning, manifesting in the form of stigma and ostracism, fuelled by the community's perception of Ebola and their cultural beliefs. Maykuth (2000:2) and Mugisa, Tumusiime and Kajubu (2007:1-3) agree and confirm that these socio-cultural beliefs indeed played a critical role in causing the widespread fear and panic.

In recent times, incidences of 'socio-cultural sanctioning' appeared during the July 2012 Ebola epidemic in Kibale district when the Daily Monitor Newspaper of Tuesday July 31, 2012 quoted, Mr. Museveni, the Ugandan President as declaring: "*I appeal to you to be vigilant, avoid shaking of hands and do not take on burying someone who has died from symptoms which look like Ebola*" (Daily Monitor 2012:4). Whilst such 'precautionary measures' helped to control the epidemic, the social branding of affected persons that ensued amplified the incidence of ostracism and stigmatisation, further underscoring the importance of understanding what Ebola means to people.

Therefore, understanding people's lived experiences, especially the deep seated beliefs about Ebola is foundational to designing appropriate epidemic response plans that address the human side of future epidemics, particularly to demystify false beliefs about the illness. This has the potential to reduce the pervasive stigma and social rejection that defines these outbreaks. This is particularly vital given Uganda's vulnerability to future outbreaks as affirmed by CDC (2011:1-2) and WHO (2012c:1), ultimately demonstrated by the occurrence of up to five epidemics within this decade.

### **1.2.3. Nature of Ebola haemorrhagic infection**

Ebola haemorrhagic fever is a highly infectious illness caused by RNA viruses of the genus '*Ebola*' and family '*Filoviridae*'. Ebola virus is among the most virulent pathogens that infect humans and great apes, inducing acute fever and death within a few days, in up to 90% of symptomatic individuals (Sanchez, Geisbert & Feldmann 2006:1409-1410; Leroy, Gonzalez & Baize 2011:964). Currently, the five known species of Ebola are Bundibugyo Ebolavirus (BEBOV), Zaïre Ebolavirus (ZEBOV), Sudan Ebolavirus (SEBOV), Reston Ebolavirus (REBOV) and Taï Forest Virus (TAFV, formerly Cote d'Ivoire Ebolavirus, CIEBOV), all named after the country or location where virus was first isolated. Ebola Reston does not cause any fatality in human beings, but it is lethal to primates such as chimpanzees and monkeys as shown during several animal outbreaks (CDC 2010:1-3; Leroy et al 2011:964-965).

Ebola is typically a zoonotic disease transmitted accidentally to animals or humans by direct contact with live or dead animals that have been infected from a natural reservoir. To date, the natural reservoir from which infections spread to wild animals

like gorillas, chimpanzees and duikers still remains unknown, although three African fruit bat species *Hypsignathus monstrosus*, *Epomops franqueti* and *Myonycteris torquata*, have been implicated as playing a bridging role in transmitting the virus to either humans or other ape populations (Swanepoel, Leman & Burt 1996:321-325).

King (2010:2-4) explains that once the virus enters human populations, it gets transmitted from person-to-person by direct contact with infected blood and body fluids, sweat, saliva, semen, vaginal fluid and by inoculation from contaminated instruments. The possibility for rapid human to human transmission including high case fatality rate and lack of specific treatment or vaccination makes Ebola infection a major public health issue for Africa and a bioterrorism agent globally (CDC 2010:2).

Generally, Ebola infection shows a twofold disease pattern which appears by the end of the first week of infection. This binary disease pattern according to Feldmann (2010:1896) means that patients may either show signs of multiple organ dysfunctions, ending with death or they may show signs of recovery, albeit with numerous complications. King (2010:2) confirms that in the first week of infection, susceptible patients experience rapid and extensive viral replication leading to cell and tissue death in liver, spleen, lymph nodes, kidney, lung, blood and the gonads.

In the first week, as Feldmann (2010:1896) notes, Ebola patients present with severe headache, sore throat, muscle aches and weakness and hiccups. As the disease progresses, patients vomit and may experience severe abdominal pain, diarrhoea, pharyngitis, conjunctivitis, multiple organ destruction, hypovolaemic shock and bleeding from body orifices, including eyes, nose, anus, vagina, urethra and the ears. King (2010:2-4) adds that terminally ill patients tend to experience extensive soft tissue damage, particularly within the gastrointestinal tract, often causing severe hyperaemia (large blood flow), making surface and bottom layers of the soft tissues such as in the tongue to separate, causing severe pain to patients. Towner, Sealy, Khristova, Albariño and Conlan (2008:1-4) corroborate that in susceptible patients, the disease picture changes so rapidly, that patients frequently progress from experiencing severe body pains and haemorrhage to suffering shock, respiratory arrest, leading to their death as depicted in figure 1.2, within a period of one week.



**Figure 1.2. An Ebola patient drenched in his blood, vomitus and diarrhoea.**

(Source: Murphy, F., A. 2005. Microsoft ® Encarta ® Reference Library 2005)

In the second week, non-susceptible patients begin to show signs of early recovery, which Towner et al (2008:1-2) and King (2010:2-4) assert are due to such patients' capacity to develop sufficient immunologic response against the Ebola viruses. A characteristic feature in Ebola patients is that their recovery is very slow, often associated with severe wasting, anorexia, amnesia, sexual weakness, visual and hearing difficulties, fatigue and mental problems (WHO 2011a:1-2; CDC 2011:1-4).

In addition to these complications, CDC (2011:1-4) notes, survivors of Ebola infection may also experience episodes of uveitis, ocular pain, photophobia, increased lacrimation, myalgia, arthralgia, headache, bulimia, sexual weakness, orchitis and amenorrhea and menstrual disturbances lasting up to 12 months in some survivors.

#### **1.2.4. Summary of Ebola outbreaks in Uganda**

In the last twelve years, Uganda has experienced five Ebola outbreaks. According to Okware, Omaswa, Zaramba, Opio, Lutwama, Kamugisha, Rwaguma, Kagwa and Lamunu (2002:1068), the first outbreak occurred in Gulu district in northern Uganda between October 2000 and February 2001, caused by Ebola Sudan virus strain. After five years, a second outbreak occurred, in Bundibugyo district, in western Uganda from December 2007 to January 2008, caused by a new virus strain, Ebola Bundibugyo (WHO 2011a:1-2). Two years later in May 2011, WHO (2011b:2) announced a third outbreak in Central Uganda, in Luwero district caused by Ebola Sudan virus. The fourth outbreak began in July 2012 in Kibale district in South Western Uganda, again due to Ebola Sudan (Mugerwa & Ayebazibwe 2012:1-2). The fifth and the latest outbreak occurred in Luwero district, Central Uganda, the site of the May 2011 Ebola outbreak. This latest outbreak which began in the month of November 2012 was linked to Ebola Sudan strain (Kityo 2012:1-2; WHO 2012c:1-2).

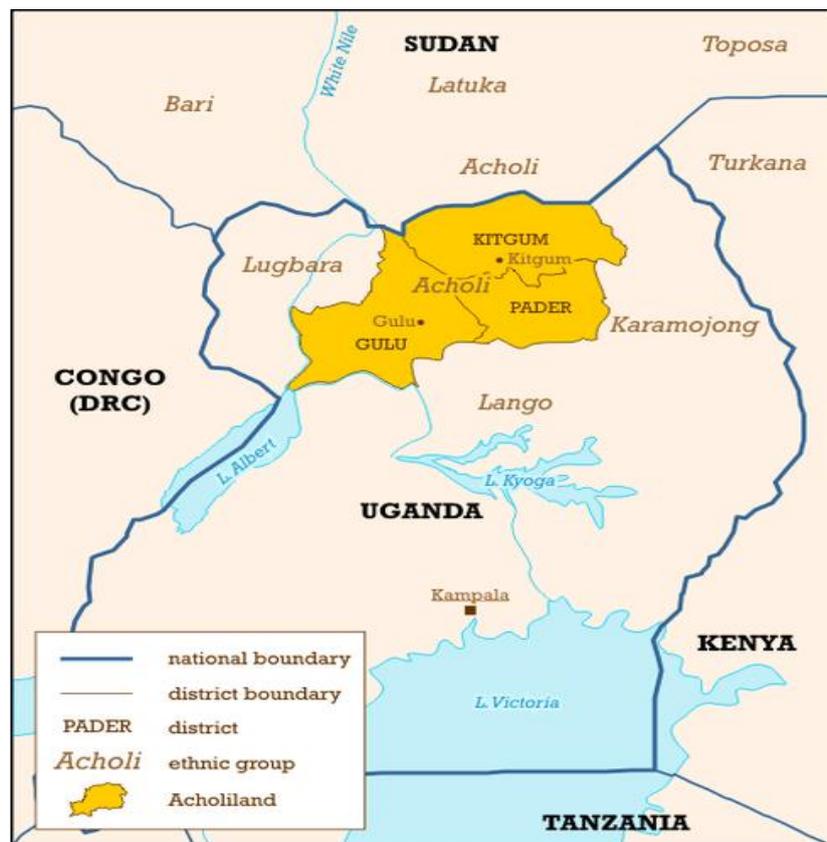
##### **1.2.4.1. The 2000 Ebola Sudan outbreak in Gulu District**

This outbreak began in 2000 in Gulu district (refer to figure 1.3) gaining prominence on October 8, 2000, when the then Medical Superintendent of St. Mary's Hospital, Gulu, and the Gulu District Director of Health Services reported an unusual febrile illness associated with haemorrhage and high mortality to the Ministry of Health in Kampala. This "strange" illness was later confirmed as Ebola by the National Institute of Virology, NIV in South Africa on 14<sup>th</sup> October 2000 (Zaramba 2000:1-2). After confirmation, an emergency response team comprising the national task force on haemorrhagic fevers, Gulu district authorities, the WHO Country Representative and representatives of other development partners, was set up to establish principles for epidemic response, surveillance, case management, social mobilisation and logistics management (Uganda National Health Research Organisation, UNHRO, 2001:2-6).

In Gulu district, Matua and Locsin (2005:132) explain that one of the key interventions consisted of instituting an active surveillance system to determine the extent and magnitude of the outbreak; identification of disease foci and facilitation of early case detection. However, at the national level, the epidemic response efforts were managed by an inter-ministerial committee that coordinated government resources

and carried out political mobilisation (Zaramba 2000:3). Internationally, in response to the local epidemic response team's appeal for international intervention, local experts were later joined by international experts from WHO (Geneva), CDC (USA) and NIV (South Africa). According to Kaguna (2001:4), the local response team reinforced by international experts brought the epidemic under control by instituting key disease prevention strategies including contact tracing, establishing burial teams, community education, stopping traditional healing and burial practices, discouraging large public gatherings and updating hospital based infection control protocols, among others.

This Ebola outbreak which later spread to two other districts, namely Mbarara and Masindi caused 425 infections and 214 (51%) deaths, of which, 393 (93%) were from Gulu, 27 (6%), from Masindi and 5 (1%), from Mbarara (WHO 2001:42-44). According to Lamunu, Lutwama, Kamugisha, Opio, Nambooze, Ndayimirije and Okware (2002:3), the infection spread mainly through attending funerals of presumptive case patients, intra-familial transmission and nosocomial transmission.



**Figure 1.3. Map of Uganda showing the Acholi subregion.**

(Source: <http://en.wikipedia.org/wiki/Acholi>, Accessed 15<sup>th</sup> April 2010).

With regard to the human aspects of the epidemic, Taylor (2000:1-2) points out that the outbreak resulted in extensive fear, panic and hysteria, not only in Uganda and in East Africa, but far beyond these borders. In fact, the print and online newspaper banners from the time stating: Ebola claims Gulu hospital head (IRIN news, December 6, 2000); “Ebola Outbreak Leads to Suspension of Church Services” (Christianity Today, October 1, 2000); and “The disease of year 2000 was the Ebola fever” (New Vision, January 8, 2001), all testify to this unprecedented observation.

Wendo (2001:6) argues that this anguish may have been caused by the frightening disease picture, exacerbated by existing social and cultural perspectives that fuelled the panic. This fear and panic led the public to indiscriminately ostracise and stigmatise contacts, survivors, health workers and their families. Nakazibwe (2001:2) declares that prevailing socio-cultural perspectives combined with widespread fear of infection led to widespread antisocial overtones among them refusing patients and close relatives from accessing public utilities like watering wells and worship places.

This antisocial reaction lingered around for a long time and, as Maykuth (2000:1-2) expresses, the outbreak and the associated rumours and panic had far reaching effects in the neighbouring countries in East Africa as well. In Kenya, for example, Telewa (2000:BBC Online News, 24 November 2000) reports that news of the outbreak led authorities to deport over 100 Ugandans attending a conference in Nairobi, despite medical doctors confirming that none of them was actually infected. Such unwarranted occurrences underscore the need to understand the basis for the hysterical response of the public towards those known or suspected to have Ebola.

#### **1.2.4.2. The 2007 Ebola Bundibugyo outbreak in Bundibugyo district**

The second Ebola outbreak occurred in Bundibugyo district in western Uganda (refer to figure 1.4). MacNeil, Farnon, Wamala, Okware, Cannon, Reed, Towner, Tappero, Lutwama, Downing, Nichol, Ksiazek and Rollin (2010:1969-1970) maintain that this outbreak was attributed to a previously unknown Ebola species, now Bundibugyo Ebolavirus (BEBOV). The outbreak resulted in 149 infections, 37 deaths and a case fatality rate of 25% (Wamala, Lukwago, Malimbo, Nguku, Yoti, Musenero, Amone, Mbabazi, Nanyunja, Zaramba, Opio, Lutwama, Talisuna & Okware 2010:1087-1088).





**Figure 1.5: Experts examine an Ebola “suspect” in Bundibugyo district.**  
 (Source: Claude Mahoudeau, Associated Free Press and Getty Images).

Often times, these antisocial overtones were so entrenched that as Butagira, Bogere and Mugisa (2007:6) substantiate, even health workers known or suspected to be working in the hospital isolation units were targeted. Butagira (2007:2) adds that during this outbreak, survivors were equally shunned, with many relatives refusing to take survivors discharged from the isolation units. Womakuyu (2009:20) concurs and affirms that this rejection did not only affect patients, survivors and health workers; even close family members of infected persons were targeted as well. The words of a sister to an Ebola patient, who lamented that...*“I was forced to stay away from the public for three months...everybody thought the whole family had also contracted it [Ebola]...even relatives could not visit us,”* (Womakuyu 2009:20), substantiates this claim of widespread social cultural sanctioning orchestrated by the local population.

As the infection spread, so did the fear and uncertainty among the public, to the extent that attendance in churches and mosques plummeted and the clergy abandoned age old rituals that involved direct body contact such as congenial greetings. In churches, the clergy abandoned the practice of using bare fingers to serve Holy Communion for fear of infection and instead they opted to using spoons (Butagira, Bogere & Karugaba 2007:1-2). Although such drastic changes may have helped to minimise the spread of infection, they undoubtedly increased people’s anxiety levels. Mugisa, Tumusiime and Kajubu (2007:32-33) note that this fear

associated with Ebola was not only restricted to Uganda and Kenya (with deportation of Ugandans), but it also led the other two neighbouring countries, Rwanda and the DRC to impose strict travel restrictions on Ugandans and other visitors from Uganda, as a precautionary measure to minimise the further spread of the illness to their area.

#### 1.2.4.3. The May 2011 Ebola Sudan outbreak in Luwero District

Uganda's third Ebola outbreak started in May 2011 in Luwero district, 60 kilometres north of Kampala, Uganda's capital city (refer to figure 1.6) in Central Uganda, caused by Ebola Sudan (SEBOV) subtype (WHO 2011b:1-2). Musanje (2011:2) reports that the outbreak that killed a 12-year-old girl accounting for a case fatality rate of 100% too caused widespread unrest in surrounding districts. According to Baguma and Nankya (2011:1), the confirmation of Ebola outbreak in Luwero led to widespread panic and hysteria among the population, demonstrated by the Sunday Vision's article of the time: *"Government asked to disinfect taxis"* (Nabatanzi 2011: 2).



Figure 1.6. Map of Uganda showing Luwero District.

(Source: <http://www.ugandamission.net/aboutug/map1.html> Accessed 7 Sept 2012)

To minimise the spread of infection, Baguma (2011:3) claims, the government warned the public to stay calm and advised them to avoid sex, hosting visitors or visiting, mass gatherings and public transport. Sekanjako and Nabatanzi (2011:4) report that in response to the request by the Uganda Taxi Operators and Drivers Association (UTODA), the national body that oversees the welfare of private public transporters, the Ministry of Health officials embarked on disinfecting taxis and cars from Luwero to not only prevent further spread of Ebola, but to allay people's anxiety.

This call to disinfect the taxis (public service vehicles) by the national chairman of UTODA, was in response to the observation that, *"passengers using the main terminal in Kampala were scared of the epidemic and [would] sometimes shun those travelling from Luwero"* (Nabatanzi 2011:1). In addition to other remedies, Baguma and Nankya (2011:1) point out that the Ministry of Health officials at that time also encouraged the public to avoid direct contact with "body fluids of persons suffering from Ebola through use of personal protective materials, such as gloves and masks" as well as by timely and correctly "disinfecting beddings and clothing of persons suspected and confirmed to be infected with Ebola". Whenever death occurred, the community was advised to use protective gears to ensure safe burial of the dead.

As witnessed in the previous outbreaks, Musanje (2011:2) contends that although the aforementioned "infection control" remedies may have worked in salvaging the public from further outbreaks, they inadvertently heightened the public's perception of vulnerability, further fuelling fear and panic which resonated not only among the locals, but spread far beyond the borders of Luwero district and Uganda as well. In fact, Omolo (2011:1) recounts that, as Uganda's 3<sup>rd</sup> Ebola outbreak raged on, authorities in neighbouring Kenya, Tanzania, DRC and Rwanda were equally scared. As a result they embarked on double checking safety controls at their border posts with Uganda, as fear and rumours spread across the border that the Ebola outbreak in Uganda may well have spread to these countries. Consequently, this time as in previous outbreaks, Uganda's neighbours declared "high alert status" especially at the border posts as a preventive strategy to ensure they were shielded from Ebola.

#### 1.2.4.4. The July 2012 Ebola Sudan outbreak in Kibale District

The fourth Ebola outbreak began in July 2012, when incidences of unfamiliar disease appeared in Nyanswiga village, Nyamarunda sub-county of Kibale district (WHO 2012a:1; Businge 2012a:1), killing villagers and creating untold fear and panic (refer to figure 1.1). The New Vision team on 30 July 2012 reported that the affected families initially thought the “bizarre disease” was either the work of witchcraft or evil spirits. In response they took the first patients to a local shrine for ‘prayers’, which too failed to stop the deaths. This created enormous panic among the locals. The Guardian (29 July 2012) quoted local health officials as saying that “weeks of speculation about the cause of a strange disease prompted many people to flee their homes”. With local residents unsure of what was causing the unprecedented illness and death, some villagers abandoned their homes to escape what they thought was an illness linked to bad luck or evil spirits because people were falling ill and dying (Guardian 2012:2).

This “inexplicable” outbreak was later confirmed to be caused by Ebola Sudan virus on July 28 2012, from the blood and tissue samples at the Uganda Virus Research Institute (UVRI) in Entebbe. In a press statement, the Ugandan President Yoweri Museveni explained that the delay in confirming Ebola arose because the disease symptoms “*were a bit atypical of Ebola,*” allowing the illness to spread to other villages (Museveni 2012:4). In Kibale, following this declaration of Ebola outbreak, many terrified residents left their homes. In the Guardian of 29 July 2012, reporter Ni Chonghaile (2012:1) quotes a terrified local resident, as saying: “*We have to move to safer places because we can easily get infected by this disease here*”; as they fled. The fear and panic was apparent. This announcement created so much panic in the district that even patients admitted to Kagadi (district) hospital prior to confirmation of Ebola fled out of fear. Businge (2012b:2), a journalist who visited the hospital where Ebola patients were being admitted confirmed that, “*when the New Vision team visited the hospital on July 28, 2012, all wards were empty*”, the patients had all fled.

As in previous outbreaks, the Ugandan Ministry of Health alongside key stakeholders and partners, WHO, CDC, Médecins Sans Frontières (MSF), Holland, Uganda Red Cross and World Vision embarked on various epidemic response operations. This

included contact tracing and follow up, establishing a temporary isolation ward and instituting a surveillance program to curtail further spread of the disease (Businge 2012a:2; 2012b:2). In order to ensure efficiency, these response activities were coordinated by task forces at both national and district levels, under the auspices of the health ministry and an inter-ministerial committee on Ebola (WHO 2012a:1-2).

In terms of the human aspects of the outbreak, much like during earlier outbreaks, this outbreak too created panic and anxiety and had far reaching impact on the local community, within Uganda and in the region. In Kibale district, in addition to people fleeing their homes (Ni Chonghaile 2012:1), several schools closed as well (Businge 2012a:1-2). In Kampala, several kilometres away from the epicentre of this outbreak, fear gripped health workers at Mulago hospital, Uganda's National Referral Hospital; after it emerged that a patient from Kibale district, they had treated the previous week had tested positive for Ebola. In distress, the nurses and doctors who had attended to this patient were quoted as lamenting, *"We handled the patient without adequate protection totally ignorant that she had Ebola"* (New Vision 2012a:4). As with previous outbreaks, this epidemic terrified the entire population; for several months, rumours and false claims of new cases continued to emerge in several districts in the country.

In an effort to calm the nation's anxiety, President Museveni addressed the nation on the national TV on July 29, 2012, and issued a press statement the following day on 30 July 2012, appealing for calm while at the same time cautioning the public about the illness. He is quoted as stating that: *"...I therefore appeal to you to be vigilant, avoid shaking of hands; do not take on burying somebody who has died from symptoms which look like Ebola instead call the health workers to be the ones to do it and avoid promiscuity because these sicknesses can also go through sex"* (Museveni 2012:4). Despite such appeals for calm and sensibility, the level of fear and panic remained unusually high in Uganda. To illustrate the level of hysteria that prevailed at the time, despite the assurance from the head of state, two weeks later, Nakigozi (2012:2) reported that in Mukono district news of a suspected Ebola patient admitted at Kayunga district hospital caused severe panic and hysterical response which led to both patients and attending health workers to flee the hospital for fear of infection.

This Ebola related social frenzy was not limited to Uganda and the East African region. This time at the international scene, it led Team Malawi to cancel a friendly soccer match with Uganda earlier scheduled in Blantyre, Malawi. In a press statement, the Football Association of Malawi, said: *“We have cancelled the friendly on advice from the government following the escalation of the Ebola disease in Uganda”*. Gleeson and Hart (2012:1-2) of Reuters News in Blantyre, reported that Team Malawi had cancelled the soccer match ahead of the 2013 African Nations Cup preliminaries with Team Uganda, citing the outbreak of the deadly Ebola virus.

In terms of disease management, emphasis was put on medical management of suspected and confirmed cases in the isolation wards using supportive therapy and reducing further spread of infection through community surveillance. In addition, response efforts focused on counselling, rehabilitating and distributing information about Ebola and its transmission to vulnerable communities in the area. According to WHO (2012b:1) the intervention of psychosocial counselling, targeting communities prior to discharging survivors and contact persons before returning home, proved effective, because it allayed peoples’ fears and reduced the associated stigma, enabling survivors, families and contacts to be accepted back to their communities.

As Uganda’s fourth Ebola outbreak came under control, the WHO (2012d:1) issued an alert on 17 August 2012 that, Uganda’s neighbour to the west, the DRC, was experiencing another outbreak caused by Ebola Bundibugyo virus in the Isiro and Dungu Health Zones of its Orientale Province. Although this outbreak was unrelated to the ending Ebola Sudan outbreak in Kibale district, it highlights the need to better understand the human side of Ebola outbreaks so that more effective epidemic response efforts can be designed and implemented during outbreaks in the future.

#### **1.2.5. Current management practices of Ebola epidemics**

Current epidemic control interventions are multi-stage and informed by the medical model, aimed at minimising infection transmission in both healthcare and community settings, reducing case fatality, strengthening epidemic response and capacity building for surveillance and epidemic control and safe burial as shown in figure 1.7 (Mupere, Kaducu & Yoti 2001: 60-65; Médecins Sans Frontières, MSF 2008:1-2).

However, despite successes recorded through this approach, critics of the medical model maintain that it negates the human side of these epidemics, despite manifestations of repeated occurrence of panic, social isolation and stigma. The persistent occurrences of these antisocial overtones emphasise the need to better understand the publics' perception of what Ebola means to them as individuals.



**Figure 1.7. Burying deceased Ebola patients in Gulu, Uganda.**  
(Source: Dr. Yoti Zabulon, St. Mary's Hospital, Lacor, Gulu, Uganda, 2001)

In response to these persistent antisocial overtones, Kirunda (2009:2) reports that epidemic response teams have begun to counsel and support victims and their families as part of social mobilisation. These have been achieved through radio broadcasts, mobile film vans, leaflets, brochures and through posters designed to reduce antisocial sentiments in the community. This shift in focus is evidenced by the International Society of the Red Cross and the Red Crescent Societies' (ICRC) report indicating that during the 2011 Ebola outbreak in Luwero district, a large part of the community mobilisation efforts consisted of passing key messages to demystify misconceptions and false information about the disease. The ICRC (2011:2) adds that in addition to counselling and supporting affected families, part of their work was encouraging locals to avoid practices that enhance the spread of the illness, among them staying away from greetings, large gatherings and handling of dead relatives.

### 1.2.6. Psycho-social consequences of Ebola outbreaks

Generally, news of Ebola outbreaks are a source of psychological and social strain usually driven by fear inducing news headlines in local, regional and international newspapers and television. In the last several years, news of Ebola outbreaks have continued to result in fear and anxiety, leading to far reaching psychosocial implications on the public even far away from the epicentres of these outbreaks. Frightening headlines such as: *“Is Ebola spreading from Gulu?”* (Africa online news November 2, 2000); *“Kenya, Fearing Risk of Ebola Virus, Deports 137 Ugandans”* (Associated Press , November 25, 2000); *“Uganda on alert as Ebola fever breaks out in DRC”* (Kirunda, 2009, Daily Monitor, January 1, 2009); *“Ebola Pushes Kampala into Panic”* (Igihe Network, July 30, 2012); *“Panic grips Uganda, as Ebola outbreak kills 14”* (Reuters News, 28 July 2012) as well as, *“Ebola outbreak sees tourists cancel holidays to Uganda”* (Telegraph, August 02, 2012) among others, all add to instances of fear, anxiety and despair. As Sokol (2002:18-22) notes, such fear and anxiety have negative consequences on people’s lives, but most importantly of those individuals directly affected by these outbreaks, including their close family members.

Informed by studies done in Gulu district after the 2000 Ebola outbreak, Hewlett and Amola (2003:1242-1244) describe that the scary disease picture, especially the high fatality rate and the unfamiliar burial practices triggered widespread fear and panic in the population. In affirmation, Matua and Locsin (2005:150) contend that the fear of infection is the most powerful stimulus for neighbours turning away friends, even to the extent of diverting routes away from affected homes. Kabanankye (2001:3) similarly reports that abrupt cessation of established social practices such as congenial gestures of sharing of domestic items and communal eating, prompted by the fear of infection have become characteristic of serious disease outbreaks, overriding the close ties that exist among families and local community members.

These antisocial nuances unfortunately often reach far and wide. Ocwich (2000:4) and Wendo (2001:6-8) recall that during the 2000 Gulu Ebola outbreak, survivors and their family members were refused to mix freely with others, while those in trade were shunned and their business transactions became limited only to unsuspecting

customers. However, once such customers discovered that they had purchased goods from Ebola survivors, they promptly returned these “contaminated” goods, leading to further alienation. In support, Onencan and Tokwiny (2001:2) state that the ostracism was so overt that survivors and their families were even barred from public gatherings like schools, prayers, markets and even walking along village paths. Hewlett and Amola (2003:1246) add that children who lost one or both parents were not spared either; they were abandoned, fearing they might harbour the Ebola virus.

Locsin, Barnard, Matua and Bongomin (2003:158) in corroboration affirm that this psycho-social burden on affected persons and their families is worsened by the ‘culturally sanctioned’ and ‘medically approved’ strict protocols that characterise epidemic response efforts. In conclusion, the researchers affirm that, whilst such epidemic control protocols may succeed in minimising the spread of the illness, the dehumanising actions that arise thereof, especially the manner in which suspected persons are handled, as depicted in figure 1.8 exacerbate the panic in the public, as it brings to reality the possibility that they too may also be humiliated in the near future.



**Figure 1.8. Extreme caution: disinfecting an Ebola suspect in Gulu.**  
(Source: The New Vision Newspaper, Regional News: Tuesday December 5, 2000:10)

In another dimension, Hewlett and Hewlett (2005:295) describe that Ebola outbreaks have in the past also led to emergence of vigilante groups to “protect” their communities by targeting suspected sources of infection such as survivors, orphans and health workers. Mason (2008:2) validates this claim by confirming that during the 2007 Ebola Bundibugyo outbreak, vigilante groups in areas surrounding the epicentre of the epidemic vandalised and destroyed survivors’ properties, including burning their houses to undermine their re-integration into the villages. Such violence directed at ‘victims’ of Ebola, Locsin, Barnard, Matua and Bongomin (2003:157) explicate, results in senseless loss of lives and destruction of property as depicted in figure 1.9. Such inhumane occurrences according to Kabanankye (2001:40) are constant reminders for and support better understanding of what Ebola means to the affected.



**Figure 1. 9. Ebola patients hut burnt during the 2003 DRC Ebola outbreak.**  
(Source: Ebola in Congo: virus, poacher and fetish, Mbomo © Epelboin 2004)

### **1.3 THE PROBLEM STATEMENT**

Uganda continues to experience outbreaks of Ebola, characterised by widespread panic, ostracism and social stigma. The occurrence of five outbreaks (WHO 2012a:1), within twelve years, coupled with the discovery that the African fruit bat *Rousettus aegypticus* (see section 3.3.4), found naturally in Uganda, is implicated in the transmission of Ebola viruses between human epidemics (Bogere 2007:5; WHO 2011a:2; Leroy et al 2011:968) all attest to Uganda’s vulnerability to future epidemics. In fact, based on literature and Uganda’s geographical position (CDC 2011:1-2),

I anticipated that an outbreak was likely to resurface in the near future as it did in July 2012. However, despite these outbreaks, most studies continue to focus largely on the biomedical aspects of the epidemic, thereby underscoring the need to understand the human aspects of these outbreaks, especially people's reaction to the epidemics.

This paucity of research geared towards explicating and understanding the human aspects of the illness means that it is still unclear how people experience the phenomenon of living under a constant threat of Ebola, including how they perceive the illness, what their reactions symbolise and what the experience means to them. Hence, understanding such human experiences is critical because affected persons and close family members have continued to face and live with numerous consequences (see section 1.3.5) which they have to cope with during the aftermath.

Furthermore, understanding people's reaction to Ebola is critical to provide evidence based information that health teams and policy makers may use to counter rampant antisocial reactions through social health education. Anyinam, Papaconstantinou and Coffey (2007:1-2) agree that understanding and appreciating human experiences of health and illness, joy and suffering, hope and resilience are essential to engaging fully with individuals, families and communities in the co-construction and provision of authentic and meaningful nursing care. Boykin and Schoenhofer (2001:12-15) hold a similar view and affirm that understanding devastating lifetime experiences offers a great opportunity for compassionate and competent nursing care. Such statements further support inquiries geared towards illuminating people's experiences with Ebola.

#### **1.4 RESEARCH PURPOSE**

The purpose of this study was to:

- gain a clear understanding of how people experience the phenomenon of living under a constant threat of Ebola, especially how they perceive Ebola, what their reactions towards Ebola symbolise, including their reactions towards persons and families affected by Ebola.
- propose guidelines as well as perspectives that healthcare workers and policy makers may use to address the human aspects of similar epidemics in future.

## 1.5. RESEARCH OBJECTIVES

The objectives of this research study were to:

- explore the lived experience of living in constant anticipation of Ebola outbreak.
- ascertain a clear picture of experiences of survivors and their close family members regarding their lived experiences with Ebola outbreak.
- describe the experiences of survivors and family members during and after the Ebola outbreak so as to generate theory about these experiences and to propose guidelines to improve epidemic response in future.
- understand more fully the structure and meaning of these lived experiences as immediately experienced by survivors and their close family members.

## 1.6 THE GUIDING RESEARCH QUESTIONS

The grand tour question was:

- How do you experience living under a constant threat of Ebola? Or,
- How do you experience the constant threat of Ebola?

The phenomenon of “living under a constant threat of Ebola” was unearthed by exploring survivors’ and their close family members’ experience of “anticipating an infection from an existing outbreak” to explicating their feelings and reactions following another outbreak in a geographically prone area. To facilitate better understanding, the following grand tour themes were explored with every participant:

- How do you experience living under a constant threat of Ebola?
- How do you perceive Ebola? Or, what does Ebola mean to you?
- What does the public’s reaction towards Ebola symbolise?
- How do you explain the public’s response to affected individuals and families?

The grand tour themes facilitated exploration of the perceptions and meanings that survivors and family caregivers assigned to their lived experiences, enhanced by the hints provided by each participant during the in-depth phenomenological interviews.

## 1.7. RESEARCH PARADIGM

Parahoo (2006:471) defines a research paradigm as the beliefs and values, which particular research communities share about a phenomenon which may or may not be researched, including the methodologies involved. Denzin and Lincoln (2000:157) submit to a similar view and define a research paradigm as “basic set of beliefs that guide action”, dealing with first principles, ‘ultimates’ or the researcher’s worldviews.

A qualitative research approach grounded this study, which according to Denzin and Lincoln (2011:8) is a research approach that stresses “*socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry*”. The qualitative researcher strives to answer the questions that stress how socially constructed experiences, such as stigma related to Ebola are created and given meaning. The choice of this approach is in agreement with Creswell’s (2009:12) exposition of qualitative research as a well-grounded process of inquiry that may be used to understand a social or human problem through building a holistic picture of the situation, using words instead of figures, presenting the issues as seen through the eyes of participants, through a close interaction with participants in the natural setting in which the phenomenon occurred. Holloway (2005:4) affirms that through qualitative research, the researcher develops an understanding of a participant’s experience and presents this experience in a lively manner so that its reality, the nuances and context, all become apparent.

Creswell (2012:47) maintains that qualitative research is best used when there is a problem or needs of a group that cannot be easily measured quantitatively, by using numbers, but instead needs to be explored in sufficient detail. Creswell proposes that qualitative research is also appropriate when there is need to understand a complex issue: “*when the details can only be established by talking directly with people, going to their homes or places of work, and allowing them to tell the stories unencumbered by what we expect to find or what we have read in the literature*” (Creswell 2012:48).

The researcher's choice of a qualitative research approach is further supported by the belief that human experience is best understood using modalities that lend themselves well to in-depth study in natural settings. In contrast, the quantitative research approach was deemed inappropriate because "lived experience" which underpins this investigation and plays a central role in holistic patient care are difficult to investigate quantitatively. As Denzin and Lincoln (2011:3) maintain, qualitative research studies '*things*' in their natural settings, and attempts to make sense or interpret these phenomena in terms of the "*meanings*" people bring to them. Similarly, as Burns and Grove (2011:17) contend, such naturalistic forms of inquiry are appropriate to investigate emotional responses associated with lived experiences, in this case, the experience of constantly anticipating Ebola outbreak as lived in Kibale.

## **1.8. RESEARCH DESIGN AND METHOD**

A research design is defined by Polit and Beck (2010:74) as the researchers' overall plan for addressing a research question, including strategies to enhance the study's integrity. Creswell (2012:49) declares that a research design is the researcher's plan or proposal to conduct research and involves the intersection of the researcher's philosophy, strategies of inquiry and specific methods. The researcher settled for a qualitative research design in agreement with Creswell's (2009:12) exposition that it is suited to investigate phenomena from the view point of those who experience it.

A research method on the other hand refers to specific steps, procedures and strategies used to gather and analyse the data generated (Polit & Beck 2010:567). The researcher chose the phenomenological method because it fits well within the qualitative research domain and is appropriate to study poorly conceptualised phenomena, in this case, living in constant anticipation of Ebola outbreak (Polit & Beck 2010:267). The basis for this is the fact that phenomenology allows the researcher to, "*zu den sachen*", "go back to the things themselves", and to discover and lay bare, what lies hidden in people's experiences by allowing these 'original perspectives' to emerge and to manifest in their descriptions (Van Manen 1990:184).

### **1.8.1. The Research Design**

In choosing an appropriate research design, Creswell (2009:5) advises researchers to select an approach with a fitting philosophical worldview, identify the approach of inquiry related to this worldview and specific methods or procedures of research that translate the approach into real practice. The researcher's choice of a qualitative research approach is further supported by Denzin and Lincoln's (2011:9) view that qualitative research approaches enable researchers to discover, understand and describe meanings people assign to their lived experiences. A qualitative inquiry, Polit and Beck (2010:565) elucidate, entails in-depth and holistic investigation of human phenomena through collection of rich descriptive data and then analysing it.

In chapter 4, a detailed presentation of the study's design is articulated.

### **1.8.2. Research Method**

A phenomenological method was chosen to conduct this study. The method is underpinned on the classical human science assumption espoused by Guba and Lincoln (1989:105) which states that, there is but no single reality, implying that each individual has their own reality. Therefore, to arrive at an individual's reality of an event, an appropriate research method is required. In the current study, Wertz's (1983, 1985, 2005, 2011) Empirical Psychological Reflection (EPR) method was chosen as the study's analytical framework because the phenomenological research method was believed to be well suited for articulating the meanings and structures of survivors' and caregivers' experiences (Polit & Beck 2010:263; Wertz 2011:133). With roots in Duquesne phenomenological psychological research tradition, this method is inspired by Husserlian phenomenological principles and has over time evolved to include features consistent with interpretive phenomenological inquiry (Bäckström & Sundin 2007:246; Streubert & Carpenter 2011:85; Wertz 2011:131-33).

This phenomenological method allows researchers to methodically reflect on participants' experiences of situations, explicate their lived meanings including structures of these lived experiences. In affirmation, Munhall (2007:217) and Wertz

(2011:133) declare that phenomenology enables researchers to unravel the “essence” of lived experience, which is key to understanding clients’ experiences which when properly understood facilitates patient-centred care (Denzin & Lincoln 2011:11). Indeed in healthcare, it is such nuances from people’s life experiences that allow healthcare professionals to plan, design and deliver authentic and meaningful healthcare to affected individuals, families and communities (Anyinam et al 2007:1-2).

True to qualitative research paradigms and phenomenological methods, I gathered data using in-depth interviews (Polit & Beck 2010:267), asking participants to describe their experiences in detail, supported by field notes. These descriptions were then analysed to arrive at experiences relevant to the phenomenon of living in constant anticipation of Ebola outbreaks. In addition, the researcher also explored various contextual issues related to the public’s reactions towards those affected by Ebola, particularly the structure and meanings of these lived experiences.

In Chapter 2, phenomenology as a philosophy and a research method is discussed.

#### **1.8.2.1. Population**

Polit and Beck (2010:75) define population as all individuals or objects with common, defining characteristics that meet a designated set of criteria for inclusion in a study. With regard to the present study, the term ‘population’ refers to all survivors and their family members who experienced the July 2012 Ebola outbreak in Kibale district.

In Chapter 4, details pertaining to the study population are further articulated.

#### **1.8.2.2. Sampling**

The researcher used three qualitative sampling techniques of purposive, convenience and criterion sampling to draw survivors and family members for inclusion into the study. Purposive or judgemental sampling according to Polit and Beck (2010:312) involves purposely selecting individuals judged to be typical of the population or particularly knowledgeable about the subject. Convenience sampling involves

selecting the most readily available people as participants (Polit & Beck 2010:319). Selection of survivors and their family members started with those who were present and readily available to participate in the study. In other words, as Burns and Grove (2007:214) articulate these people happened to be in the right place at the right time during data collection. Criterion sampling, as Polit and Beck (2010:320) point out, involved consciously selecting prospective survivors and caregivers from the target population who met the selection criteria of:

- having been infected and survived an Ebola infection.
- witnessing a close family member get infected with Ebola.
- consenting to participate and share experiences in the study.
- granting permission to be audio-recorded during and after the interview.
- expressing readiness to share their lived experiences with the investigators.
- demonstrating the ability to competently describe their lived experiences.

In Chapter 4, further details pertaining to the sampling method are deliberated upon.

### **1.8.2.3. Data Generation Approach**

Data generation is the “*precise, systematic gathering of information, relevant to the research purpose*” (Burns & Grove 2009:43). In order to ensure accurate research findings and conclusions, Brink (2006:141) recommends employment of high quality data collection techniques. In keeping with the chosen phenomenological method:

- Data were generated using in-depth interviews using four grand tour themes explored in further detail using cues that appeared during the interviews.
- Each participant was assisted to describe their lived experience exhaustively and as freely as possible, without leading the discussions.
- Each interview was recorded on high quality digital recorders alongside detailed field notes to safeguard against accidental interview data loss.
- The interview instrument consisted of the interview guide and the interviewer(s), especially their openness to existence of “multiple” realities.

As suggested in literature, a key aspect of descriptive phenomenology considered during the research process is bracketing (refer to section 2.3.6), the process widely understood as identifying and holding in abeyance one's preconceived beliefs and opinions about the phenomenon under study (Polit & Beck 2010:268). However, the form of reduction used in the current study is the form consistent with interpretative research tradition that requires the researcher to remain open and engage in reflexivity to help the researcher identify and keep track of the pre-understandings.

The details of how the reductive process occurred are explicated in section 2.3.6.

#### **1.8.2.4. Data recording**

As Patton (2003:8) recommends, high quality recording was emphasised throughout the interview sessions to guarantee quality recording and clear transcription of the data. According to Patton, "as a good hammer is essential to fine carpentry, a good recorder is indispensable to fine fieldwork [qualitative interview]" (Patton 2002:380). Sommer and Sommer (1997:118) agree that a high quality recording of interview sessions is essential especially when such information is the final source for data analysis. The researcher thus ensured the recorders were of best possible quality.

In Chapter 4, detailed discussion on the interview process is elucidated.

#### **1.8.2.5. Data analysis**

Qualitative data analysis is defined by Polit and Beck (2010:565) as "*the organisation and interpretation of narrative data for purposes of discovering important underlying themes, categories and patterns*". Norwood (2000:375) supplements that qualitative data analysis involves ordering vast amounts of narrative data in order to document and communicate general conclusions about the phenomenon. I analysed all the research data manually using MS Word, instead of using the available qualitative analysis software such as "*Atlas.ti*", "*NVivo*", "*CATMA*". This choice was intended to keep me firmly grounded to allow conceptualisation of the nuances in each transcript.

In Chapter 4, details about the various elements of data analysis are explained.

## 1.9. MEASURES TO ENSURE TRUSTWORTHINESS

As Polit and Beck (2010:490) assert, qualitative researchers agree on the importance of rigor in qualitative research to ensure “quality” work. The concept of “rigor” according to Thomas and Magilvy (2011:151) refers to the various procedures a researcher may use to establish quality, trust or confidence in the findings of a study. In qualitative research, quality control measures to achieve rigor, termed, “*trustworthiness*”, are likened to the quantitative concept of “*reliability*” and “*validity*”. I endeavoured to follow the five “gold standard” criteria of trustworthiness: credibility, transferability, dependability and confirmability as advanced by Lincoln and Guba (1985:301), and the authenticity criterion espoused by Guba and Lincoln (1994:114).

In addition to the five criteria, I also engaged in “*bracketing* and *reflexivity*” to improve the study’s rigor and to reduce bias (Creswell 2007:37; Grbich 2013:113). As articulated in section 1.8.2.3, I engaged in a form of bracketing consistent with interpretative phenomenological research framework by “*remaining open to participants’ realities*” and engaging in *self-reflexivity* and avoided any premature conclusions about observations within participants’ narratives. I also promoted the study’s rigor by remaining flexible during the theme identification phase, ensuring that agreements were reached with the thesis promoter first, before preliminary themes were considered as “*final*”. This “*external quality controller*” role of the promoter and *my openness and flexibility* (as instrument) ensured that the themes and categories generated were authentic and were appropriately supported by “actual” data portions.

In Chapter 4, the strategies used to ensure the study trustworthiness are discussed.

## 1.10. META -THEORETICAL FOUNDATIONS OF THE STUDY

Polit and Beck (2010:530) regard meta-theoretical assumptions as principles that the investigator uses to ground the conceptualisation, conduct, analysis and documentation of a study. The assumptions that grounded this study are derived from phenomenology and in turn related to existential philosophy. The philosophical principles that underpinned the current study include ontological, epistemological, methodological, axiological as well as rhetorical assumptions (Creswell 2007:15):

### **1.10.1. Ontological assumptions**

Ontological assumptions focus on conceptions of reality and the nature of being. According to Rayo (2007:428-30), ontology asks the question: “What is the nature of reality?” Through out the study, I assumed from ontological standpoint that reality is:

- multiple, subjective and mentally constructed (Guba & Lincoln 1989:105).
- lived experiences are culturally and socially constructed (Kramp 2004:106).
- meanings are a blend of participant and researcher views (Flood 2010:10).

### **1.10.2. Epistemological assumptions**

Epistemological assumptions deal with production of knowledge and address questions such as: “what is knowledge?”, “how can reality be known?”, and “how does the inquirer relate to the participant?” (De Gialdino 2009:4). In view of this perspective, I further assumed from an epistemological standpoint that:

- researchers and participants interact closely (Streubert & Carpenter 2011:28).
- knowledge is co-created by researcher and participants (Polit & Beck 2010:18).
- participants’ stories need to be interpreted (Newell & Burnard 2006:58).

### **1.10.3. Methodological assumptions**

Methodological assumptions relate to the process of knowledge generation (Mertens 2009:59) and help to answer the philosophical question, “How do we obtain knowledge?” Throughout the study, I assumed from methodological viewpoint that:

- phenomenology is suited to study subjective questions (Polit & Beck 2010:72).
- in-depth interviews allow experience sharing (Streubert & Carpenter 2011:35).
- individuals can reflect on experience long after it has happened (BBC 2011:1).

#### **1.10.4. Axiological assumptions**

Axiological assumptions according to Williams (1998:2) relate to the role of values in research. It deals with whether the researcher's values should be suspended in order to understand others' lived experiences or whether these values should be incorporated to mediate and shape the researcher's understanding of the experience (Shuib 2011:8). In this regard, I assumed from the axiological standpoint that:

- values help in conceptualising human realities in research (Gericke 2012:515).
- a researcher's values and passion motivate the research project (Rohan 2011:4).
- acknowledging values and biases is central to phenomenology (Shuib 2011:8).

#### **1.10.5. Rhetoric assumptions**

Rhetoric assumptions relate to the choice of language used in communicating the research findings (Johnstone 2004: 261). In terms of language, I assumed that:

- informal (everyday) language facilitates understanding (Johnstone 2004:262).
- using language indicative of an involved and deeply passionate investigator portrays the co-participation of the researcher in the inquiry (Rohan 2011:4).
- choosing words acceptable to qualitative paradigm is vital (Creswell 2009:175).

### **1.11. ETHICAL CONSIDERATIONS**

Ethics is defined as a system of moral values, that is concerned with the degree to which research procedures adhere to professional, legal, and social obligations to the research subjects (Polit & Beck 2010:553), as well as the institution at which the research was conducted and the integrity of the researcher (Van der Wal 2005:154). The ethical issues discussed in the study relate to participants, institutions, the researcher's integrity and domain specific issues consistent with the study's nature:

- Ethical issues related to participants are their right to self-determination, privacy, fair treatment and protection from harm and discomfort (Parahoo 2006:112).
- Ethical considerations related to the institutions involved relate to issues of informed consent and anonymity as advocated by Van der Wal (2005:154).
- Ethical considerations related to the scientific integrity relate to issues of misconduct like data fabrication, falsification and plagiarism (Mongwe 2007:110).
- Domain specific ethical considerations are issues that arose due to the sensitive nature of the study, and include concerns of stigmatisation, discrimination and social isolation as experienced by survivors and their families (McGarry 2010:9).

In chapter 4, details of general and domain specific ethical issues are articulated.

## **1.12. SCOPE AND LIMITATION OF THE STUDY**

### **1.12.1. Scope**

The scope of the study is limited to understanding and describing the perception of the public with regard to what it means to live under constant threat of an Ebola outbreak. It focuses on what being infected or witnessing the infection and recovery of an Ebola patient means, including symbolism of the reaction of the public towards persons affected by Ebola. This study illuminates the lived experiences of survivors and family care givers who endured the July 2012 Ebola outbreak in Kibale district.

### **1.12.2. Limitations**

Burns and Grove (2005:38) consider limitations as restrictions or problems in a study that may decrease generalisability or usefulness of the findings. In the present study, despite efforts to ensure accuracy, the researcher is aware of its shortcomings. According to Giorgi (1983:148), qualitative research studies such as this, however well-intentioned, still experience shortcomings, related to the research situation, data generation process, study method and communication of the findings, as follows:

#### **1.12.2.1. Limitation related to research situation**

I was acutely aware that a single research study is insufficient to document everything about Ebola experience, meaning that the findings only represent a specific aspect of the outbreak. The findings were thus explicated in a way that showed specific aspects of the experience investigated. In the end, I was cautious in proposing the applicability of these findings to other situations (Delmar 2010:117).

#### **1.12.2.2. Limitations related to constitution of research data**

I was also aware of the possibility of constituting “*atypical*” data because the purposive and convenient sampling methods could have led to inclusion of participants with unrepresentative characteristics. Aware of this limitation, I was cautious in generalising the findings to entire populations. Also I provided sufficient data to help others in understanding and evaluating the findings (Delmar 2010:117).

#### **1.12.2.3. Limitation related to research method**

Furthermore, I was also aware that the phenomenological method is unable to tap all the information that transpired during the research process (Mongwe 2007:28). Hence to inform the reader about which aspect of the ‘Ebola experience’ was explored, participant’s personal reflections were obtained, analysed and presented in particular contexts for the reader to better understand them (Mays & Pope 2000:51).

#### **1.12.2.4. Limitation related to interpreting and communicating the findings**

Finally, I was conscious of the fact that no set of data is so ‘unequivocal’ that it can be interpreted and presented in only “*one*” direction (Mongwe 2007:28). This implies that *my* direction for analysis and communicating the findings may not have been the best to recognise the Ebola experience, despite consistent and deliberate efforts to communicate the findings in manner that allows scholars to recognise commonalities and differences in this study with that found in similar situations (Delmar 2010:122).

### **1.13. SIGNIFICANCE OF THE STUDY**

The findings have the potential to contribute positively in the following areas:

#### **1.13.1. Significance to clinical practice**

The findings have generated new understanding of survivors' and family caregivers' experiences of being affected by Ebola, which is critical for better epidemic response during future outbreaks, especially in relation to the holistic care of affected persons.

#### **1.13.2. Significance to health policy**

The research is significant in that the findings may contribute towards development of more comprehensive and humane healthcare protocols that better address health needs and concerns of survivors and the general public in times of similar outbreaks.

#### **1.13.3. Significance to nursing (health professionals) education**

The experiences of survivors and their family members provide a basis for better preparation of nurses and other care providers to care for patients with such frightening disease conditions in future, especially in Ebola prone great lakes region.

#### **1.13.4. Significance for general public**

The findings provide an understanding of what it means to live under constant threat of Ebola, by elucidating the experiences of survivors and family caregivers to broaden the public's understanding of what it means to be affected by Ebola. This knowledge is critical in changing people's overall perceptions and beliefs about Ebola outbreaks.

#### **1.13.5. Significance to nursing (health) research**

The research findings have the potential to generate further inquiry into other areas comparable to the experience of living under constant threat of resurgence of a life threatening illness. Chinn and Kramer (2004:146) insist that such studies often prompt further research relevant and related to the discipline and practice of nursing.

## 1.14. DEFINITION OF KEY CONCEPTS

In this section, the meanings of key terms as used in the thesis are explicated:

- 1.14.1. **Outbreak:** A sudden onset of a disease (MacMillan Dictionary 2002:1006).
- 1.14.2. **Epidemic:** The occurrence of a disease in a community clearly in excess of normal expectations (Stedman's Dictionary 2000:292).
- 1.14.3. **Lived Experience:** A series of events and situations undergone by persons directly affected by Ebola during and after the illness (Webster's New Encyclopaedic Dictionary 1996:353) and includes productivity, relationality and meaningfulness in the context of the person's larger life (Wertz 2011:2).
- 1.14.4. **Phenomenology:** A qualitative research tradition, rooted in philosophy focused on lived experiences and their meanings (Polit & Beck 2010:85).
- 1.14.5. **Methods:** Specific steps, procedures and strategies the researcher uses to gather and analyse research data generated (Polit & Beck 2010:560).
- 1.14.6. **Methodology:** The broad research approach chosen to answer the research question categorised as qualitative or quantitative (Polit & Beck 2010:259).
- 1.14.7. **Ebola Haemorrhagic Fever:** A severe and fatal disease that results from infection with a lipid-enveloped single stranded RNA virus causing shock and bleeding abnormalities in humans and primates (WHO 2012b:1).
- 1.14.8. **Ebola Virus:** A lipid-enveloped single stranded RNA virus that causes shock and bleeding abnormalities in humans and primates leading to death in upto 90% of the cases; currently five strains (subtypes) are known (WHO 2012b:1).
- 1.14.9. **Antibody:** Proteins produced by an organism's immune system to recognise foreign substances (CDC 2012:7).
- 1.14.10. **Antigen:** A foreign substance that stimulates the body's immune response by triggering production of antibodies to fight them. Antigen/antibody response is an important part of a person's immunity to disease (CDC 2012:7).
- 1.14.11. **Biosafety levels:** Combinations of work practices, safety equipment, and facilities, designed to minimise exposure of workers and environment to infectious agents; measured from level 1 to 4 based on the potential to cause serious human disease, person-to-person transmission, aerosol infectivity and availability of proven therapy against the agent (CDC 2012:7).

- 1.14.12. Case-Fatality Ratio:** The number of cases of a disease ending in death compared to the number of cases, expressed as a percentage (CDC 2012:7).
- 1.14.13. Disease:** A condition in which the functioning of the body or part(s) of the body is interfered with or damaged (CDC 2012:7).
- 1.14.14. Host:** An organism in which a parasite lives and is nourished (CDC 2012:8)
- 1.14.15. Infection:** Entry and development of infectious agent in body (CDC 2012:8).
- 1.14.16. Immunoglobulin (IgG):** An antibody present in blood serum indicative of a recent or remote infection, prevalent 3 weeks after infection (CDC 2012:8).
- 1.14.17. Immunoglobulin (IgM):** Refers to one of many antibodies present in blood serum which is usually indicative of an acute infection (CDC 2012:8).
- 1.14.18. Reservoir:** Any person, animal, arthropod, plant, soil or substance in which an infective agent normally lives and multiplies, with the infectious agent primarily depending on the reservoir for its survival (CDC 2012:8).
- 1.14.19. Surveillance of disease:** The on-going systematic collection and analysis of data and the provision of information which leads to action being taken to prevent and control the spread of an infectious disease (CDC 2012:8).
- 1.14.20. Virus:** Is an extremely tiny infectious agent that is only able to live inside a cell, composed of two parts, the outer protective shell and inner part made of genetic material, which may be either RNA or DNA (CDC 2012:8).

## **1.15. STRUCTURE OF THE THESIS**

The thesis consists of Chapters 1 to 8, the details of which are summarised below:

- **Chapter 1: Introduction and orientation to the study**

The chapter introduces and contextualises the study by providing background information about the study as well as the design chosen to implement the study.

- **Chapter 2: Phenomenology: methodological foundations of the study**

The chapter provides an account of the origins and essence of phenomenology as a philosophy and a research approach that informed the conduct of the present study.

- **Chapter 3: Preliminary Literature Review**

Ebola virus and the haemorrhagic syndrome and coping strategies related to life threatening illnesses and health needs of persons experiencing them are presented.

- **Chapter 4: Research Design and Methods**

The research design, methods and techniques employed in data generation, data analysis as well as data presentation, including ethical considerations are discussed.

- **Chapter 5: Data Analysis**

The plan used to analyse survivors' and caregivers' lived experiences are explicated.

- **Chapter 6: Presentation of data with literature support**

The synthesised data are presented in form of themes, categories and subcategories supported with post hoc literature to enhance audit trail and credibility of the findings.

- **Chapter 7: Relating emergent construct to existing theories**

In this chapter, "adaptation", the all-encompassing concept is discussed, incorporating key concepts from existing theories in nursing and the human sciences.

- **Chapter 8: Summary, conclusions, recommendations, limitations and guidelines**

In this final chapter, the research process, the key findings, conclusions, recommendations and limitations are summarised; and specific guidelines proposed.

## **1. 16. CONCLUSION**

This chapter introduces the study and contextualises the research problem. In the second chapter, phenomenology, the methodological foundation of the study follows.

## CHAPTER 2:

### PHENOMENOLOGY: METHODOLOGICAL FOUNDATIONS OF THE STUDY

#### 2.1. INTRODUCTION

In this chapter, the methodological implications of phenomenology as a research approach and a philosophy is presented. Phenomenology was chosen based on Wojnar and Swanson's (2007:172) and Finlay's (2009:6) assertion that it is well suited to explore human phenomena that require understanding from the first-hand perspective of those who have experienced it, by returning to a fresh and rich description of the experience. The term "phenomenology" arose from the word "phenomena" which originated from the Greek word, *phaenesthai*, which, "means to flare up" or to "show itself". A phenomenon is therefore anything that presents itself to human consciousness (Moustakas 1984, in Dowling 2007:132). The related term "phenomenology" was introduced by philosophers Kant, Hegel and later Brentano, who intellectually motivated Husserl to develop phenomenology (Dowling 2007:132).

#### 2.2. ORIGIN AND ESSENCE OF PHENOMENOLOGY

Phenomenology originated from the disciplines of philosophy and psychology in the 20th century against the reductionist approach in the natural sciences, which tended to explore human phenomena independent of the person experiencing the phenomenon. Husserl thus sought to create a rigorous and unbiased approach to study 'things as they appear' in human consciousness to enable the inquirer to "come face to face with the ultimate structures of consciousness" or "essence" of the experience (Koch 1995:827). Husserl was interested in "essences" because he wished to turn philosophy into a process which could find logic, laws and absolute facts, grounded on a perfect method (Owen 1994:3; Smith 2011:2). Husserl wished that his method of inquiry would have no crises of its foundations, with no paradoxes arising along the way. He also desired that its method would be internally coherent, and based on unquestionable "self-evident truths" (Husserl 1981, in Owen 1994:3).

Phenomenology thus differs from other human science approaches like ethnography, symbolic interactionism (grounded theory) and ethnomethodology, largely because phenomenology makes a distinction between the “*appearance*” and “*essence*” of “*things*”, with emphasis on the “*first-person experience*” (Wertz 2011:52); to be achieved by aiming for truth, logic and rigorous self-critical thought (Owen 1994:18).

Phenomenological inquiry starts with what appears primarily in the first person’s consciousness (non-verbal awareness) and studies the overall relations of meaning that appears through sensation to verbalised thought, in definitive experiences, turning abstract philosophical ideas and imperatives into “*tangible*” object-directed (intentional) awareness and deriving specific meanings from these experiences (Owen 1994:20; Wertz 2011:52). Phenomenology concentrates on asking; “*what the nature or meaning of something is*” and demands the inquirer to look at the world “*as we meet it in the immediate experience*”. Unique to phenomenology is that it does not produce empirical or theoretical observations; rather it offers accounts (explanation) of experienced time, body, space and human relations as we live them, altered by our unique lived experiences (Van Manen 1990:184), which is the researcher’s key focus.

Stewart and Mickunas (1990) as explained in Creswell (2007:58) declare that the “phenomenological method” is grounded on the following presuppositions:

- *A return to the traditional tasks of philosophy*; which according to Owen (1994:18) and Creswell (2007:58) is a return to the search for wisdom. This re-orientation arose as a result of philosophy becoming limited only to exploring human phenomena through empirical means a practice called “*scientism*.” Wertz (2011:52) explains that Husserl developed phenomenological method on the premise that because human beings have the capacity for consciousness, humans are fundamentally different from the “material nature of the objects of science”, thus requiring investigative approaches that are different from those existing within the physical (hard) sciences (Flood 2010:8).

- *A philosophy without presuppositions*; meaning that phenomenology is founded on the assumption that investigating human phenomena requires “*suspension*” of all judgments about what is considered real (Creswell 2007:58). This suspension of pre-understanding is what Husserl calls ‘*epoche*’ of “*natural attitude*” (Wertz 2011:124). According to Flood (2010:9), Husserl believed that in order to bring out the essential components of a particular lived experience, the inquirer needed to shed all their prior knowledge about the subject to prevent their personal biases and preconceptions from unduly influencing the findings of the inquiry (LaVasseur 2003:409; Finlay 2009:6-7).
- *The intentionality of consciousness*; which means that phenomenology is grounded on the assumption that consciousness is always directed “outwards” towards an object, implying that human reality is inextricably related to one’s consciousness of it (Creswell 2007:59; Wertz 2011:52). This suggests that consciousness is always “*intentional*” and indivisible from its object and not self-subsisting (Husserl 1929/1973, as explained in LeVasseur 2003: 411).
- *The refusal of the subject-object dichotomy*, which means that the reality of an object is only perceived within the “meaning of the experience” from an individual’s perspective. Creswell (2007:59) explains that informed by the presupposition of intentionality, Husserl rejected the notion of Cartesian dualism of subject-object differentiation. This gave rise to the notion of reality as perceived by one being constructed in and out of the interaction between oneself and the social as well as the cultural context of the world in which one exists (Crotty 1998, in Flood 2010:8; Van der Zalm & Bergum 2000:212-214).

### **2.2.1. Definitions of Phenomenology**

The term “*phenomenology*” has been defined slightly differently by various scholars and is not always used in reference to the tradition begun by Husserl in European philosophy during the 20<sup>th</sup> century (Wertz 2011:52). In psychology, the word “*phenomenology*” has been used more broadly to characterise any work in research, theory, or practice that emphasises “*first-person*” experience, while in psychiatry; its

use often denotes “*descriptive knowledge of the symptoms of mental disorders*” (Wertz 2011:52). However, despite the divergent ways through which phenomenology is understood, it has become a credible approach for studying human consciousness and for clarifying the foundations of philosophy and science. The phenomenological method has thus continued to influence generations of scholars across disciplines in humanities, human sciences and arts (Wertz 2011:52).

In the context of this study, the term “*phenomenology*” is used to refer to the approach to knowledge, originated and strongly influenced by Husserl and other proponents who subscribe to his epistemological perspectives. In this regard, Wertz (2005:175) considers phenomenology as “*a low-hovering, in-dwelling, meditative philosophy that glories in the concreteness of person-world relations and accords lived experience, with all its indeterminacy and ambiguity, primacy over the known*”. This view is expanded in Wertz (2011:52), where phenomenology is elucidated as the “*knowledge discipline that investigates consciousness in both ordinary day life and in science, while emphasising the intentionality of consciousness, the self-transcending way that consciousness relates to other objects*”. In the context of the current research, the focal object is articulating the phenomenon of living in “*constant anticipation of Ebola and dealing with the outbreak as survivor and family caregiver*”.

According to Dowling (2007:132), phenomenology is a rigorous and unbiased study of things as they appear in consciousness in order to arrive at their ‘essence’. In like manner, phenomenology to Finlay (2009:6) is a “*return to embodied, experiential meanings, through methods that are responsive to both the phenomenon and the subjective interconnection between the researcher and the researched; aiming for fresh, complex, rich descriptions of experiences as concretely lived*”. Similarly, to Polit and Beck (2010:267), phenomenology is a method whose principal aim is to explore and understand people’s everyday life experiences, while Streubert and Carpenter (2011:73), consider it is a science that explores and describes the appearance of things or phenomena. In this regard, phenomenology thus refers to a descriptive human science methodology which seeks to pertinently explore and describe human phenomena in order to find hidden meanings and requires the researcher to assume an attitude of *openness* to let the unexpected meanings “*emerge*” (Mostert 2002:3-4).

## 2.2.2. Evolution of Phenomenology

The transformation of the phenomenological movement started from its origins in philosophy and psychology. This evolution according to Streubert and Carpenter (2011:75) progressed through three main developmental phases of the preparatory phase, German phase and the French phase, the explication of which now follows:

### 2.2.2.1. Preparatory phase

Streubert and Carpenter (2011:75) state that the preparatory phase of phenomenology was given prominence by the works of philosopher and psychologist, Franz Brentano (1838-1917), and his student Carl Stumpf (1848-1936). At this stage, as Cohen, Kahn and Steeves (2000:6-8) explain, Brentano wanted to make psychology, the precursor to phenomenology, a scientific discipline, whilst Stumpf used experimentation to discover the connection between the elements of human perception and thus founded experimental phenomenology. The primary focus at this point was mainly *clarification* of the concept of “*intentionality*” (refer to section 2.3.4).

### 2.2.2.2. German phase

Pringle, Hendry and McLafferty (2011:7) point out that the two prominent leaders during this phase are Edmund Husserl (1857-1938) and Martin Heidegger (1889-1976). Husserl advocated for philosophy to become a pure science that would restore deeper contact with human concerns and thus fronted the idea that phenomenology should become the ideal foundation for all philosophy and science (Dowling 2007:131-132). The focus of Husserlian phenomenology is epistemological (refer to section 1.10.2), emphasising knowledge generation from lived experience (Racher & Robinson 2003:465). Husserl believed that everyday lived experience as perceived by consciousness was valuable and that consciousness should be the primary object of scientific inquiry and human knowledge development (Lopez & Willis 2004:727-8).

Martin Heidegger, a student of Husserl, moved his idea that human consciousness equated to knowledge at a higher level. Racher (2003) as explained in Dowling

(2007:133) says that although Heidegger agreed with Husserl that phenomenology should focus on lived experience, he differed from Husserl's insistence on describing rather than understanding lived experience. Heidegger thus promoted the idea that the focus of phenomenology should move from knowledge generation (epistemology) to interpretation and meaning (ontology) of lived experience (refer to section 1.10.1). As Koch (1996:827) and McConnell-Henry, Chapman and Francis (2009:8) explain, for Heidegger, the focus of phenomenology should be deriving meaning and understanding from those who have had a particular lived experience first-hand. The concepts that emerged during this developmental phase are “*essences*” (section 2.3.5); “*intuiting*” (section 2.7.2.1) as well as “*reduction or bracketing*” (section 2.3.6).

### **2.2.2.3. French phase**

The predominant leaders of the French phase of the phenomenological movement are philosophers Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961). According to Treanor (2010:1-2), Marcel emphasised that philosophy should begin with concrete experiences rather than abstractions, while Sartre pursued philosophical reflection and literary creativity (Flynn 2012:2-3) and Merleau-Ponty concentrated on analysing concrete human experiences, perceptions, as well as difficulties of human existence (Flynn 2011:1-3). Furthermore, Merleau-Ponty is also acclaimed for championing the idea that human beings are their bodies and that because of lived experience, one cannot separate the mind from the body; and the object of a thought from the subject. The concept that emerged at this phase is “*embodiment*” or “*being-in-the-world*” (section 2.3.7).

## **2.3. PHENOMENOLOGICAL VIEW OF HUMAN NATURE**

The phenomenological view of human nature evolved as the philosophical movement progressed and have come to influence the process of phenomenological research. The concepts that emerged are “*lifeworld*”, “*lived experience*” “*consciousness*”, “*intentionality*”, “*essence*”, “*reduction*”, “*bracketing*”, “*embodiment*”, “*being-in-the-world*”, “*intersubjectivity*”, “*being-in-the-world-with-others*”, and “*hermeneutic circle*”.

### 2.3.1. Lifeworld

The concept “life world” is defined by Mostert (2011:2) as the “everyday world we live in, with all its’ taken-for-granted attitude, the world of lived experience. Van Manen (1997) as explained in Mostert (2002:2) quotes Husserl as describing lifeworld as “*the world of immediate experience*”, the world as “*already there*”! Lifeworld should thus be understood as the world as lived by a person, complete with worldviews, relations and experiences, within which one has lived experience and dwells (Mostert 2011:3).

### 2.3.2. Lived Experience

The term “*lived experience*” is described by Mostert (2011:2) as “*that which is lived by a person at a given time, in a given place, in their lifeworld. It is pragmatic and implicates the totality of life. It’s already there and is part of our awareness*” (Mostert 2011:2). Lived experience is central to phenomenology and without it there would be no phenomena to investigate (Mostert 2011:3). In support, Van Manen (1997) affirms that lived experience is very central and may be considered the starting point and the end point of phenomenological research (Van Manen 1997, cited in Mostert 2002:3).

### 2.3.3. Consciousness

The word “*consciousness*” is defined by Giorgi (1997, as cited in Mostert 2011:4) as being “*those things that present themselves in the lifeworld*”. Without being conscious of the presence of a thing, it cannot be part of the lifeworld of a person, and cannot be investigated. To explore a phenomenon in the lifeworld is to explore it first as it presents itself to consciousness within the context of the lifeworld (Mostert 2002:3-4).

### 2.3.4. Intentionality

The term “*intentionality*” is defined by Prim and Cunha (2006:2-5) as the “*inseparable connectedness of the human being to the world*”. It is the phenomenological concept that structures the relation between the person and the world. Van der Wal (2005, as cited in Mongwe 2007:37) clarifies that the term intentionality is not to be understood to mean intention or having good intentions, but rather it is the driving force that helps humans *know* what they intend to *know*. Intentionality means that if a person is angry

(object), then they are angry about something (subject), this is because conscious is always conscious of and directed at something concrete, implying that *“to be in a state of desire, implies something is being desired”* (Giorgi 1997, as cited in Mostert 2011:4). In view of this affirmation, it therefore suffices to note that the orientation to intentionality (object directedness) is not always conscious, but rather only available to human consciousness upon careful retrospective reflection (Mostert 2002:5-6).

### **2.3.5. Essence**

The term *“essence”* refers to the essential or core meaning of a “thing” before social and cultural meanings are attached to it (Mostert 2002:3). According to Van Manen (1997), *“essence”* is that which makes *“a thing what it is”, without which it would not be perceived “as is”*. In order to “discover the essence of an occurrence, the inquirer should begin by exploring the *“whatness?”* of the phenomenon, by asking, *“What it is like?”* to experience the phenomenon, and then proceed to the question, *“What is it like for me in my circumstances?”*(Van Manen 1997, as cited in Mostert 2002:3).

### **2.3.6. Reduction**

The term *“reduction”* or *“bracketing”* is defined as a return to the original awareness of the phenomenon under investigation (Streubert & Carpenter 2011:76). Husserl believed that bracketing would help researchers to achieve a state of *‘transcendental subjectivity’* which Wojnar and Swanson (2007:173) consider the state of consciousness where the researcher successfully abandons their lived reality and describes the phenomenon being investigated in pure form. This original awareness, Wertz (2005:168) maintains arises when the researcher adopts a *“phenomenological attitude”* characterised by two methodological procedures, referred to as *“epochés”*.

According to Giorgi (2008:41), *“epochés”* are *“cautions”* or *“abstentions”*, which help to shield researchers from undue influences that may short-circuit or bias their description of the experience in the purest possible form. The first is the *“epoché of the natural sciences”* (Husserl 1939/1954, as cited in Wertz 2005:168) which requires the researcher to set aside all knowledge that is not part of the phenomenon,

including scientific theories, explanations, hypotheses and conceptualisations and past knowledge, especially beliefs emanating from researchers' past experiences. This "*epoche*" facilitates researchers' access, "*to the things themselves (den sachen selbst)*", and requires one to identify prior knowledge and to put it out of play, making no use of it while listening to, interacting with and analysing the entire research data.

This first *epoche* delivers the researcher to the *pre-reflective* world, the "natural attitude", the pre-scientific life-world ("*lebenswelt*"), where there is unreflective (taken-for-granted) apprehension of the world, exactly as it is experienced in everyday life by participants (Wertz 2005:168). It is at this point that the second procedure, the "*epoche of natural attitude*" comes to play. As Wertz (2005:168) explains, it requires a transformation of the researcher's attitude from the "*natural (uncritical) attitude*", assuming every existence and taking "things" (situations) for granted, to one where, the researcher questions reflectively what different aspects of a lived experience mean for those who experience them. This second "*epoche*" allows the researcher to empathically enter and reflect upon the lived world of the other and apprehend the various meanings of lived experience as "*given*" to the participant (Wertz 2005:168).

### **2.3.7. Being-in-the-world (embodiment)**

The concepts "*being in the world*" and "*embodiment*" refer to the belief that all human acts are constructed on the foundation of perception or original awareness of some phenomena (Merleau-Ponty 1956, as cited in Streubert & Carpenter 2011:77). Munhall (1989), points out that "*being-in-the-world*" refers to the way human beings exist, act or are involved in the world; as a nurse or as a parent, while "*embodiment*" relates to the reality that "*one is aware of being-in-the world only through the body; that is, one gains access to the world only through their body; one feels, thinks, tastes, touches, hears and is conscious through the opportunities the body offers*" (Munhall 1989, as cited in Streubert & Carpenter 2011:77). Hence, *embodiment* and *being-in-the-world* imply that individuals cannot be defined as a separate entity, away from the way they relate to their world and with others (Todres & Wheeler 2001:3-4).

### 2.3.8. Being- in- the- world-with- others (intersubjectivity)

Anderson (1991:29) argues that the notion of *'being-in-the-world-with-others'*, means that humans make sense of the world and create meanings out of them through socially constructed approaches through on-going relations between people. Becker (1992:14) asserts that according to Heidegger, human beings should best be understood as *'being-in-the-world-with-others'* because any experience of oneself and another always occurs within an interpersonal framework. Cohen, Manion and Morrison (2000:84-90) agree that meanings of situations are constructed through a *dialectical* process that arises out of the interaction between people. Husserl expanded the notion of *being-in-the-world-with-others* to the concept of *transcendancy*, which implies that humans have a capacity for *self-awareness*. This means that *self-awareness* leads to *intersubjectivity*, the awareness that others have the same self-reflective ability. The awareness of the self, promotes awareness of others, which makes intersubjectivity basic to human understanding. In fact, Husserl (1989, in Duranti 2010:7) noted that self-consciousness and consciousness of the other is inseparable, meaning one's perception of a situation may be used to derive perceptions of others about the subject since meanings are derived intersubjectivity.

### 2.3.9. Hermeneutic circle of understanding

Hermeneutic circle of understanding is described as *"a process that moves forward and backward, never closing and final, uncovering the phenomenon through a rigorous interaction with the parts and the whole"* (Allen & Jensen 1990:245; Annells 2006:707). It refers to processes from which meanings are derived out of interactions between researcher and participants, working outward and backward from self to the event and from the event to the self (Allen & Jensen 1990:245; Dowling 2007:134).

In the thinking of Fry (2009:2-4), hermeneutic circle is the relationship of understanding between the reader and the text, manifested by the reader moving between parts and whole text, beginning with preconception about the whole experience from studying a part of the text, and then clarifying it by moving back to the whole experience again, and then back to the *"part"* already *"understood"* and

further returning to the whole text again, until a deeper understanding of the whole and the parts of the experience are achieved. This circular process involves the researcher constantly clarifying their understanding of the part and whole of the text as the reading and reflection continues. As the interpretative reading continues, the researcher's understanding of the whole and parts of the phenomenon is continuously challenged and clarified by the insights that continue to emerge as the researcher penetrates deeper into the lived experience accounts, revealing what lies hidden in the texts (Allen & Jensen 1990: 245; Dowling 2007:134-135; Fry 2009:4-5).

The processes resulting in "*hermeneutic circle of understanding*" have been referred to as the "*scientific phenomenological reduction*" (Giorgi 1997; Giorgi & Giorgi 2003, in Finlay 2008:11) and "reflexivity" (Finlay 2008:11; Van Manen 2011:1-2). To gain access to the essence of a phenomenon, the process of understanding requires the researcher to "*become fully and thoughtfully involved as if engaging in a dance of moving forward and moving back*" (Halling & Goldfarb 1991:328; Finlay 2008:11-12).

### **2.3.10. Reflexivity**

The term *reflexivity* can be understood as thoughtful evaluation of the intersubjective dynamics between the researcher and researched (Finlay 2008:3). It involves critical self-reflection of how the investigator's (researcher's) background, assumptions, position and behaviour impacts on the research process. A closely related concept of reflection involves '*thinking about*' something after the event. Hence through *reflection* or *reflexivity*, an immediate, dynamic self-awareness about an occurrence can be captured (Finlay & Gough 2003, as cited in Finlay 2008:3; Finlay 2009:12).

## **2.4. TRANSITIONS OF THE PHENOMENOLOGICAL MOVEMENT**

The phenomenological movement has transitioned over the centuries from emphasising only "*pure*" description in earlier (Husserlian) years to focusing on *interpretation* and later *embodiment* in the later years characterised by interpretation of people's experience (Lopez & Willis 2004:727; McConnell-Henry et al 2009:8; Van Manen 2011:1-2). This affirmation is supported by Lopez and Willis (2004:727) and Giorgi (2008:34) who maintain that Husserl's ideas about pure psychologism gave

rise to “*eidetic*” or “*descriptive*” phenomenology, the foundational premises from which the transition to “*interpretive*” phenomenology would later take place. This transition from “*pure description*” to “*interpretation*” was led by Heidegger (McConnell-Henry et al 2009:8), later, Gadamer and Ricoeur (Van Manen 2011:1). This change to interpretation emphasised “*bodyliness*” of human beings and led to emergence of the concepts of “*embodiment*” and “*being-in-the-world*” through the works of Marcel, Sartre and Merleau-Ponty (Streubert & Carpenter 2011:76; Van Manen 2011:2).

#### **2.4.1. Descriptive Phenomenology**

In descriptive phenomenology, the inquirer explores, analyses and describes phenomena as free as possible from presuppositions while maintaining the richness, breadth and depth of the experience, to gain “*a near-real picture*” of the phenomenon (Van der Zalm & Bergum 2000:212; McConnell-Henry et al 2009:7). Husserl was convinced that subjective experience is central to scientific investigation because human actions are influenced by what they perceive as being “*real*” to them and what is real is, *what is in consciousness* (Lopez & Willis 2004:727; Giorgi 2008:33). In order to grasp this reality, a researcher according to Husserl, should seek to obtain the content of human consciousness in a “*pure form*”, devoid of any *preconceptions*. This led to the notion of “*phenomenological epoche*” which is the Greek word for “*bracketing*”. This requires the researcher during the inquiry process to shed all their prior knowledge to grasp essential elements of an experience they are studying (Giorgi 2008:38; McConnell-Henry et al 2009:8; Streubert & Carpenter 2011:76-78).

Another assumption is Husserl’s belief in “*universal essences*” or “*eidetic structures*” which are claims of features of lived experience that are common to all human beings who have experienced a particular phenomenon (Lopez & Willis 2004:728). Husserl maintained that there is only one correct interpretation (“*universal essence*”) of lived experience regardless of the person’s history and context (Wojnar & Swanson 2007:173). This belief that ‘*essence*’ of lived experience could be abstracted without consideration of the context reflects the value of traditional science and was Husserl’s attempt to make phenomenology a rigorous science, consistent with prevailing tenets of the scientific paradigm to promote approval of these views (LeVasseur 2003:413).

### 2.4.2. Interpretive phenomenology

Interpretive phenomenology arose when Heidegger steered away from some of the views of Husserl and began to search answers to the *meaning of being* and to focus pertinently on gaining a deeper understanding of lived experience (Van der Zalm & Bergum 2000:212; Van Manen 2011:3-4). Although related to Husserlian descriptive phenomenology, interpretive phenomenology has distinct features that define how it guides inquiry. In support, Dowling (2005:133) and Van Manen (2011:3) concur that phenomenology becomes hermeneutical when its method and focus is *interpretive*; to attain deeper understanding rather than simply *describing* people's lived experiences.

This shift of focus to *interpretation* and *understanding* is evident in the work of Heidegger who argues that all description is always already an interpretation (Finlay 2008:8) and saw understanding as an inevitable basic structure of our being-in-the-world (Heidegger 1929/1962, in Finlay 2008:8). Heidegger championed the belief that human beings are *interpretive* by nature and are always trying to find significance and meanings in their lives influenced by the *context* in which they find themselves (Wojnar & Swanson 2007:174). Buttressed by this belief, Heidegger held the conviction that, understanding human beings should not occur in isolation of their culture, social context or the historic period in which they live. This belief implied that for the current study, the lived experiences of survivors and their family members should be understood from within the *local context* of each of the study participants.

Interpretive phenomenology was developed further by Heidegger's followers Gadamer, Ricoeur, Marcel, Sartre and Merleau-Ponty. Gadamer explored the role of language, nature of questioning, phenomenology of human conversation, significance of prejudice, historicity and tradition in human understanding (Van Manen 2011:4). Gadamer held the view that hermeneutic experience is made possible through language and therefore developed a distinctive and dialogical approach to phenomenology emphasising understanding from within the linguistically expressed perspective of tradition (Malpas 2009:2). Ricoeur's contribution to the hermeneutic discourse regards how meanings are deposited and mediated through myth, religion, art and language (Van Manen 2011:4). Key to Ricoeur, according to Dauenhauer and

Pellauer (2011:2) was the affirmation that human understanding comes through our relation to the world and our life with and among others in the world in which we live.

Marcel's is credited for insisting that philosophy "*speaks*" in ordinary language with a focus on concrete human experience. "*We should employ current forms of ordinary language which distort our experiences far less than the elaborate expressions in which philosophical language is crystallized*", Marcel emphasised (Marcel 1965, in Treanor 2010:2). Sartre explicated the notion of intentionality by insisting that human reality, which Heidegger called; "*being-in-the-world*" is primarily posited through its *ontological* concerns rather than its *epistemic* relationships (Flynn 2011:2). This means that for human beings what matters is what has "*meaning*" to them and not necessarily what may be considered as important aspect of *knowledge*. This assertion implies people live their lives concentrating on *meaningful* aspects of life.

Merleau-Ponty emphasised that phenomenology seeks to understand the relationship of human consciousness and the nature of being: whether biological, psychological or social (Flynn 2011:3). He held the view that consciousness meant existence in and toward the world through the body, experiencing the world through the possibility of our bodies (Van Manen 2011:1-2). He further clarified that phenomenological inquiry does not yield unquestionable or 'absolute' knowledge as earlier affirmed by Husserl.

Instead, Merleau-Ponty declares that the "most important lesson which the [phenomenological] reduction, [methodological process of researcher suspending prior knowledge], teaches us, is the impossibility of a complete reduction" (Merleau-Ponty 1945/1962, in Finlay 2008:10; Van Manen 2011:2) because humans are incapable of transcending pre-understandings which is key in knowledge generation.

### 2.4.3. Influence of descriptive and interpretive phenomenology on research

Whilst both approaches to phenomenology depend on lived experience and have a shared history, differences exist between the research methodologies in relation to:

- focus of the research study.
- role of prior knowledge in the research process.
- outcome and goal of the research process.
- value of context in the research process.
- application of knowledge generated within professional frameworks.

Lopez and Willis (2004:727) posit that these differences influence knowledge generation, including how findings are used to augment disciplinary understanding.

#### 2.4.3.1. Focus of the research study

Generally, descriptive phenomenology focuses on knowledge generation that emphasises *“direct exploration, analysis and description of a particular human phenomenon as free as possible from unexamined presuppositions, aiming at maximum intuitive presentation”* (Spiegelberg 1975, in Streubert & Carpenter 2011:81; Finlay 2008:12). In other words, descriptive phenomenology seeks to answer the question, “what is it like to undergo a particular experience?” In order to get a clear picture of what the experience is like, the researcher focuses on describing the experience in question as faithfully as possible so that others are able to “see” and “feel”, the first-hand experience, without the researcher articulating any information related to the social or cultural or political context of the person whose lived experience is being articulated (Van Manen 1990:184; Dowling 2007:132-133).

However, for the interpretive phenomenologist, the focus shifts to deeper understanding of the lived experience (Racher 2003, in Dowling 2007:133) and the process of inquiry concentrates on unveiling otherwise hidden meanings in the experiences (Spiegelberg 1975, in Streubert & Carpenter 2011:84). Interpretive phenomenologists *“attend”* to the individual for whom the experience has meaning.

McConnell-Henry and colleagues (2009:10) supplement that interpretive research departs from “*simply raising awareness about a phenomenon*”, by simply describing it; to “*attaining a broader and deeper understanding*” of what the phenomena means to those who experience them within their *social-cultural contexts* and *entire being*.

#### **2.4.3.2. Role of prior knowledge in the research process**

In descriptive phenomenological research, as Husserl advocated, the researcher is expected to shed and keep in abeyance all their personal knowledge related to the subject of inquiry (Giorgi & Giorgi 2003:249; Lopez & Willis 2004:727) through *bracketing*. Husserl believed that *bracketing* helps in achieving a state of ‘*transcendental subjectivity*’ which Wertz (2005:172) and Wojnar and Swanson (2007:173), say helps researchers to abandon their lived reality and glean the lived experience in question in its pure form. Wojnar and Swanson (2007:173) contend that it is this desire for “reduction” that has led some descriptive phenomenologists, albeit with opposition, to propose that researchers should withhold an *in-depth* literature review *prior* to investigation to prevent getting ‘*contaminated*’ with prior knowledge. Descriptive phenomenology attempts to ensure that researcher’s pre-understandings do not *creep* inadvertently into research findings (Dahlberg 2006:16; Finlay 2008:11).

However, within the interpretive framework, *pre-understandings* are not *bracketed* but rather become part of the research findings. This is based on the notion by Heidegger (1929/1962, as cited in Finlay 2008:8) that interpretation is an inevitable and basic structure of our being-in-the-world, implying that whenever an “*object*” is interpreted as “*something*”, such an interpretation is founded essentially upon the interpreters’ pre-understanding, because as Heidegger declares, “an interpretation is never a presuppositionless apprehending of something presented to us, rather, pertains to the whole of being-in-the-world”, thus bringing forth the impossibility of transcending the researcher’s pre-understandings (Heidegger 1929/1962, cited in Finlay 2008:8)

In corroboration, Lopez and Willis (2004:729) add that within the interpretive tradition, the researcher’s presuppositions are considered valuable guides and make inquiry a more meaningful undertaking. As Lowes and Prowse (2001, as cited in Streubert &

Carpenter 2011:85) posit, hermeneutic differs from other approaches because it does not require researchers to bracket their preconceptions during data analysis, but rather requires the researcher to exercise what Finlay (2003:108; 2008:15), Wertz (2005:172) and Van Manen (2011:1-2) describe as *openness, empathy and reflexivity*. In fact, Koch (1995:831) declares that it is *impossible* to rid one's mind of the background of understandings that led the researcher to undertake a particular inquiry. Heidegger is further quoted as saying there is no "*such thing as interpretive research, free of the judgement or influence of the researcher*" (McConnell-Henry et al 2009:9). Contrary to Husserl's belief that presupposition "*taints*" the research data (Paley 2005:111; Giorgi 2008:41), for Heideggerian researchers, pre-understandings are believed to facilitate deeper understanding of lived experiences (Flood 2010:10).

#### **2.4.3.3. Outcome of the research process**

In descriptive phenomenology, the outcome of research is arriving at what Husserl called "*universal essences*" or "*eidetic structures*" which are "pure" description of what an experience is without being unduly tainted by the researcher (Husserl 1936/1970:152, in Finlay 2008:8; Tymieniecka 2003, in Wojnar & Swanson 2007:174). Descriptive phenomenology Wertz (2011:124) clarifies, aims to "unveil" how a particular lived experience presents itself, with "nothing added and nothing subtracted", ensuring that the knowledge generated reflects the "*situation-as-experienced-by-participants-first-hand*". This is why Newstrom and Davies (2002:77) portray descriptive phenomenology as a form of inquiry that aims to accurately describe an experience and not generate theories or explanations about it, resulting in the description of "*what an experience is like*" (Giorgi 2008:34; Wertz 2011:125).

The process of generating "*pure description*" and the "*universal essences*" is facilitated by reduction and supported by the belief that there are features to any lived experience that are common or "given" to all persons who have had the experience (Lopez & Willis 2004:728; Giorgi 2008:38). Descriptive phenomenological inquiry, considers the researcher as an "*alien*" whose role is to grasp "*what something is*", from the first-hand ("I") perspective of those who experience it (Wertz 2011:52) and

then meticulously describe critical elements with emphasis on its “*individual*” or “*universal*” features as desired (Giorgi 2008:39; Streubert & Carpenter 2011:82).

In contrast, the goal of interpretive phenomenological research is to enter another’s world and to discover the wisdom, possibilities and understandings therein (Polit & Beck 2010:268). In agreement, Wojnar and Swanson (2007:175) explain that the goal of hermeneutic inquiry is to identify participants’ meanings from the blend of the researcher’s understanding of the phenomenon, participant-generated information, and data obtained from other sources (McConnell-Henry et al 2009:8). This “final product of inquiry” is what Flood (2010:10) describes as “*co-constitutionality*”; Gadamer, “*fusion of horizons*” (Fitzroy 2012:1) and is in turn comparable to Heidegger’s “*hermeneutic circle*” of understanding (Streubert & Carpenter 2011:85).

This understanding of the essential elements of the phenomenon described as “*fusion of horizon*”, “*hermeneutic circle*” and “*co-constitutionality*” occurs when the researcher’s horizon (consisting of social, cultural or interpersonal *views*) (Fry 2009:2) and the meanings attributed by participants *intersect* (Flood 2010:10), thus making *understanding* possible. Dowling (2005:134) posits that the hermeneutic process becomes a dialogical process as the horizon of the interpreter and that of participants is combined (“co-constituted”) to form the “*new meaning*” of the event.

In the view of Fitzroy (2012:2), to achieve ‘*fusion of horizons*’, the interpreter during the hermeneutic circle of understanding constantly questions and re-questions their fore-knowledge in an effort to *spawn* emergence of new perspectives specific to the phenomenon. In line with Brykczynski and Benner’s (2010:116) stance, interpretive research focuses on understanding socially situated meanings, habits and practices from within a person’s life world, thereby allowing common, taken-for-granted (or concealed) meanings and social practices to become more visible and intelligible (Spiegelberg 1975, in Streubert & Carpenter 2011:84; Lopez & Willis 2004:729-730).

#### 2.4.3.4. Value of context in the research process

Another difference between the two phenomenological methodologies relates to the concept of “*radical autonomy*”, which arises from Husserlian approach to knowledge generation. Plotka (2011:423) explains that for Husserl, human beings are free agents uninfluenced by the environment and culture in which they live, implying that, for him and his followers the impact of culture, society, and politics on the individual to choose and act does not matter (Lopez & Willis 2004:728). Accordingly, the environment in which a person lives is believed not to influence their lived experiences (Wojnar & Swanson 2007:174) and so researchers operating within this realm of phenomenology simply concentrate on describing the essential features of the phenomenon without paying attention to socio-cultural contexts of the people experiencing the phenomenon (Mackey 2005:183; Dowling 2007:132). Husserl also fronted the idea that this approach results in a *single* correct interpretation of lived experience because reality is understood as being objective and independent of history and context (Allen 1995, in Lopez & Willis 2004:728). Hence knowledge obtained within this philosophical framework extracts the essence of lived experience in a context free manner, consistent with the views of traditional positivist science.

In interpretive phenomenology, however, Heidegger and his followers conjure that human beings are inextricably linked to and embedded in their world (Mackey 2005:181) to such an extent that their subjective experiences are inevitably influenced by the social-cultural contexts in which they find themselves (Mackey 2005:183; Flood 2010:9). The thrust of knowledge generation thus shifts to explicating what the individual’s narrative about their life experiences imply in their circumstance (context) (Lopez & Willis 2004:729). It is for this reason that Benner (2001:39) advises that, the meanings of lived situations should be understood and interpreted within the context in which it is found. This context bound knowledge generation leads to what Todres and Wheeler (2001:4) refer to as “*positional knowledge*” or “*situated meanings*”, which requires the researcher to take into account lifeworld realities of time, space, relationships, body and culture and to elucidate these experiences within well-defined contexts while articulating lived experience (Van Manen 1990:101; Van der Zalm & Bergum 2000:212; Flood 2010:8).

#### **2.4.3.5. Application of the knowledge generated within professional disciplines**

A fifth difference between the two methodologies relates to how knowledge generated using either of them augments professional knowledge. According to Lopez and Willis (2004:729) because descriptive phenomenology results are knowledge that is context free and universal in nature, research efforts within this framework are largely geared towards understanding what it is like for a person or a group of people to experience a phenomenon. Hence professional knowledge is built by generating new knowledge about a poorly understood phenomenon so that others can know its “distinct” or “essential” elements to allow for a “generalised description” of the said phenomenon (Lopez & Willis 2004:728; Streubert & Carpenter 2011:82).

In contrast, hermeneutic phenomenology generates knowledge that may be used to describe a poorly understood lived experience but within the context of the person experiencing the phenomenon (Mackey 2005:183). It does not only generate new knowledge about the characteristics of a poorly understood phenomenon (whatness), but rather it goes into detail to obtain participant’s description of a typical experience, because the process of inquiry within interpretive realm requires the participants to explicate how the phenomenon affects their relations with others, experiences of their body, space and time in order to place the lived experience in the context of daily living (Smith 1987, in Lopez & Willis 2004:729). The approach thus generates knowledge that accurately pictures how a given experience affects people in their normal “landscape” of life as teachers, nurses or drivers (Lopez & Willis 2004:729). This contextual understanding hinges on Heidegger’s (1962) reiteration that people’s realities are invariably related to the world in which they live, since people cannot abstract themselves from their world (Heidegger 1962, in Lopez & Willis 2004:729).

In the present study, cognisant of these differences, an analytical (Wertz’s 1983/2011) approach that subscribes to both descriptive and interpretive elements of phenomenological inquiry was chosen. So that in addition to describing the “unique individual” and “universal” essences of participants’ lived experiences of constantly anticipating an Ebola outbreak, additional information would also be generated to understand the meanings of survivors’ and family caregivers’ experiences. The

interpretive aspects would also inform how these experiences influence their “*being-in-the-world*”, within the contexts of culture, their lifeworld existentials of time, space, body and relations as well as their personal, family, social, work and community life.

## **2.5. FOCUS OF PHENOMENOLOGICAL INVESTIGATIONS**

In literature and as affirmed by Finlay (2009:9), there are largely two broad areas of phenomenological inquiry: first, description of unique individual (*idiographic*) essences of lived experience and second; description of the universal (*general*) aspects of lived experience. These considerations that underlie both approaches have formed the basis for the contest between phenomenological investigators.

### **2.5.1. Focusing on unique individual essences of lived experience**

The principal aim of this approach is focusing on the individual uniqueness of lived experience. According to Finlay (2009:9), phenomenologists towing this line explicitly seek out *idiographic* meanings in an attempt to understand the individual which may or may not offer general insights. The emphasis on idiographic meanings is explicated by phenomenologists subscribing to the Interpretative Phenomenological Analysis (IPA) variant of phenomenology influenced by the interpretative and hermeneutic elements within the phenomenological movement, which according to Finlay (2009:9) has been popularised in the United Kingdom in recent times by scholars such as Smith and Osborn (2003); Finlay (2003); Ashworth (2006); Eatough and Smith (2006) and Finlay and Molano-Fisher (2008). This approach captures examples of convergence and divergence, as opposed to focusing solely on ‘*commonalities*’ in lived experience descriptions, deciphering valuable insight from first-person accounts of lived experience (Uprichard 2010:72,85; Pringle, Drummond, McLafferty & Hendry 2011:20-22). The core of IPA is investigating construction of meaning behind a phenomenon and seeing the person who has experienced the phenomenon first hand as “*expert*” and learning from them to better understand the experience from their own perspective (Uprichard 2010:72; Pringle et al 2011:21-22).

In essence, this form of phenomenological research aims to “learn” from individuals about their unique lived experiences, by investigating the similarities and differences regarding how people who experience the “same phenomenon” conceptualise the phenomenon (Uprichard 2010:72; Pringle et al 2011:21). Hence the focus here is explicating the unique individual experiences. Finlay and Ballinger (2006, as cited in Pringle et al 2011:21) explain that the focus of IPA is to explore individuals’ perceptions and experiences by concentrating on an *idiographic* approach, making sense of the personal experiences of the participants by focusing on their cognitive, linguistic, affective and physical being (Pringle et al 2011:21-22). The IPA framework thus seeks out only the idiographic meanings and attempts to understand an individual’s perspectives, without being keen on *general aspects* of the phenomenon. The implication of this approach is that the primary intention of the inquiry is not to offer general insights into a particular experience (Finlay 2009:9). Nowadays, the IPA is increasingly being used to explicate patients’ and health service users’ perspectives related to illness and health service provision (Pringle et al 2011:24-5).

### **2.5.2. Focusing on the essential and universal essences of lived experience**

This approach to phenomenology is championed by descriptive phenomenologists such as Giorgi (2008:36) and Wertz (2011:50-52) whose work is strongly influenced by the transcendental tradition of Husserl, where the focus is to throw light on both essential and general structures of phenomenon (Finlay 2009:9). These scholars concentrate on elucidating the “general structures” of lived experience; that is, aspects of the lived experience shared by many, by clarifying the nature of the phenomenon in a more traditional, normative and scientific sense. To do this, the phenomenologist starts by distinguishing single individual’s particular way of experiencing the phenomenon being investigated from a more general way that belongs to all people experiencing the same experience through the process of “*free imaginative and empirical variation*”. Then to arrive at the “general” aspects of the lived experience in question, the researcher obtains several “*individual*” descriptions in order to come up with a “*typical essence*” of the phenomenon (Giorgi 2008:37).

Typically this approach begins with constructs of several accounts of individual experiences and comparing them to one another for individual uniqueness as well as universal similarities (Van der Wal 2013:1). Then to arrive at general aspects of the experience, the researcher projects the idiographic analysis (individual) findings through imaginative and empirical variation processes to explicate the general sense of the phenomenon. This means that after identifying each participant's "*individual psychological structure*" of the experience, the researcher then moves beyond these particular individual instances of the phenomenon to "*general aspects*" of the phenomenon. In the context of this study, the experience varied from anticipating, experiencing and surviving Ebola as unique personal experiences to general aspects of anticipating, experiencing and surviving Ebola and related life threatening conditions. Explicating "*individual*" experiences of the phenomenon is consistent with the first-hand, "*I*" perspectives which grounds phenomenology (Wertz 2011:52). The "*general*" aspect of the experience agrees with Husserl's belief that such research should emphasise "*universal aspects*" of people's lived experiences. This is relevant because this study is partly informed by Husserlian perspectives (Finlay 2009:9-10).

By focusing on both individual and universal essences of lived experience, scholars such as Wertz (1985/2011) and Halling (2008, in Finlay 2009:10) have adopted a middle position by towing the line that phenomenology should emphasise both the particular (idiographic) and general (universal) aspects of lived experience, focussing more or less on individual or general aspects of the experience; depending on the level of generality or individuality the researcher would like to achieve as dictated by the research objectives. The scholars who espouse both aspects of lived experience argue that idiographic aspects of lived experience can also be considered general, because it is through these idiographic perspectives that general structures emerge.

Certainly, Wertz (2005) lays credence to this view by asserting that it is possible to move beyond particular '*individual*' instances to the '*general*', because "*what is generally qualitatively true is also necessarily evident in each individual instance encountered*" as long as the researcher goes through a series of procedures to establish general qualitative knowledge from individual psychological structures

(Wertz 2005:172-3). It is for this reason that Wertz's (1983, 2005, 2011) method was chosen so as to tease both idiographic and general aspects of the Ebola experience.

## **2.6. PHENOMENOLOGY AS A RESEARCH METHOD**

As a research method, phenomenology is principally concerned with elucidating first-person experience of a phenomenon (Wertz 2011:52). This focus on the "I" aspect of lived experience is underpinned on the notion that reality is best understood when "seen through the eyes" of those who experience a phenomenon first-hand. In explicating, first-person experience, the inquirer needs to focus on understanding what these lived experiences are like and what they mean to those who go through them (Vivilaki & Johnson 2008:86; Giorgi 2008:38; Streubert & Carpenter 2011:78). In order to ensure accurate conceptualisation of a first-person perspective of an experience, the researcher during the phenomenological investigation is expected to:

- conform to the tenets of phenomenology as philosophy and research method, throughout the process of data generation, analysis and reporting, ensuring that the study is appropriately descriptive, employs reduction, explores intentional relationships between persons and situations and discloses the essences of meanings engrained in the lived experiences using techniques such as imaginative/empiric variation and adopts phenomenological attitude and reflexivity (Giorgi 1989, in Wertz 2005:75; Finlay 2009:8; Wertz 2011:161).
- generate data that is narrative, rich and concrete (Wertz 2005:171), clearly reflecting accounts of lived situations rather than researcher's hypotheses, opinions and explanations of the phenomenon. The narrative data should reflect participants' first-hand accounts of what happened, how it happened and what the occurrence means to them in their contexts: as parents, teachers. This means that the phenomenological researcher seeks, explicates and derives meaning from first person accounts of a live experience, starting off with descriptions in everyday language (Wertz 2005:171; Wertz 2011:52).

### **2.6.1. Conducting phenomenological research**

The use of descriptive and interpretive variants of phenomenology as research method has continued to expand from initial beginnings in philosophy and human science disciplines, to its current usage in several disciplines such as nursing and healthcare, because of its suitability to describe lived experience meaningfully (Brykczynski & Benner 2010:113; Polit & Beck 2010:268; Streubert & Carpenter 2011:72). In practice, the specific analytical steps taken during an inquiry depends on whether the researcher is aligned along descriptive or interpretive frameworks.

In this study, I chose Wertz's (1983, 1985, 2005, 2011) Empirical Psychological Reflection (EPR) research approach, as explained in detail in section 5.4. Although this analytical approach is linked to the Duquesne tradition and inspired by Husserl's descriptive phenomenology, it has evolved over the years to include features that are consistent with general hermeneutic phenomenological research principles such as those advanced within Ricoeur's (1976) hermeneutic-phenomenological philosophy.

Wertz's (1983/2011) research framework was chosen because its detailed approach to inquiry allows the researcher to capture both "*unique individual*" experiences as and "*general aspects*" of lived experience (Wojnar & Swanson 2007:177) at the same time, allowing for examination of *contextual features* of these experiences in embodied, relational and temporal ways, in this case as lived by survivors and family caregivers, to promote deeper understanding (Koch 1999:21-22; Benner 2001:40).

#### **2.6.1.1. Wertz's (1983/2011) Empirical Psychological Reflection Approach**

Wertz's (1983/2011) analytical framework consists of three specific phases of reflection. The researcher is required to adopt a specific attitude or stance while performing the methodological procedures or research activities in each phase. These three phases of reflection are followed by the fourth phase, phenomenological describing or writing (Giorgi 2009, as cited in Wertz 2011:132; Wertz 2011:131).

### 2.6.1.1.1. Phases of Empirical Psychological Reflection

The empirical psychological reflection proceeds through the four phases of:

- constitution of revelatory descriptions (open reading).
  - psychological analyses of the individual (idiographic analysis).
  - psychological analysis of the general (nomothetic analysis).
  - structural understanding and description (comprehensive understanding).
- **Constitution of Revelatory Descriptions (Open reading)**

This first phase of data analysis according to Wertz (1985:164) aims at generating well-organised description of the lived experience, expressed in everyday language of each participant. Also referred to as “*data cleaning*” or “*open reading*” phase, it consists of several steps, where the researcher reads entire transcripts to get sense of the whole (Wertz 2011:131) and culminates in exclusion from each transcript all irrelevant data from the interview, leaving only those statements that reveal the experience *precisely* as it occurred as explicated in further detail in section 5.4.1.1.

This first step is consistent with principles of general hermeneutic research enterprise, which begins with the researcher reading the text as whole to gain an impression of the whole text, followed by formulation of thoughts about its meaning (Streubert & Carpenter 2011:85). This phase that culminates in the documentation of the researcher’s general “*impression of the text*” is what scholars of the general hermeneutic phenomenological movement (Lindholm, Uden & Rastam 1999:103; Lindseth & Norberg 2004:149; Bäckström & Sundin 2007:246) term “*writing the interpretative summaries of individual interviews and coding for emerging themes*”.

In this phase of data analysis, all interview data were individually reviewed to gain a “better sense” of the phenomenon of anticipating, experiencing, surviving and living after an Ebola outbreak. This initial reading, termed “*open reading*” (Wertz 2011:131) or “*naïve reading*” (Bäckström & Sundin 2007:246), focused on how survivors and family caregivers perceived Ebola, including what they thought people’s reaction towards them symbolised, including how it affected their everyday lives. These *initial*

*impressions*' of the lived experience were documented and discussed with the thesis promoter (advisor) who served as external expert and quality checker. This process led to several discussions and modifications until agreements were reached about each meaning unit. At this point, I then moved to detailed analysis of each transcript.

- **Psychological Analyses of the Individual (Idiographic Analysis)**

This second phase of analysis, referred to as the procedure of "*intentional analysis*", in Wertz (2005:172; 2011:126) is a reflective process which involves the researcher carefully reading each revelatory description (clean description), in order to arrive at what Wertz (2011:142) terms "*Individual Psychological Structure*" (IPS) of the phenomenon. This step involves the researcher empathetically immersing in and reflecting deeply upon each participant's revelatory description (Wertz 2005:172; 2010:272; 2011:126), the specific details of which are presented in section 5.4.1.2. This second step is consistent with general hermeneutics' *structural analysis* or *thematic analysis* step (Lindseth & Norberg 2004:150) and involves identifying patterns of meaningful connections through "*interpretive reading*" (Streubert & Carpenter 2011:85). This is what Wertz (2011:131) describes discriminating "*meaning units*", that is, segments of the description that are relevant to the research interests and whose size and content lend themselves to fruitful analytic reflection to answer the research question, which upon further reflection, results in themes (Lindseth & Norberg 2004:150; Wertz 2011:132). As advocated in Wertz (2011:132), the researcher posed to each meaning unit specific research questions and reflected upon them in-depth to identify and document unique aspects of each experience.

- **Psychological Analysis of the General (Nomothetic Analysis)**

The third phase of data analysis as Wertz (1983:227; 2011:132) explains, involves further psychological reflection to learn and portray the lived experience in "*general*" terms. This required the researcher to move from the "*psychology of individual experience*" to the "*psychology of the experience in general terms*", that is, across individuals and circumstances with similar attributes. This phase culminates into "*General Psychological Structure*" of the experience (Wertz 1985:188; 2011:150).

In the context of this study, the unique individual aspects of the phenomenon which each meaning unit revealed were explicated through the reflective processes of “free imaginative variation” (Wertz 2011:132) and “empirical variation or reflection” (Van der Wal 2013:1). This entailed keeping in mind the various contexts of survivors and family caregivers, and reflecting upon them deeply until “*general knowledge*” about the phenomenon emerged from each meaning unit as explained in section 5.4.1.3.

- **Structural understanding and description (Comprehensive understanding)**

The fourth step, which Wertz (2011:132) refers to as *structural understanding and description* phase, involves integration and description of insights that were gained during reflections on the meaning units. This final step entails meaningful organisation of the investigated psychological phenomena as a “*structural whole*”. This concept is referred to as “*comprehensive understanding*” in general hermeneutic research tradition (Lindseth & Norberg 2004:150; Bäckström & Sundin 2007:244). Here the researcher reflects on the themes in relation to the research questions and the study context, to generate comprehensive understanding of the experience (Bäckström & Sundin 2007:244; Wertz 2011:132). The phase culminates in presentation of a holistic and comprehensive view of the experience, gleaned from reflections during open reading and in-depth reflection of the themes (Lindseth & Norberg 2004:150; Bäckström & Sundin 2007:244; Giorgi 2009, as cited in Wertz 2011:131; Wertz 2011:132). The details of this phase are articulated in Chapter 6.

#### **2.6.1.1.2. Basic stances or attitudes during empirical psychological reflection**

To facilitate meaning making and theme identification process, Wertz (1983:204; 2011:132) advocates that the researcher should adopt five (5) basic stances or attitudes throughout the idiographic and nomothetic levels of data analyses, through:

- empathic immersement in the situations described.
- slowing down and dwelling in each moment of the data.
- magnification and amplification of the situation as experienced.
- suspension of belief and employment of intense interest in experiential detail.
- turning from objects to personal and relational meanings and significance.

Details of how each of the five stances was observed are discussed in section 5.4.2.

### 2.6.1.1.3. Specialised procedures of empirical psychological reflection

To arrive at unique individual or general essence of lived experience, Wertz (1983:206; 2011:132) clarifies that the researcher needs to engage in several active operative procedures throughout idiographic and general levels of data analyses. The entire analysis phase consists of 15 procedures, 11 of which are utilised during the individual level of analysis phase to obtain unique individual aspects of the experience; then, more 4 steps are engaged during general level of analysis, where general elements of the phenomenon are identified, as highlighted in section 5.4.3.

### 2.6.2. Presentation of the research findings

The findings as presented in Chapter 6, were arrived at through classifying all critical elements in survivors' and caregivers' lived experience accounts and then describing each of them, singularly, on their own, and then, within the context of their relationship to one another (Streubert & Carpenter 2011:82; Wertz 2011:160). These findings were presented from the view point of the "unique individual experiences" as well as from "general or invariant aspects" of the phenomenon. This analytical step was influenced by Van Manen's (2011:2) recommendation that lived experience accounts should be presented in an evocative, expressive, transcendent and poetic manner, for the reader to grasp both the "facts" and "emotions" associated with it.

As Van der Zalm and Bergum (2000:212) put it, the "*facts*" related to the phenomenon served as building blocks of "*new knowledge*" about the lived experience, while the "*emotions*" help to create in the reader's mind, a "*phenomenological reverberation*" to enable them to 'see' the Ebola experience from the "*eyes, skin and heart*" of those affected first-hand. This writing was also meant to ensure that the lived experience descriptions resonated buoyantly with participants and that they could be validated through mutual recognition by those closely involved with the experience: survivors, caregivers and the community (Creswell 1998:289).

To add to vividness of the findings, I included "raw interview data", into the final descriptions, by incorporating participants' verbatim expressions to enable readers to follow various aspects of the lived experience (Wertz 2011:161; Van Manen 2011:2).

Therefore, by making references to concrete participant situations (data units) and the different contexts of their lifeworld situations, the researcher “opened” a window into the survivors’ and family caregiver’s lifeworlds. This allowed the researcher to provide the reader intuitive understanding of survivors’ and family caregiver’s lived experiences by presenting features of the original knowledge, that is “*the things themselves*”, which Husserl terms, *den Sachen selbst* (Wertz 2011:161). This was facilitated by the use of relevant variants of ordinary everyday language so that the lived experience descriptions are more understandable and meaningful to others.

## 2.7. MOTIVATION FOR SELECTING PHENOMENOLOGY

The following factors explicated by scholars Koch (1999:22), Finlay (2009:6), Polit and Beck (2010:267) and Wertz (2011:124), as well as Streubert and Carpenter (2011:72), motivated the researcher to employ a phenomenological method to illuminate the phenomenon of living in constant anticipation of an Ebola outbreak:

- Phenomenology is a descriptive, qualitative study of human experience that attempts to faithfully conceptualise the processes and structures of mental life including meaningful ways the world is given through experience. The aim is to provide descriptive and meaning-oriented knowledge that reflects *situations-as-experienced* (Wertz 2011:124). This method allowed clarification of the Ebola experience by clearly documenting in everyday language what the survivors and caregivers experienced before, during and after the epidemic.
- Phenomenology, a rigorous, critical, systematic method of investigation is a recognised qualitative research approach applicable to the study of phenomena important to nursing (Streubert & Carpenter 2011:72). The phenomenological method brings to language perceptions of various human experiences, especially poorly understood phenomena, like living in constant anticipation of an outbreak. This research approach was chosen to study the lived experiences of survivors and family caregivers as a strategy to understand salient issues related to the human side of such devastating

diseases so that these perspectives may inform decisions, enrich patient care and serve to improve the overall epidemic response during future epidemics.

- Phenomenology investigates subjective phenomena in the belief that critical truths about reality are grounded in people's lived experiences (Polit & Beck 2010:267). This study that is geared towards a clearer and a broader understanding of human experience of suffering in this case, anticipating, experiencing and living after an Ebola outbreak, falls within the "*realm*" of human knowledge inquiry scrutinisable using a phenomenological approach.
- Phenomenology provides researchers opportunity to "return to embodied, experiential meanings aiming for a fresh, complex, rich description of a phenomenon as it is concretely lived" (Finlay 2009:6). The rich descriptions of lived experience accounts evoke in the reader "*impressions*" of the phenomenon and through the shared meanings we have as humans, different people may come to understand what it means to experience a particular phenomenon. The method thus provided the rich descriptions that will help to broaden people's current understanding of the human side of Ebola outbreaks.
- Phenomenology provides nursing (healthcare) the possibility for improving care or understanding issues critical to nurses themselves and the nursing clientele as individuals, families and the larger community. Koch (1999:22-24) maintains that phenomenological inquiry augments nurses' understanding of patients' life experiences and their interpretation of such experiences. Therefore, a clear understanding of the meaning and the relevance of lived experience consolidates nursing's position to foster the well-being of clients who often require health care in unfamiliar and complex situations. This reality makes phenomenological research approach attractive for nurse researchers.
- Streubert and Carpenter (2011:94) add that phenomenology offers the opportunity to describe and clarify phenomena that better inform nursing education, research and practice. These perspectives have continued to provide impetus for evidence-based practices within nursing, thereby

promoting advancement of nursing education, management and practice. Jasper (1994:313) as cited in Streubert and Carpenter (2011:94) explains that the relevance of phenomenological method for nursing is that it supports new initiatives for nursing care especially where the subject matter is not amenable to other investigative and experimental methods as in the natural sciences. The phenomenological method provides a credible approach through which phenomena pertinent to nursing can be explored, analysed and documented.

## **2.8. CONCLUSION**

Phenomenology is a fundamental field of inquiry in nursing. As a research method, phenomenology aims at elucidating human experience by bringing to language human experience. Phenomenology has developed from the works of philosophers Brentano, Stumpf, Husserl, Heidegger, Merleau-Ponty, Gadamer and Ricoeur among others. Central to the phenomenological movement are concepts such as intersubjectivity, embodiment, being-in-the-world, intentionality, essence, lived experience, reduction, bracketing, fusion of horizons, fore structures, hermeneutic circle and interpretation. As the philosophical movement transformed over the years, and across continents, two forms of phenomenology have come to dominate the research platform: descriptive phenomenology and interpretive phenomenology, both of which have as their central goal description of lived experience (Streubert & Carpenter 2011:94). Phenomenology is thus the most suited method for this study.

In Chapter 3, literature relevant to this study is presented and discussed pertinently.

## CHAPTER 3: PRELIMINARY LITERATURE REVIEW

### 3.1. INTRODUCTION

Literature review refers to a systematic search of existing information about a phenomenon being studied and entails reviewing and summarising existing evidence (Polit & Beck 2010:558). In qualitative research, some authors suggest that literature review should be done only after data analysis (Streubert & Carpenter 2011:25), claiming that it contributes to bias and unduly interferes with pure description of the phenomenon. However, I share Creswell's (2005:79) opinion that preliminary review of literature is essential because it helps to focus and give direction to the study. Streubert and Carpenter (2011:25) also hold the view that reviewing related literature prior to data collection helps to refine the research question, select a theoretical framework and build a case for why and how the study will be conducted. Streubert and Carpenter (2011:25) add that post hoc review of literature helps the qualitative researcher to place the findings of the study within the context of the already "known".

Creswell (2005:79) considers review of literature before, during and after data collection vital to ensure that the research reflects current knowledge in the area and incorporates what others have done to enrich the process and outcome of a study. Polit and Beck (2010:170) too are of the opinion that literature review provides readers with background for understanding current knowledge about the phenomenon and to illuminate the significance of the study. I settled for preliminary literature review, prior to data collection to give direction for the study followed by thorough review of literature following data analysis as Streubert and Carpenter (2011:25-26) advocate. Moreover, Van der Wal (1999) as cited in Mongwe (2007:51) thinks that reviewing literature early in the study facilitates the researcher's entry into the first moment of the research process; that is identification of the phenomenon and how to articulate it. I countered the "investigator bias" that is believed to arise by engaging in preliminary review of literature through reflexivity. This was achieved by remaining aware of these "*pre-understandings*" and *open* to participants' ideas. The post hoc literature review helped in placing the findings in context of what is known.

### **3.2. GUIDING FRAMEWORK FOR LITERATURE REVIEW**

The literature review begun with synthesis of pertinent and most recent information on Ebola virus and the haemorrhagic syndrome. The effects of socio-cultural perspectives related to life threatening disease on individuals and families were explored, including life experience accounts of life threatening and highly stigmatised conditions. The review ended with coping strategies and needs of affected persons.

The search of literature was mainly internet based using the UNISA electronic library repertoire and other resources including those suggested for qualitative research in the UNISA Department of Health Studies, Tutorial letters MNUALL-L/301/2006 and MNUALLL/301/0/2012. The researcher also used CD-ROMS and online databases like CINAHL, MEDLINE, Scopus, Ovid and PubMed to review e-books, journal articles in nursing, public health, mental health, medicine and infectious diseases. Literature came from print books, master's dissertations and doctoral theses, as well as from newsletters and newspapers. This information was carefully analysed for relevance and meaningfulness, summarised and then categorised to focus the study.

### **3.3. EBOLAVIRUS AND THE HAEMORRHAGIC SYNDROME**

This section enunciates the classification, morphology, infection process, natural ecology and method of transmission of Ebola virus and global epidemic patterns of outbreaks including diagnostic criteria, pathogenicity, clinical features, immunology and current therapeutic and epidemic management and containment strategies.

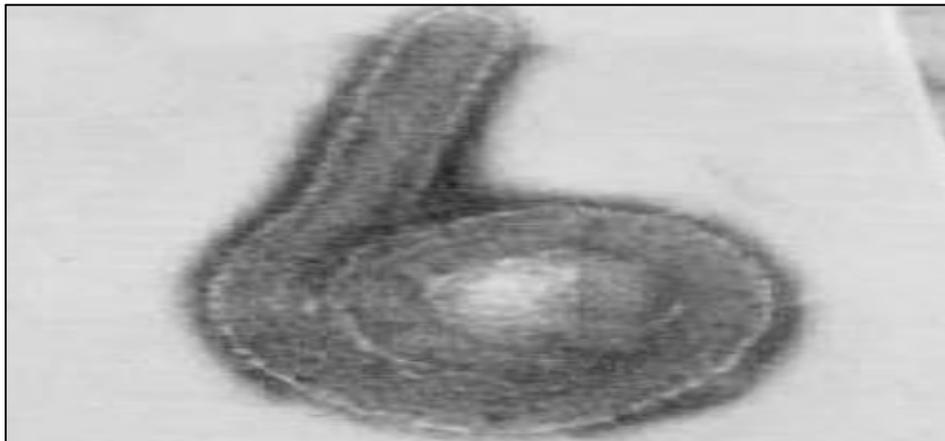
#### **3.3.1. Classification and taxonomy**

The Centres for Disease Control and Prevention, (CDC) (2010:1-2) classifies Ebola virus as Biosafety Risk Group 4 agent, (refer to section 1.14.11), the highest scale of biosafety rating, due to the high health risk it poses for laboratory personnel and the public. Sanchez, Geisbert and Feldmann (2007:1409) point out that Ebola is a lipid-enveloped, single, negative stranded Ribonucleic Acid, RNA virus, of the genus *Ebola* in the family *filoviridae* and order *Mononegavirales*. According to WHO (2012:1-2) and Qiu, Fernando, Melito, Audet, Feldmann, Kobinger, Alimonti and

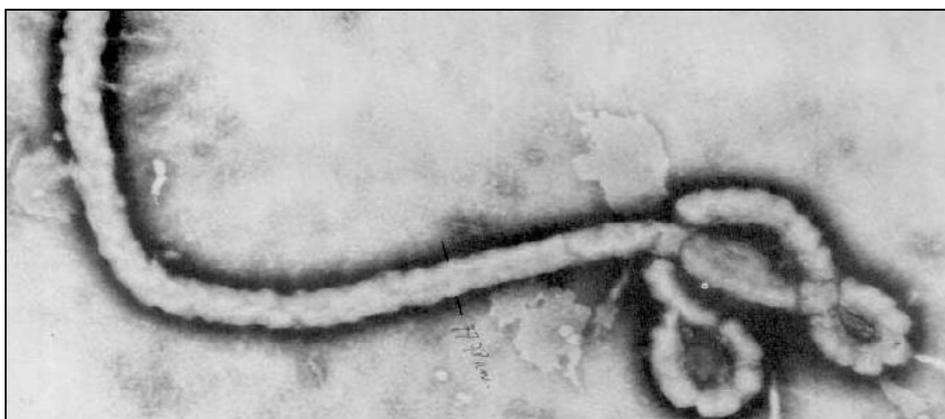
Jones (2012:1575), Ebola and Marburg viruses are the only filoviruses that cause severe haemorrhagic fever syndrome in humans and non-human primates such as monkeys and chimpanzees. When compared, the CDC (2012:1-3) confirms that to date (January 2013), Marburg virus consists of only one specie whilst Ebola virus comprises five species including Bundibugyo Ebolavirus (BEBOV), Zaïre Ebolavirus (ZEBOV), Sudan Ebolavirus (SEBOV), Reston Ebolavirus (REBOV) and Tai Forest Virus (TAFV, formerly, Cote d'Ivoire Ebolavirus (CIEBOV). All these Ebola virus subtypes are named after the country or location in which the virus was first isolated.

### 3.3.2. Morphology

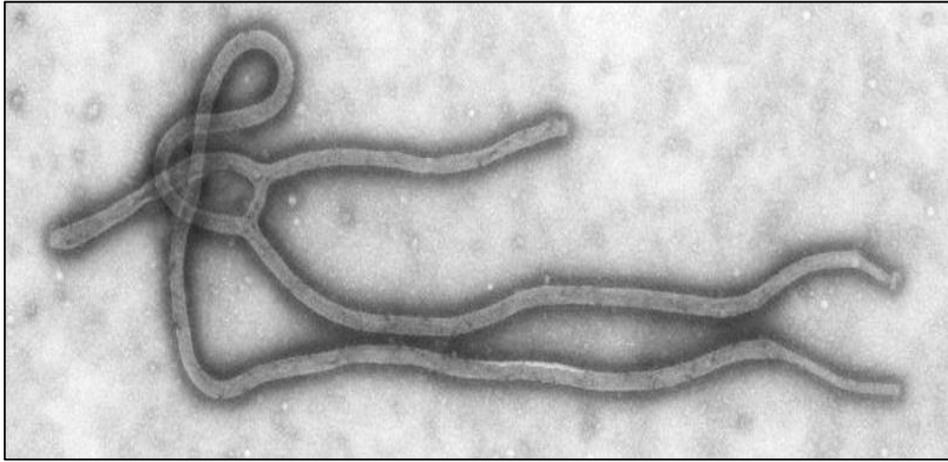
In innate states, Ebola viruses are filamentous and pleomorphic and often take on different shapes; may be long filaments, branched, 'U'- shaped, '6'-shaped or circular forms (Leroy et al 2011:964) as shown in figures 3.1, 3.2 and 3.3. Generally, Ebola virus particles have a uniform diameter of 80 nm but vary in lengths up to 14000 nm (Sanchez, Geisbert & Feldmann 2006:1409-1410; Feldmann & Geisbert 2011:849).



**Figure 3.1. A figure “6” form of the Ebola virus filament (Pattyn 1978:70)**

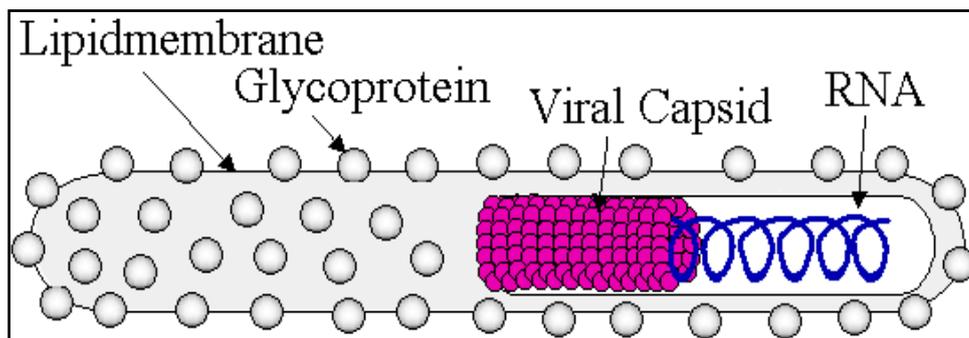


**Figure 3.2 A filamentous form of the Ebola Virus (Pattyn 1978:69)**



**Figure 3.3 A branched form of the polymorphic Ebola virus (CDC 2008:2)**

Structurally, Sanchez, Geisbert and Feldmann (2006:1409-1412) describe Ebola viruses as consisting of three layers: a surface glycoprotein layer, a lipid membrane envelope and internal tubular helical nucleocapsid as shown in figure 3.4.

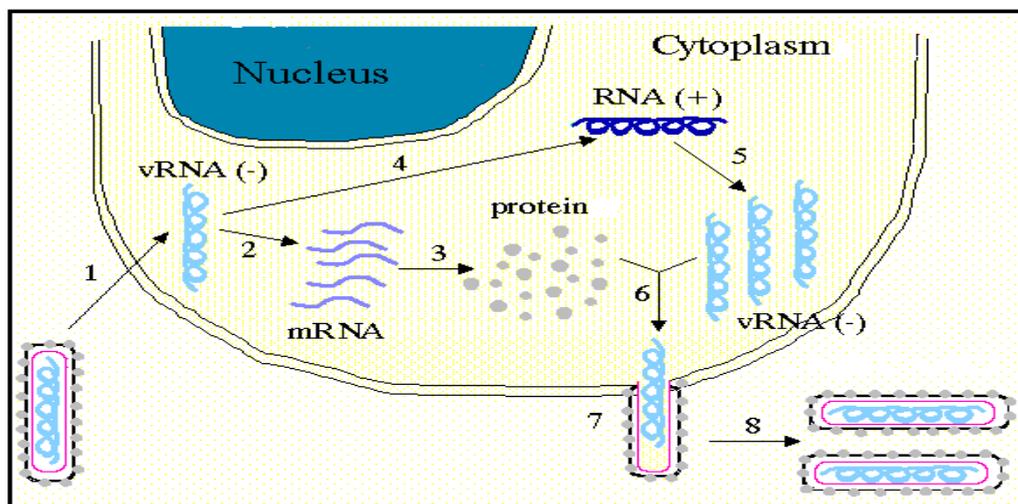


**Figure 3.4 Diagrammatic representation of Ebolavirus layers (Waterman 1999:2)**

According to Feldmann and Geisbert (2011:849), the surface layer of Ebolavirus consists of glycoprotein spikes about 7-10 nm long, spaced at approximately 10 nm intervals. These glycoprotein spikes enhance virus entry into the host cell, acting as mediators for receptor binding and membrane fusion. The outer lipid membrane envelope (Sanchez, Geisbert & Feldmann 2006:1409-1412) surrounds the internal helical nucleocapsid, while the inner most layer of the virus consists of a complex helical nucleocapsid structure and houses the negative stranded viral genome which controls viral replication (Qiu, Fernando, Melito, Audet and Feldmann 2012:1575-6).

### 3.3.3. Infection of host cell and viral replication

Wool-Lewis and Bates (1998:3155-3160) explain that Ebola infects different cell types including macrophages, fibroblasts, hepatocytes and endothelial cells mediated by the glycoprotein spikes leading to endocytosis, the process by which cells engulf molecules and other biological particles. According to Volchkov (1999:36), Weissenhorn, Carfi, Lee, Skehel and Wiley (1998:605) and Richardson, Dekker, Croyle and Kobinger (2010:439) as the engulfed virus replicates, the continuous budding of the virus particles eventually destroys the host cell as shown in figure 3.5.



**Figure 3.5 Schematic expression of Ebola virus replication (Waterman 1999:3)**

The process of viral replication as affirmed by Yang, Delgado, Xu, Todd, Nabel and Sanchez (1998:1036) is mediated by synthesis of a positive RNA strand that serves as a template for synthesis of additional viral genomes. As replication continues, the cytoplasm of the host cell develops “inclusion bodies”, which are small particles containing new viral nucleocapsids, which later assemble, eventually budding off as new viruses as they attain their outer lipid membrane from the infected host cell membrane, killing them (Takada, Robison, Goto, Sanchez, Murti, Whitts & Kawaoka 1997:14764-14769). In fact, Noda, Sagara, Suzuki, Takada, Kida and Kawaoka (2002:4855) explain that as the process of budding off of newly formed virus particle continues, the host cell breaks apart and as this continues, a cascade of related events may be triggered ending up triggering the lethal haemorrhagic syndrome.

### 3.3.4. Ecological and geographical distribution of Ebola viruses

Feldmann and Geisbert (2012:3) classify Ebola haemorrhagic fever as a classical zoonosis, because of its ability to be transmitted naturally from vertebrate animals to humans and vice-versa. The CDC (2010:1-4) confirms that despite the fact that non-human primates have repeatedly been a source of infection for humans, the natural reservoir of the virus still remains unknown. In the past, rodents have been named by Morvan, Deubel, Gounon, Nakouné, Barrière, Murri, Perpète, Selekon, Coudrier, Gautier-Hion, Colyn and Volehkov (1999:1193) as being the natural reservoirs, and more recently, bats have been implicated by Leroy, Kumulungui, Pourrut, Rouquet, Hassanin, Yaba, Délicat, Paweska, Gonzalez and Swanepoel (2005:575) as well. Similarly, evidence of Zaire Ebola virus in naturally infected fruit bats has been documented by Pourrut, Délicat, Rollin, Ksiazek, Gonzalez, Leroy (2007:176), and Leroy and others (2005:575) following detection of viral RNA and antibodies in three tree-roosting species: *Hypsignathus monstrosus*, *Epomops franqueti*, and *Myonycteris torquata*. However, despite these efforts, Feldmann and Geisbert (2012:3) confirm that to date (December 2013) the Ebolavirus has not been isolated from any naturally infected animals. What is clear is that the virus is endemic in rain forests of Africa and the Western Pacific region and that like humans, non-human primates get infected directly from 'unknown' natural reservoirs (Schnirring 2008:2).

In recent times several studies have been conducted to identify the natural reservoir of both Ebola and Marburg virus. This is in keeping with Feldmann and Geisbert's (2012:3) report that laboratory observations in Uganda showed that some bats infected experimentally with filoviruses do not die, raising the possibility that they may be the natural reservoirs. This discovery, as reported by Ampaire (2007:16) and Bogere (2007:5) led scientists to engage in a large scale effort to test African fruit bats in south-western Uganda. The study involved collecting blood and organ samples from the fruit bats from their habitats in the gold mines and caves in the region and then analysing the specimen in the laboratory as in figure 3.6. These laboratory findings according to the WHO (2007:1-2; 2012b:2-4) corroborate earlier findings in Gabon and the DRC on similar bat species, further augmenting the claim that the African fruit bats of the *Pteropodidae* family may be natural host of filovirus.

Fabiansen, Kronborg, Thybo and Nielsen (2008:3949-3952) concur because the liver and spleen samples that tested positive for Marburg virus genes were analysed using the highly specific Reverse Transcription-Polymerase Chain Reaction method.



**Figure 3.6. Simon Wakaalo, UVRI and Pierre Rollin, CDC, collecting bat specimens**

(Source: [http://www.who.int/features/2007/marburg\\_fever/photo\\_story/en/index8.html](http://www.who.int/features/2007/marburg_fever/photo_story/en/index8.html)).

Similar field investigations in Gabon and DRC according to Towner, Pourrut, Albarino, Nkogue, Bird, Grard, Ksiazek, Gonzalez, Nichol and Leroy (2007:1-5), proved that one of the bat species, the African fruit bat *Rousettus aegypticus* naturally carries the Marburg virus. It was concluded that the African fruit bat or closely related species may be responsible for maintaining the virus between epidemics. This implies a high risk for more areas to experience Ebola outbreaks in future because these bats are found across Sub-Saharan Africa (Leroy et al 2005:2).

### **3.3.5. Method of transmission of Ebolavirus**

The primary mode of transmission from the natural reservoir to humans or primates remains unknown according to the CDC (2010:1-2) although most outbreaks appear to be zoonotic. However, the Centre for Infectious Disease Research and Policy, CIDRAP (2009:1-3) notes that despite being zoonotic, filoviruses are neither spread continuously from person to person nor do they remain latent in primates. The main secondary mode of transmission from person-to-person has been nosocomial infection starting with contact with blood and body fluids from an infected person.

WHO (2008:2) also documents that infection occurs through direct inoculation from contaminated instruments and infected droplets via mucous membranes, in addition to the cases of secondary infection to humans after handling primates (CDC 2008:2).

In hospitals, the CIDRAP (2009:1-4) reports, that health workers may become infected while treating patients through close contact, especially when they don't use proper precautions or barrier nursing. In community settings, Lamunu and colleagues (2002:4) report that burial ceremonies especially funeral rituals are key in spreading the virus, particularly where direct contact is made while fulfilling cultural burial rituals involving deceased relatives. Once infected, the CDC (2009:1-2) reports that the incubation period ranges from 2 to 21 days and as the infection progresses, patients become contagious, especially after developing the early signs and symptoms of the disease - particularly high grade fever and severe headache. Generally, larger outbreaks have tended to occur after infected patients enter healthcare systems where barrier nursing and epidemic control practices are inadequate (CDC 2009:2).

### **3.3.6. Ebolavirus outbreaks and epidemic patterns**

The declaration by WHO (2008:1-2) that Ebolavirus is endemic in tropical rainforests of Zaire, Sudan, Central African Republic, Gabon, Nigeria, Ivory Coast, Liberia, Cameroon and Western Pacific underscores the possibility of more epidemics in these areas and in the surrounding regions in the future. This claim is further supported by the sporadic Ebola epidemics that have continued to occur as affirmed by Feldmann and Geisbert (2012:20) and WHO (2012:1-2). In the subsequent section, seasonal and historical outbreak patterns of Ebola outbreaks are described.

#### **3.3.6.1. Seasonal Ebola outbreak patterns**

According to Pourrut et al (2007:177), most Ebola epidemics have tended to occur at the end of the rainy season or the start of the dry season. In tropical Africa, dry seasons usually run from December to February and June to August, whilst the wet seasons spread over March to May and September to November. As Pourrut et al (2007:181) and Leroy et al (2005:575) affirm, most outbreaks in both humans and great apes tend to occur between December and February and from June to August.

Langevin and Barclay (1990:357) clarify that the increased Ebola outbreaks during the two 'windows' may be linked to the two birthing periods of the three bat species identified as potential EBOV reservoirs (refer to section 3.3.4) which occur during the dry seasons at a time when fruit is scarce in the forest. The scarcity of forest fruits due to the seasonal variations and the concomitant increase in the great ape and bat populations result in competition for fruit during these periods, creating conditions for closer and increased contact. It is this increased contact between the naturally infected fruit bats and the great apes that appears to favour the appearance of Ebola outbreaks in human populations for similar seasons (Pourrut et al 2007:182).

This claim is further supported by Pinzon, Wilson, Tucker, Arthur, Jahrling and Formenty (2004:664-674) who attribute this outbreak pattern to increased activity levels of possible vectors and hosts resulting from altered behaviour patterns and reproductive cycles coinciding with rainfall and associated environmental changes. In agreement, Monath (1999:127) contends that nonhuman primates, squirrels, bats and arthropods are more active and reproduce seasonally, thus seasonal outbreaks.

### **3.3.6.2. Historical overview of previous Ebola outbreaks**

Peters and Le Duc (1999:ix-xvi) contend that although most sources quote the first Ebola epidemic to be the October 1976 Ebola outbreak in Yambuku, in the DRC, serological evidence suggests that there was an earlier Ebola-like infection during the Yellow fever outbreak in Ethiopia between 1961 and 1962. Zaramba (2000:2-5) also reports that another Ebola like outbreak discovered using retrospective analysis of stored human sera occurred in 1972 in Zaire, now DRC. This outbreak was observed at a point when a physician developed an Ebola-like disease after performing an autopsy on a patient who had presented with similar Ebola-like signs and symptoms.

The current focus on Ebola started in October 1976, after local health authorities reported that an unknown haemorrhagic illness which began on 26 August 1976 was causing massive deaths in Yambuku along the banks of a river named Ebola in northern DRC. This Ebola River is the headstream of the Mongala River, which is a tributary of the Congo River. It is after this river that the genus of filoviruses *Ebola*

*virus* and the five known species of Ebola virus are named (Wikipedia 2012:1). This outbreak was eventually contained with the help of WHO by quarantining local villagers in their communities, sterilising medical equipment and providing protective clothing to medical personnel involved in caring for the sick (WHO 1978a:247-270).

This outbreak occurred simultaneously in the southern Sudanese Western Equatoria towns of Nzara, Maridi and Tombura and Eastern Equatoria DRC towns of Yambuku and Bumba. WHO (1978b:271-293) reports that the Sudan outbreak resulted in 284 cases and 150 deaths and a case-fatality rate of 52%. In the DRC, there were 318 cases and 280 deaths and a case-fatality rate (CFR) of 88%. In both outbreaks, personal contact and contaminated needles and syringes facilitated the spread of infection. In Table 3.1, various Ebola outbreaks that have occurred are summarised:

**Table 3.1. Chronology of cases and Ebola outbreaks (CDC 2013:1-2; WHO 2013:1-2)**

<b>CHRONOLOGICAL SUMMARY OF KNOWN EBOLA OUTBREAKS</b>					
<b>Year</b>	<b>Country</b>	<b>Species</b>	<b>Cases</b>	<b>CFR</b>	<b>Characteristic /salient features of outbreak</b>
1976	Zaire	Ebola-Zaire	318	280 (88%)	Yambuku area affected. Infection spread by direct contact and use of contaminated syringes-needles in low hygiene hospitals.
1976	Sudan	Ebola-Sudan	284	151 (53%)	Nzara and Maridi affected. Infections spread by direct contact in hospitals. Many medical and nursing personnel infected.
1976	England	Ebola-Sudan	1	0 (0%)	Laboratory infections by accidental needle stick injury.
1977	Zaire	Ebola-Zaire	1	1 (100%)	Outbreak noted retrospectively in the village of Tandala.
1979	Sudan	Ebola-Sudan	34	22 (65%)	Nzara and Maridi affected. Epidemic occurred in same location as 1976 outbreak.
1989	USA	Ebola-Reston	0	0 (0%)	Ebola-Reston virus introduced into Virginia, Texas and Pennsylvania facilities by monkeys imported from the Philippines.
1990	USA	Ebola-Reston	4	0 (0%)	Ebola-Reston virus introduced again into Virginia, Texas by monkeys imported from the Philippines. Four humans developed antibodies to the virus, none became sick.
1990	Philippines	Ebola-Reston	3	0 (0%)	High mortality among cynomolgus macaques in USA. Three people developed antibodies, none became sick.
1992	Italy	Ebola-Reston	0	0 (0%)	Ebola-Reston virus introduced into quarantine facilities in Sienna by monkeys imported from the same export facility in the Philippines involved in episodes in USA.
1994	Gabon	Ebola-Zaire	52	31 (60%)	Mékouka and other gold-mines in the rainforest. Initially believed to be yellow fever, later diagnosed in 1995.

1994	Ivory Coast	Ebola-Ivory Coast	1	0 (0%)	Scientist became ill after autopsy on wild chimpanzee in Tai Forest; patient treated in Switzerland and survived.
1995	DRC (Zaire)	Ebola-Zaire	315	250 (81%)	Kikwit area affected. Index patient worked in the forest. Epidemic spread through families and hospitals because of contact.
1996	Gabon	Ebola-Zaire	37	21 (57%)	Mayibout area affected after hunters ate dead chimpanzee meat. The hunters and their family members became sick as well.
1997	Gabon	Ebola-Zaire	60	45 (74%)	Booué area affected. Index case patient was a hunter who lived in a forest camp. The disease spread through close contact.
1996	South Africa	Ebola-Zaire	2	1 (50%)	Physician travelled from Gabon to Johannesburg, after treating an Ebola patient, became ill and the nurse who cared for him also got infected, but later died.
1996	USA	Ebola-Reston	0	0 (0%)	Ebola-Reston virus was introduced into a quarantine facility in Texas by monkeys imported from the Philippines. No human infections were identified.
1996	Philippines	Ebola-Reston	0	0 (0%)	Ebola-Reston virus identified in a primate export facility in the Philippines. No human infections were reported.
2000 2001	Uganda	Ebola-Sudan	425	224 (53%)	Gulu, Masindi, and Mbarara districts affected. Infection spread through funerals, direct contact with patients and families, and providing medical care to Ebola patients without adequate protective measures.
2001 2002	Gabon	Ebola-Zaire	65	53 (82%)	Outbreak occurred over the border of Gabon and the Republic of the Congo (RC).
2001 2002	Republic of Congo	Ebola-Zaire	57	43 (75%)	Outbreak occurred over the border of Gabon and the RC. This was the first time Ebola was reported in RC.
2002 2003	Republic of Congo	Ebola-Zaire	143	129 (89%)	Epidemic occurred in the districts of Mbomo and Kéllé in Cuvette Ouest Département.
2003	Republic of Congo	Ebola-Zaire	35	29 (83%)	Outbreak occurred in Mbomo and Mbandza located in Cuvette Ouest Département.
2004	Sudan	Ebola-Sudan	17	7 (41%)	Yambio county in Southern Sudan. Outbreak was concurrent with measles.
2007	DRC	Ebola-Zaire	264	187 (71%)	Kasai Occidental Province in Central DRC.
2007 2008	Uganda	Ebola-Bundibugyo	131	42 (32%)	Bundibugyo district in Western Uganda. A new strain with different features reported by MOH and WHO.
2008	Philippines	Ebola-Reston	6	0 (0%)	First known occurrence of Ebola-Reston in pigs. Six workers from the pig farm and slaughterhouse developed antibodies but did not become sick.
2008 2009	DRC	Ebola-Zaire	32	15 (47%)	Mweka and Luebo health zones of Kasai Occidental Province in Central DRC.
2011	Uganda	Ebola-Sudan	1	1 (100%)	Single case in Luwero district in Central Uganda. Rapid response limited the outbreak to the index case patient.
2012	Uganda	Ebola Sudan	24	17 (71%)	Kibale District in Western Uganda.
2012	DRC	Ebola Bundibugyo	77	36 (47%)	Outbreak occurred in Isiro and Viadana districts in Province Orientale in Eastern DRC.
2012	Uganda	Ebola Sudan	19	4 (24%)	Ebola Sudan in Luwero District, Central Uganda. Outbreak declared Ebola-free on 16 January 2013.

### **3.3.7. Ebola Virus Disease**

Ebola haemorrhagic fever (EHF) is the official name of the human disease caused by any of the five known Ebola viruses: Bundibugyo Ebolavirus, Zaïre Ebolavirus, Sudan Ebolavirus, Reston Ebolavirus, and Taï Forest Virus (also known as Cote d'Ivoire Ebolavirus). The CDC (2012:1-2) emphasises that although Ebola outbreaks are relatively rare, localized and small, they almost always result in widespread fear, capturing media attention due to high fatality rates, the lack of definitive treatment and the potential to be used as a bioweapon. Clinically, Ebola presents with a sudden onset of symptoms following an incubation period of 2-21 days (Hartman, Towner & Nichol 2007:161) starting with nonspecific symptoms, such as fever, malaise, anorexia, headache, sore throat, abdominal pain, vomiting, diarrhoea, myalgia, arthralgia and rash (Feldmann & Geisbert 2011:849). In advanced disease, as Raabe and Borchert (2012:69) note, patients may develop haemorrhagic symptoms including epistaxis, petechiae, mucous membrane bleeding and internal bleeding.

These features of the Ebola syndrome are discussed in further detail in section 1.2.3.

#### **3.3.7.1. Diagnosis of Ebola Virus Disease**

Clinical diagnosis of Ebola is indicated after occurrence of clusters of cases with prodromal fever, bleeding tendencies and person-to-person transmission usually associated with prostration, lethargy, wasting, and diarrhoea and skin rash (Raabe & Borchert 2012:69). The WHO (2011:1-2) and CDC (2012:1-2) recommend that diagnosis of Ebola may be confirmed in the laboratory by using acute-phase serum by measuring the level of specific immunological response or by detecting viral antigen and genomic RNA or isolating virions. The antibodies IgM and IgG formed against the viruses are measured through immunofluorescence assay (IFA), immunoblot or enzyme-linked immunosorbent (ELISA) assay (WHO 2011:1-2). The viral antigen and genomic RNA may also be detected using immunohistochemistry, immunofluorescence, antigen detection ELISA and reverse transcription-polymerase chain reaction (RT-PCR) techniques (CDC 2012:1-2). Sometimes, direct detection of virus particles is performed using electron microscopy (CDC 2012:1-2). As a safety measure, all diagnosis occurs only in BSL-4 laboratories under maximum biological containment conditions to reduce the risk of infection to the laboratory personnel.

### 3.3.7.2. Pathogenicity and histopathology

In terms of pathogenicity, Feldmann and Geisbert (2011:849) state that Zaïre Ebolavirus (ZEBOV) has the highest virulence with a case fatality rate of 60-90% followed by Sudan Ebolavirus (SEBOV) with a case fatality rate of 40-60% and Bundibugyo Ebolavirus (BEBOV) species with a case fatality rate of 25-40%. The fourth subtype, Cote d'Ivoire Ebolavirus (CIEBOV), according to De Wit, Feldmann and Munster (2011:1-2) occurred only once in 1994 where it killed large populations of chimpanzees in Taï forest, in Ivory Coast (Cote d'Ivoire) and infected an ethologist (animal behaviour scientist) who later survived, after hospitalisation in Switzerland. The fifth species, Reston Ebolavirus (REBOV) causes no fatal disease in humans, although it is lethal to non-human primates such as chimpanzees and monkeys and has been associated with several animal outbreaks globally (WHO 2012:1-2).

The pathogenicity of Ebola is due to the direct and indirect damage inflicted by the infective process. The direct effect is due to replication of the virus on the cells and tissues, while the indirect effect is associated with activation of the pro-inflammatory cytokines leading to systemic inflammation, depletion of T- lymphocytes resulting in low immunity and initiation of coagulation abnormalities (de Wit et al 2011:3-4). The infective process results in necrosis and abnormalities in the liver, spleen, heart, kidney, lung, bone marrow tissues and peripheral blood (CDC 2010:2; WHO 2011:2):

In the liver, Geisbert, Hensley, Larsen, Young, Reed, Geisbert, Scott, Kagan, Jahrling and Davis (2003:2347-2370) report that the infective process results in marked elevation of hepatic enzymes, hyperaemia and focal hepatocellular necrosis. Sanchez, Lukwiya, Bausch, Mahanty, Sanchez, Wagoner and Rollin (2004:10370-77) add that loss of functionality in liver cells also occurs because ordinary liver cells (hepatocytes) and specialised cells (Kupffer bodies) become impregnated with fat.

In the spleen, the destruction that occurs according to Feldmann and Geisbert (2012:5-6) relates to affinity of Ebolavirus to monocytes, macrophages and dendritic cells which spread to the spleen from the initial infection site through the lymphatic system. The spleen shows severe hyperaemia and cellular depletion of the red pulp

and atrophy and necrosis of lymphoid follicles (CDC 2009:3-5). According to Zaki and Goldsmith (1999:97-101) the invasion of the spleen leads to tissue destruction and deposition of toxic residue within functional splenic tissue resulting in splenic failure.

In the heart, the myocardium is most affected. Imam et al (2001:30-35) and Geisbert et al (2003:2347-8) explain that there is proteinaceous oedema with accumulation of inflammatory cells within the connective tissues of the myocardium. In advanced disease, Wahl-Jensen, Afanasieva, Seebach, Stroher, Feldmann and Schnittler (2005:10442) report fibrin deposition following bleeding into the pericardial spaces.

The kidneys also become affected as the disease progresses. The glomeruli become inconspicuous and epithelial cells of the tubules, especially the nephrons undergo fatty degeneration, necrosis and desquamation. Also the Bowman's space and tubules become filled with fibrin, resulting in renal dysfunction (CDC 2009:2-4).

In the lungs, the functional unit, alveoli become atelectatic, meaning they collapse resulting in reduction of gaseous exchange because their walls become thick due to increased cellularity. Geisbert et al (2003:2347-2370) report that further reduction of alveoli functionality occurs due to fibrin and virus particles deposition within the alveoli walls and alveoli spaces, decreasing their capacity for gaseous exchange.

In addition to the organs, body cavities and the bone marrow also get affected. Imam et al (2001:32-35) explain that in fatal cases, bleeding occurs into the gastrointestinal, pleural, peritoneal, pericardial cavities and renal tubules. The bone marrow shows, increased cellularity characterised by high levels of monocytes, plasma cells and eosinophils (CIDRAP 2009:1-6) resulting in necrosis and vacuolisation of granulocyte precursor cells leading to cell death (Klenk et al 1998:5-6; Imam et al 2001:32-35).

In peripheral blood, Waterman (1999:2) reports the presence of activated lymphocytes or lymphoblasts, also called "virocytes". There is also reduction in platelet count (thrombocytopenia) triggering disseminated intravascular coagulation and reduction in white blood cell count (leukopenia) resulting in bacteraemia and viraemia (CIDRAP 2009:3). The peripheral blood picture is an important indicator of

the disease prognosis as demonstrated during the 2000 Ebola outbreak in Uganda, when Sanchez et al (2004:10370) found that low levels of circulating T lymphocytes signified fatal disease, while stable T lymphocyte count was associated with survival.

### **3.3.7.3. Clinical Features of Ebola Virus Disease**

The first accurate clinical description of Ebola is attributed to Dr. Ngoy Mushola, who was part of the medical team during the 1976 outbreak in Yambuku hospital in DRC (Piot et al 1978:7). In the first patient's notes, Mushola describes the clinical presentation of this hitherto unknown disease as: "the illness is characterised by a high temperature of about 39°C, haematemesis, diarrhoea with blood, retrosternal and abdominal pain, prostration with articulations and rapid evolution to death after a mean of three (3) days"; pioneering descriptions true today as they were back then!

In the early phase of the disease, following the incubation period, patients experience a sudden disease onset characterised by severe frontal headaches radiating to the occipital region (CDC 2009:1-6). Patients also experience acute fever with temperatures of over 39°C, general weakness, incapacitation, cervical and lower back pain and joint pains of the large joints (WHO 2008:1-4; Feldmann & Geisbert 2012:3-4). On examination, the patients are very sick looking, lethargic and have expressionless faces with deep-set eyes, known as "ghost face". Kumar and Clark (2002:62-63) as well as Shoemaker, MacNeil, Balinandi, Campbell, Wamala, McMullan, Downing, Lutwama, Mbidde, Ströher, Rollin and Nichol (2012:1480) complement that the patients experience rapid and severe weight loss due to loss of appetite and dysphagia due to the very painful throat lesions and severe symptoms.

After 2-3 days, WHO (2008:1-4) reports that patients begin to experience gastrointestinal symptoms including severe and cramping abdominal pain, nausea and haematemesis (blood in vomitus) and bloody diarrhoea. After the 3<sup>rd</sup> and 4<sup>th</sup> day, patients may also experience severe sore throat, which is perceived as a feeling of "lump" in the throat, thereby worsening the dysphagia (Kumar & Clark 2002: 62-63). By the 5<sup>th</sup> day, CDC (2010:4-5) reports symptoms of conjunctivitis, chest pain, dry cough, dehydration and haemorrhagic symptoms, varying from *maelena* (dark-brown

stool containing digested blood) and slow oozing of frank blood from gums in less severe cases, to brisk bleeding from multiple orifices and injection sites in fulminant cases occur. In severe cases, intense epistaxis (nose bleeding), gum haemorrhage, haematemesis, haemoptysis (vomiting frank blood), vaginal bleeding, purpura (bleeding into skin) and scarification of injection sites occurs. Shoemaker et al (2012:1480) emphasise that patients may also present with pruritic generalised maculo-papular rash, jaundice, tinnitus, haematuria, vertigo, amenorrhoea, oliguria, polyuria, hiccoughs and lymphadenitis. Further, Feldmann and Geisbert (2012:3-4) add that patients may experience hepatosplenomegaly and facial oedema due to multiple organ involvement while in pregnancy spontaneous abortion is common.

After 6 to 8 days, there is involvement of the central nervous system, manifested by somnolence, delirium and coma (CDC 2009:1-6). This period also marks the modal peak of the disease process, characterised by the binary phenomenon of where patients may either markedly improve and convalesce or develop multi-organ failure and die in shock (Kumar & Clark 2002:62-63). In patients who survive, Feldmann and Geisbert (2012:3-4) report slow recovery, often lasting several weeks to several months associated with severe incapacitation, weight loss, persistent headache, poor appetite, body weakness and reduced sexual libido among others. Survivors may also experience late complications of psychotic behaviour lasting between 3 to 9 months characterised by episodes of mental confusion, anxiety, fatigue, depression, restlessness, aggressiveness as well as musculo-skeletal pain (CDC 2009:4).

#### **3.3.7.4. Immunology of Ebolavirus infection**

Sanchez et al (2004:10370-73) observe that humoral responses to Ebola viruses can be detected as early as 10-14 days after infection and the specific antibodies formed against the viruses are directed primarily against its surface glycoproteins. This rapid high level immunological response targeting the viral glycoprotein coat is what leads to patient survival according to Ströher, West, Bugany, Klenk, Schnittler and Feldmann (2001:11026). In corroboration, Voelker (1999:1689) points out that, “an early immune response appears to be the key to surviving Ebolavirus infection”, based on studies on survivors of the 1996 Ebola outbreak in Gabon. Bonn

(1999:1161) confirms that during the early stages of infection, survivors produced increasing levels of Immunoglobulin G (Ig-G or Ig- $\gamma$ ) which target the viral coat, followed by clearance of circulating viral antigens and sustained activation of the cytotoxic T-cell pathway. The study also found that patients who died had higher concentrations of Interferon-Gamma (IFN- $\gamma$ ) and their peripheral blood cells showed extensive apoptosis compared to that of survivors. This observation received further support following discovery by Baize, Leroy, Georges, Georges-Courbot, Capron, Bedjabaga, Lansoud-Soukate and Mavoungou (2002:163-165) that early and well regulated inflammatory responses characterised by low levels of interferons and reactive oxygen and nitrogen species are associated with recovery. Sanchez et al (2004:10370-2) and Feldmann and Geisbert (2012:7) confirm that defective body response associated with increased blood concentrations of nitric oxide in patients that results from inappropriate response to Ebola virions leads to patient death.

Baize (1999:423-426) while analysing serial plasma samples from patients of the 1996 Gabon Ebola outbreak, at Institut Pasteur, Lille, France, also found that survival was related to “orderly and well regulated humoral and cellular responses”. The team concluded that impaired humoral responses with absent specific IgG and barely detectable IgM indicated failure to control virus replication, hence a fatal outcome. This observation received credence in recent times from Mohamadzadeh, Chen and Schmaljohn (2007:556-567) and Falzarano, Geisbert and Feldmann (2012:2) who endorse that absence of a vigorous immune response and lymphopenia (low levels of T cells) due to ineffective immune response are characteristics of individuals who do not survive Ebola. This therefore suggests that both cellular and humoral responses are essential for protection against Ebola virus infection in humans and the level of immune response it elicits in the individual determines their chances of survival.

### **3.3.7.5. Therapeutic interventions and vaccination**

Feldmann (2010:1896) decries the continued absence of specific chemotherapeutic or immunisation strategy and calls for increased efforts to address this shortcoming especially in the face of newer Ebola strains. A remedy is essential to handle accidental laboratory incidents and to protect populations in endemic areas including epidemic response team members. Although no specific therapy exists as yet, Pigott

and Darling (2011:2-4) note that in critical situations, using convalescent serum may be considered as was the case during the 1995 Kikwit, Ebola Zaire outbreak when 8 Ebola patients received blood transfusions from Ebola survivors. Mupapa, Massamba, Kibadi, Kuvula, Bwaka, Kipasa, Colebunders and Muyembe-Tamfum (1999:179) report that 7 of these 8 patients who received the serum recovered. Although their survival may not be linked to the sera they received, it is nevertheless a practical solution during large Ebola outbreaks (Feldmann & Geisbert 2012:10).

In terms of progress towards vaccine development, Sarwar, Sitar and Ledgerwood (2011:126) report that most recent vaccine efforts have focused on using a live-attenuated recombinant vesicular stomatitis virus (recVSV) expressing the glycoprotein of the Zaire Ebolavirus strain. This experimental vaccine came to light in 2009, when as Pigott and Darling (2011:4-6) and Günther, Feldmann, Geisbert, Hensley, Rollin, Nichol, Ströher, Artsob, Peters, Ksiazek, Becker, Ter Meulen, Olschläger, Schmidt-Chanasit, Sudeck, Burchard and Schmiedel (2011:785) report, it was successfully administered as 'vaccination' (Tuffs 2009:1223) to a German laboratory worker after a needle stick accident while working with Ebola viruses.

To date, since no universally recommended specific therapy exists, King, Malik, Wood, Talavera, Kerkering and Cunha (2012:6-8) and WHO (2012b:3-4) recommend that the most appropriate treatment during outbreaks should focus on supportive therapy, with particular attention to patients' intravascular fluid volume, electrolytes, nutrition and comfort. This involves balancing patients' fluids and electrolytes and maintaining optimal oxygen and blood pressure levels. In addition, the CDC (2012:3-5) also encourages prompt treatment of complications such as super-infections and dehydration to prevent cardiovascular collapse and renal insufficiency. In providing this supportive therapy, strict barrier isolation, careful handling of blood and body fluids and prompt burial of deceased is mandatory to prevent possible transmission.

#### **3.3.7.6. Current epidemic management and containment**

Managing and containing Ebola outbreak is a formidable challenge, partly because the natural reservoir of the virus remains unknown, making it difficult to institute primary prevention measures. In the absence of primary prevention, the main

epidemic management relies on educating the masses and instituting secondary prevention strategies during and following Ebola outbreaks. However, for success of secondary prevention strategies, I hold that a good understanding of the public's perspectives regarding Ebola is pivotal to design effective approaches to educate the masses about the illness and its effects. Doing so would help in demystifying and reducing the fear and panic always associated with the disease. I am of the opinion that educating at risk populations using perspectives that incorporate their own understanding and beliefs about Ebola is likely to result in better epidemic control.

Current Ebola outbreak management and containment efforts may be broadly categorised as "*post outbreak interventions*". However, I propose that in addition to these post outbreak interventions, there is need for "*constant interventions*" as well. In the context of this study, "*post outbreak interventions*" refer to interventions undertaken at community or institutional levels to mitigate further spread of on-going epidemics. I propose '*constant interventions*' as actions at individual, community and institutional levels that are aimed at understanding the phenomenon of living under constant threat of Ebola as well as what the illness means to the locals, including the notions behind the public's reactions towards Ebola and then applying this knowledge to guide people in stages in-between and during outbreaks. The justification to institute both "*post outbreak*" and "*constant*" interventions is based on the notion that Ebola outbreaks in Tropical Africa and in the Archipelagos of the Philippines, appear to be on the increase and are continuing to negatively impact on the lives and livelihoods of individuals and families in these areas (CDC 2012:1-2; WHO 2012b:3).

#### **3.3.7.6.1. Post outbreak interventions**

Post outbreak interventions help to control further spread of an on-going epidemic and consist of various combative strategies that minimise infection transmission in healthcare settings, in communities and to reduce case fatality. When explained to the public well using suitable media, post outbreak interventions can minimise infection spread and make response efforts less dramatic because of fewer incidences of antisocial overtones arising out of better understanding about Ebola.

Furthermore, I suggest that “*humanising*” epidemic response efforts by respecting the dignity of the affected and finding a subtle balance between safety and local cultural rites helps to reduce the panic and ‘*psychosis*’ associated with epidemic response. Encinas (2009:1-2) agrees that awareness creation through social health education plays a significant part in minimising the hysterical reaction seen during such outbreaks. Hence understanding what Ebola means to survivors and their families, including what living in constant anticipation of an outbreak means, provides ideas that may be used to blend educative messages to calm down hysterical responses.

A salient feature of the post outbreak interventions being implemented is that they focus on active disease surveillance, laboratory confirmation; case management; social mobilisation, health education and training; resource mobilisation and improved communication (WHO 2008:2) which are based on health workers’ views, using the medical model with little attention to the human side of the epidemic. In the subsequent section, details of these epidemic response efforts are highlighted:

#### **a) *Active disease surveillance***

Surveillance refers to healthcare practitioners efforts exerted over communities to promptly detect and control outbreaks. According to Erme (2002:1-2), surveillance may be based on passive or active data collection processes. In ‘*passive*’ surveillance as Woodruff, Bornemisza, Checchi and Sondorp (2009:1-2) explain, local health authorities are notified by a clinician or laboratory after encountering a patient or sample of a notifiable disease as part of a legal obligation without further stimulus from the authorities. In ‘*active*’ surveillance, Erme (2002:1-2) clarifies that health care providers report incidences of notifiable conditions on a-case-by-case basis, usually in great detail to foster follow up by other health teams. Active surveillance involves vigorously seeking out data necessary to monitor incidences of disease and includes reviewing clinical records and carrying out community surveys.

Also referred to as ‘*case finding*’, active surveillance during epidemics is termed ‘*contact tracing*’, and it involves tracing and following-up persons believed to have been exposed to known cases of the illness including the deceased. In the case of Ebola, CDC (2008:1-4) recommends that contact persons should be isolated and

monitored for suspicious signs and symptoms for 21 days, which is the maximum incubation period of the virus, before such persons are declared by health authorities to be safe to return to their homes. Surveillance activities help to control outbreaks, therefore incorporating information about them during community education sessions during outbreaks can potentially improve the public's reaction towards the affected.

### ***b) Laboratory Confirmation***

According to WHO (2008:1-3) laboratory confirmation of initial cases is mandatory when an epidemic is suspected and is indicated up to when the epidemic is confirmed and then diagnosis is based on similarity of clinical manifestations. When the epidemic is established, CDC (2008:1-4) recommends setting up a field-screening laboratory at a nearby hospital to facilitate on-site laboratory screening and confirmation of clinical and suspect cases. In highly virulent epidemics such as Ebola, Lamunu and colleagues (2002:5-6) stress that field laboratories facilitate diagnosis and help to guide patients' care decisions. In previous outbreaks, setting up field laboratories in affected communities has been seen as a "potential source of infection" and has often attracted negative reactions from locals (Mugisa, Thawite, Ssendendo, Etengu & Kagiri 2007:3). Better understanding of the human side of Ebola, means that such perspectives that emerge from affected persons may be used to educate the public and allay their fears related to such control installations.

### ***c) Case Management***

Case management of patients during Ebola epidemics depends on whether the patient belongs to the surveillance categories of "alert", "suspect", "probable" and "confirmed". Lamunu et al (2002:3-10) explain that the "*alert*" category refers to persons with sudden onset of high fever, a sudden death and unexplained bleeding and it requires communities to notify peripheral health facilities and mobile surveillance teams to begin the contact tracing process. The "*suspect*" category applies to those living or deceased with history of contact with a known patient presenting with fever, and includes persons presenting with symptoms of headache, vomiting, loss of appetite, diarrhoea, fatigue, abdominal pain, body aches, difficult

swallowing, hiccoughs, unexplained bleeding or any unexplained death. The “*probable*” category is reserved for those who have been clinically assessed by a clinician and show most signs and symptoms. Such patients require immediate admission and close monitoring and laboratory analysis. The “*confirmed*” category refers to patients who meet the probable case definition and have tested antigen, Ig-G, Ig-M or PCR positive, as such require immediate isolation and commencement of approved supportive therapeutic interventions in the hospital (Lamunu et al 2002:3).

Okware and George (2008:3-5) point out that because there is lack of definitive therapy, case management during outbreaks should involve creation of isolation units for patients and contacts to reduce infection transmission. In the isolation unit, WHO (2012b:4-5) recommends intensive supportive therapy to maintain hydration and electrolyte balance through consistent administration of intravenous or oral rehydration fluids. King et al (2012:1-4) augments this supportive therapy involves managing shock, cerebral oedema, renal failure, coagulation disorders and secondary bacterial infection. WHO (2012b:4-5) recommends caring for these patients under strict barrier nursing and avoiding trauma to the skin by limiting injections and parenteral interventions including handling blood, secretions, catheters and suction devices and handling non-disposable equipment with care. The CDC (2012:5-6) recommends that whenever possible, HEPA-filtered respirators may be used to protect clinical staff against aerosols when attending to patients in isolation.

As patients recover, WHO (2008:4-6) recommends appropriate discharge planning because management of convalescent patients and discharge of fully recovered patients are critical aspects of epidemic management. Lamunu et al (2002:3-7) declare proper discharge helps to mitigate the widespread fear and stigma usually seen during discharge of survivors and contacts. In view of this, it is recommended healthcare providers should receive training on counselling and patient discharge.

Another critical aspect of case management as stated by Okware and George (2008:2-4) is establishment of safe burial practices which involves identifying and providing suitable burial grounds, instituting trained burial teams and developing guidelines for safe burial. In the event of death, Lamunu et al (2002:7-8) and King et al (2012:3-4) recommend safe handling of the deceased by avoiding washing and

embalming of the body and ensuring that the burial is done swiftly by trained burial teams, protected by personal protective equipment, mandatory protective wear. I am of the opinion that clearly understanding what Ebola means to the affected may provide helpful insights which could be used in designing evidence-based messages for effective discharge education and for integrating the affected with their families.

***d) Social mobilisation, health education and training***

During epidemics, social mobilisation is critical to ensure epidemic preparedness and response. During the 2000-2001 Gulu Ebola outbreak, Lamunu et al (2002:3-10) confirm that the use of the media, especially local radio stations to educate communities about the outbreak proved successful. In addition to the radio stations, the use of community drama groups also proved beneficial in fighting ostracism and stigma. Following this success, WHO (2008:1-5) has in more recent epidemics recommended the use of documentary films to enhance epidemic preparedness and response. Another aspect of social mobilisation advanced by Okware and George (2008:1-6) relates to extensive circulation of educative posters and guidelines that emphasise halting of social practices, including handshake, large gatherings, indigenous healing practices as well as cultural burial rituals until the epidemic ends.

Social mobilisation during outbreaks according to the Uganda National Health Research Organisation, UNHRO (2001:2-6) also involves training healthcare practitioners and community resource persons to participate in disease surveillance efforts. This aspect of the epidemic response is relevant because collective management of response efforts through multisectoral collaboration has proved effective in controlling the more recent Ebola epidemics. The involvement of the public in epidemic response proved useful during the 2012 Kibale district Ebola outbreak. According to the International Federation of Red Cross and Red Crescent Societies, IFRC (2012:1-5), social mobilisation of the public, coordinated by the Uganda Red Cross Society in collaboration with the national task force, which consisted of WHO, MSF, UNICEF, Africa Epidemic Network contributed significantly to mitigation efforts, hence the end of the epidemic on October 4, 2012 (New Vision 2012b:1-4). The IFRC (2012:1-5) reports epidemic control efforts consisted of trained

volunteers disseminating information about the illness in affected areas, carrying out health promotion and media campaigns; house-to-house contact tracing and follow-up; offering psychosocial support, rehabilitation and distribution of non-food items to discharged contacts, survivors and their families and training locals in epidemic control and prevention. Furthermore, I believe that better understanding of the human side of the illness through studies such as the present, stand to improve mobilisation.

#### **e) *Resource mobilisation***

During epidemics, resource mobilisation is critical requiring multisectoral collaboration between political organisations, development partners and government departments (MSF 2008:2-3). In support, Matua and Locsin (2005:125-132) declare that the resources required may be in form of finances or as hospital and laboratory equipment and supplies. In recent times, countries afflicted by Ebola outbreaks have received assistance from international organisations, such as the World Health Organisation (Geneva), Centers for Disease Control and Prevention (USA), the National Institute for Communicable Diseases (South Africa), the Institute Pasteur (France), Médecins Sans Frontières (France and Belgium) and Caritas (Belgium).

In country local support and resources usually come from local governments, non-governmental organisations, local companies, families and individuals as was documented during the 2012 Kibale Ebola outbreak. As more information about Ebola becomes available, views of those who experience Ebola may be incorporated into social health messages to educate people about the illness and to seek their contribution towards epidemic response in order to simplify resource mobilisation.

#### **f) *Improved Communication***

Effective communication during outbreaks is a vital aspect of epidemic control. WHO (2008:4) reports that increasingly, affected countries are improving information sharing between stakeholders namely government departments, religious institutions, training institutions, affected communities, the public and development partners. Lamunu et al (2002:5-6) underscore the importance of this strategy as being

essential in resource identification and mobilisation, social mobilisation and training, disease surveillance and case management and for re-integrating survivors and contacts back to their communities. A key aspect of an improved communication strategy involves early integration of the media. Lamunu and colleagues (2002:10-12) declare that early and close involvement of the media during previous outbreaks helped to shape public perception and educate them on epidemic prevention and control strategies. In more recent outbreaks, WHO (2007:2-6) reports early involvement of the media has successfully created heightened awareness for infection prevention in populations, leading to members of affected communities rushing suspected cases to isolation centres, avoiding contact with 'suspect' cases, complying with epidemic control guidelines and supporting epidemic response activities. Okware and George (2008:3-5) attribute such success in epidemic response to close involvement of media leading to accurate reporting about Ebola.

In the case of the 2012 Kibale Ebola outbreak, while the media helped to create awareness about Ebola, it too exacerbated widespread panic and anxiety in the population not only in Kibale district, but in far off places as well. The newspaper headlines such as: "Ebola Pushes Kampala into Panic" (Igihe Network 30 July 2012); Panic grips Uganda, as Ebola outbreak kills 14 (Reuters News 28 July 2012), "Ebola outbreak sees tourists cancel holidays to Uganda" (The Telegraph 02 August 2012) and "Schools close over Ebola outbreak (Businge 2012, New Vision 30 July), all point to the negative impact of the media. Such occurrences underscore the need to better understand what Ebola means to affected individuals, including what the actions of the community members symbolise, because such information may contribute towards improving the social communication strategies during outbreaks since they are more likely to be based on a better understanding of the public's views on Ebola.

#### **3.3.7.6.2. Constant Interventions**

As previously articulated, I propose that in addition to *'post outbreak interventions'*, management of outbreaks should also emphasise holistic *'constant interventions'* as well, focussing on the general population, healthcare institutions and government departments. The interventions in the constant interventions should be informed by people's understanding of what it means to be affected by Ebola including what living

under constant threat of an Ebola outbreak entails. These evidenced based information should be applied to guide populations in-between and during outbreaks.

Unfortunately at present, what could be considered as “*constant interventions*” do not adequately address the human side of the Ebola epidemic, because UNHRO (2001:4-6) reports that most interventions instituted by the Ministry of Health and development partners are targeted at macro level to enhance the country’s epidemic response and preparedness for future outbreaks. Lamunu et al (2002:8-12) similarly reports that these interventions focus on improving hospital infrastructure, diagnostic laboratories; infection control facilities and procedures; enhancing surveillance for early warning and revitalisation of vital statistics related to birth and death registration; in effect, effectively neglecting the human aspects of the Ebola epidemic.

The “constant” epidemic preparedness efforts are based on recommendations from CDC and WHO (1998:2-80) to ensure that health practitioners in affected countries are up-to-date with recommended procedures for infection prevention, reinforced by regular attendance of seminars and workshops to ensure they are better prepared to handle future epidemics. Further recommendations include ensuring health workers and community leaders keep the public informed about the nature of the disease and the necessary outbreak containment procedures for early case detection, reporting and clinical management. Although these interventions have helped to improve epidemic preparedness, they have still have not fully addressed the human aspects of Ebola epidemics as evidenced by the persistent ostracism and stigmatisation.

This implies that there is still need for more emphasis on understanding what Ebola means to the public in order to generate new perspectives which may be incorporated in health promotion activities that foster more humane public reaction during future epidemics. In-depth understanding of the survivors’ and caregivers’ experiences, including what Ebola means to them, provides opportunities to delve into people’s hearts and minds which are critical to explicating social and cultural perspectives that continue to influence reactions during and in-between outbreaks.

A discussion on key social-cultural perspectives and explanation of how they influence people’s reaction towards affected persons and families follows succinctly:

### 3.4. CULTURAL ISSUES RELATED TO DISEASE AND ILLNESS

The concept of “*culture*” according to Donini-Lenhoff and Hedrick (2000:241) is an integrated pattern of learned beliefs and behaviours that are shared among groups and include thoughts, styles of communicating, patterns of interaction, views of roles and relationships, values, practices and customs. Culture provides rules and scripts about how individuals, families and groups live and make decisions across the life course, with these rules handed down from generation to generation (Mio, Barker-Hackett & Tumaming 2009, cited in Wyatt, Williams, Gupta & Malebranche 2012:363). In affirmation, Helman (2000, as cited in Ariff & Beng 2006:2) concurs that due the complex nature of human relationships and especially how people are intricately influenced by their backgrounds, one’s culture is often the inherited ‘*lens*’ through which one perceives and understands the world, learns how to experience it emotionally and to behave in it in relation to other people, supernatural forces and natural environment. In view of the centrality of culture in human lives, understanding sociocultural dimensions underlying people’s health values, beliefs and behaviours is critical to ensure successful patient clinical outcomes during illnesses such as Ebola.

There is evidence in the literature that cultural beliefs and practices affect patients’ attitudes about medical care and their ability to understand, manage and cope with the course of an illness, the meaning of a diagnosis, and the consequences of medical treatment (McLaughlin & Braun 1998:117-120; Ariff & Beng 2006:2-4; Carteret 2011:2). In agreement, Flores (2000:14-16) much like Selim (2010:95) contend that cultural beliefs and practices significantly influence patient perceptions of health and illnesses, recognition of symptoms, impact of illness, health care seeking, communication of symptoms to care givers including their understanding of the management strategies, expectations of care and adherence to preventive measures and medications. McLaughlin and Braun (1998:117-120) add that culturally generated values also influence patient roles and expectations, including how they seek and use information about illness and treatment, management of death and dying and bereavement. The negative effects of these beliefs and practices is underpinned on the fact that they are tightly held by patients, families and communities and they have a profound impact on individuals’ choices of care

including how they behave, and their reaction to disease and illness. In the present study as affirmed in Eisenberg, Kessler, Foster, Norlock, Calkins and Delbanco (1993:246-249), the concept of disease should be understood as the “objective measurable pathophysiology that creates the illness”, while, the concept of illness, the “meaning of the disease to the individual”, regardless of the cause; be it natural, a fracture resulting from a fall; supernatural, associated with acts of God, witchcraft; or metaphysical, resulting from aggressive or unusual seasonal or climate changes.

These culturally-based health attitudes and beliefs are so crucial that depending on how deeply they are held, they can significantly impede preventive efforts, delay or complicate medical care and result in the use of remedies that can be either beneficial or harmful to affected individuals (Carteret 2011:1-2). The positive or negative effects of the beliefs arise from the wide range of understandings people have around what causes a particular disease. In communities worldwide, various explanatory models are used to understand disease causation. These models and the accompanying belief systems vary widely, from witchcraft and soul loss to germs and weak immunity (Eisenberg et al 1993:250; Carteret 2011:2). In the western world, the human body is perceived as an “intricate machine which must be kept in good working order” and illness is viewed as “a breakdown of the body machine”. However, this view contrasts widely with traditional African and Eastern philosophies about illness and cause of illness and death (Ariff & Beng 2000:2; Carteret 2011:2-3).

In Uganda, much like in most parts of Sub-Saharan Africa, cultural groups have built explanatory frameworks to illuminate the aetiology of different diseases. These models hold that disease may result from internal imbalance within the body or may arise from negative external influences related to actions of bad spirits, wizards or witches or deities. Whilst small variations may exist, Foster (1976:775), Foster and Anderson (1978:51-55) and Carteret (2011:2-3) contend that broadly speaking, disease causation in non-western settings as in sub-saharan Africa like Uganda may be explained from two frameworks: “*naturalistic category*”, related to natural causes and “*personalistic category*”, related to others, including the supernatural actors.

In the naturalistic framework, Foster (1976:775) explains that illness and health are explained in terms of impersonal, natural forces, conditions and insensate elements

in the body, such as heat, humour, cold, water content and mineral salts. In this framework, health manifests when there is equilibrium; the innate elements or conditions are in perfect balance: that is when the humours and the energies are all in the balance appropriate to the age and condition of the individual in the natural and social environment in which they live, with disease occurring when such balance is upset (Foster & Anderson 1978:51-55). According to Al Safi (2005:2-4) the naturalistic framework is used to explain simple ailments such as headaches, muscle aches and fevers whose cause is almost always specific. When a disease that is perceived as falling within the naturalistic framework occurs, the sick person or a close family member, as Foster (1976:779) explains, is expected to seek help from a specified healer who is knowledgeable in symptomatic treatment and knows locally established remedies believed to correct such “imbalances” through the use of herbs, food restrictions, massage, poultices as well as enema use among other remedies.

In the personalistic framework, disease causation occurs as a result of active, purposeful intervention of an “agent” who according to Foster (1976:775) and Alland (1964:714-715) may be a supernatural being (deity or god), a non-human being (such as ghost or evil spirit) or a human being (witch or sorcerer). The sick person is seen primarily as victim, the object of aggression or punishment directed specifically against them for reasons that concern them alone. Appiah and Gates (1999:1-2) in consonance with Foster and Anderson (1978:55-56) add that most cultures in sub-Saharan Africa, believe that individuals become prone to illness if they do not conform to certain personal or social standards or if they misbehave or breach taboos, customs and traditions expected of them or their parents. The social implication of this perspective is that people who become afflicted by serious diseases may be exposed to undue antisocial gestures by community members, emboldened by the belief that such affliction is “self-made” and may be “worthy punishment” for failure to abide by norms, thereby leading to their ostracism and neglect. Hence when a disease perceived to arise within the personalistic lens is suspected, the affected person or their close families is expected to seek curers with supernatural and magical skills, for the primary concern of the patient and their family is not the immediate cause of illness, but rather “who is responsible?” and “why did it happen to them?” (Foster 1976:778). Hence the main focus of seeking care and diagnosis

hinges on revealing why they are ill and not how they got ill (Imperato 1974-5, as cited in Foster 1976:778). The diagnostic process commences with the “curer” believed to be with supernatural powers perceived to have a direct contact with the spirit world, invokes magical powers to find out who was responsible for the disease and why the victim was afflicted. After the ‘*who*’ and ‘*why*’ have been determined, Foster (1976:778) explains that the treatment for the immediate cause may be administered by the same person, or the task may be referred over to a “*lesser carer*”, often a known herbalist which may require offering some gifts to ancestors.

In addition to Foster and Anderson’s (1978:51-56) naturalistic and personalistic model of disease causation, Grove (1919:157-182) proposes that a third explanatory framework for disease causation in sub-saharan Africa relates to the concept of misfortune. Grove explains that most African communities believe that misfortune may significantly influence a person’s life, including their proneness to good health, ill health or untimely demise. According to Grove (1919:157-182) and Foster (1978:777-778) misfortune mostly comes from “displeased” ancestors, angered by their younger kin’s failure to fulfil cultural obligations or by doing wrong intentionally. It is also believed that misfortune may come from evil influences of a person who has supernatural powers such as sorcerers or witches, being subjected onto a vulnerable person who lacks protection from ‘good’ spirits. The concept of misfortune as causative factor of disease, especially its linkage with ‘unhappy’ ancestors means that like within the personalistic framework, those who become sick through an act of misfortune risk being perceived as “serving their sentences” for wrongful acts committed by them or their parents, resulting in their undue ostracism and alienation.

Hewlett and Amola (2003:1242) expound that regardless of whether the cause of the illness is related to naturalistic or personalistic causes or acts of misfortune, the reaction of most indigenous African communities including the preferred response efforts is influenced to a large extent by the perceived severity of the illness. Hence when an illness is considered fatal, more rigorous actions are mandated and when perceived as being of low risk, less aggressive efforts are engaged. Such categorisation of disease was evident among the Acholi peoples in northern Uganda. Hewlett and Amola (2003:1244) describe that the Acholi cultural classification of

illness as 'yat' or 'gemo' came to light during the 2000 Ebola outbreak when culturally established and acclaimed protocols emerged during the infection control period.

Hewlett and Amola (2003:1244) explain that among the Acholi, an illness is categorised 'yat' if it is strange and mysterious, caused by charm or poison placed upon a person or hidden in the sick person's vicinity, and when 'yat' is suspected in a home, a traditional healer is invited to locate and remove it through a prescribed ritual which includes sacrificing a white chicken or goat to please the ancestors and chase away offending evil spirits. In contrast, a 'gemo' category refers to illnesses that are more severe than 'yat', appear suddenly and are associated with mysterious illnesses and numerous deaths in short time. It is believed 'gemo' category of illness is caused by witchcraft, charms or spirits unhappy with the affected persons or their close families or have been sent by enemies of the afflicted (Hewlett & Amola 2003:1242).

Hewlett and Amola (2003:1243) add that among the Acholi people, when 'gemo' is suspected in a family, affected persons and sometimes their close members are expected to be isolated to prevent them from mixing with other members of the village. This practice of strict banishment hinges on the belief that when a person with 'gemo' is close by, it is easier for it to 'catch' (read...as spread to) other people. This cultural protocol also requires that when such a person dies, no one is allowed to touch the body, except designated caregivers only, who are usually survivors or the elderly who are the only ones permitted to wash and prepare the corpse for a culturally befitting burial (Hewlett & Amola 2003:1243), intended to protect communities from serious illnesses. Although such measures were developed to prevent massive deaths, application of such 'gemo' related principles during serious epidemics in most of these indigenous communities has had negative consequences on individuals who have contracted such dreadful illnesses, leading to their alienation and sometimes banishment from their homes by relatives (Sensasi/WHO 2012:4).

Such occurrences, give credence to the conclusion that deep rooted social cultural perspectives strongly influence a community's reaction towards persons and families during and in between epidemics. Therefore, I propose that to design effective and holistic epidemic mitigation plans that address both biomedical and social cultural

dimensions, there is need to clearly understand the personal lived experiences related to such illnesses as well as community's beliefs about the illness. I envisage that addressing human side of future Ebola epidemics will allow demystification of false beliefs about Ebola, with the potential to reduce the ostracism and stigma that has come to define Ebola outbreaks. This postulation is vital given Uganda's vulnerability to Ebola outbreaks in future as affirmed by CDC (2012:1-2) and WHO (2012a:1-2) and currently evidenced by occurrence of five epidemics within a decade.

### **3.5. EXPERIENCING THE THREAT OF A LIFE-THREATENING ILLNESS**

The experience of living under constant threat of illness or with a life threatening illness is an important human reality that many people have to endure, especially the '*uncertainty*' that lingers in the minds of sufferers, survivors and their families. Brown and Sourkes (2006:6) explain that the effect of life threatening illness and its treatment or sequele has significant effect on the life of affected persons including their physical appearance and their psychological perception of themselves. The issue of self-concept is critical because physical or bodily changes bring about concerns about body image. In the contemporary world where self-image and worth are closely associated with individual's outward appearance, the visible markers of illness, such as skin changes, emaciation, wheelchair dependence and hair loss among others, places sufferers of life threatening illness at risk for poor body image and feelings of inferiority and low self-esteem, thereby affecting their wellbeing.

Brown and Sourkes (2006:6) maintain that compounding survivors' difficulty in adjusting to an altered body image is the fear of others' reactions to their "*altered appearance*". This fear often makes sufferers shy away from others fearing that they will be considered less than human. This overwhelming shame and embarrassment may make some sufferers to absent themselves and withdraw from social activities. In school going adolescents such negative changes tends to result in increased school dropout rates since their altered body image often interferes with their ability to maintain old friendships and importantly to develop new relationships with their peers.

Holland and Lewis (2000:2-5) explain that although the complexities associated with life threatening and life limiting illness tends to be universal, each individual tends to

respond in different ways, which may be broadly classified into physical, psychological, social and economic consequences, as presented subsequently:

### **3.5.1. Physical consequences of living with constant threat of serious illness**

The thought of recurrence of life a threatening illness is a gruelling experience for individuals who have survived life threatening conditions. Brown and Sourkes (2006:5) point out that a major physical consequence of life threatening illness is that survivors often feel restricted by the illness and the associated treatments because it tends to interfere with their sense of competence. In addition, they find the many hours spent at clinics, hospitals and home recuperating disruptive and disconcerting because it unduly impedes their daily routines. Locsin and Matua (2002:175-176) add that the threat of serious illness creates in survivors psycho-somatic consequences.

The researchers following the 2000 Ebola outbreak in Mbarara district found that contacts experienced “funny electrifying feelings” whenever they remembered or were reminded about their encounter with Ebola. The thought about Ebola made participants to experience unusual headaches while others reported feeling feverish. The researchers concluded that such psycho-somatic disturbances may persist long after the actual illness has subsided and continue to re-emerge upon a trigger. The researchers add that the sequele of disease and its discomforting residual effect on the affected person is what fuels the fear and stigma associated with such illnesses.

Cordova and Andrykowski (2003:286-290) maintain that the dread of recurrence of life-threatening illness especially the anticipation of stigma, discrimination and suffering may create in the sufferer untoward psychological burden which may trigger mental illness. McEwen (2000) as cited in Major and O'Brien (2005:393-402) agrees that people who experience ostracism and stigmatisation or who feel they are at risk of being ostracised have a greater risk of developing mental and physical health problems such as depression and hypertensive disorders when compared to non-stigmatised populations. Link and Phelan (2001:363-285) maintain that actual or perceived discrimination may ‘push sufferers to the edge of society’ including towards harmful social environments and practices which worsen their already bad situation.

### **3.5.2. Psychological implications of living with or after life threatening illness**

Living with a life threatening illness or following a highly stressful life event has several negative consequences on affected individuals. This may range from an actual experience to fear of negative influence from others. A key negative consequence experienced by survivors of traumatic experiences according to the National Cancer Institute (2012:1-2) is appearance of post-traumatic stress disorder (PTSD) symptoms characterised by survivors avoiding situations related to the trauma or thinking continuously about the trauma or becoming hysterical and fearful about situations that remind them of the hurtful experience. Frequently, PTSD manifests when individuals have experienced life limiting diseases such as cancer, HIV/AIDS or experience highly stressful events, including participating in military combat operations, natural disasters or following violent attacks as in cases of rape.

The Encyclopaedia of Human Disease and Conditions (2012:1-2) explains that when survivors of life threatening conditions experience PTSD symptoms, they may relive their terror in nightmares, flashback memories and through feelings of intense fear which in extreme cases may interfere with their everyday life. Porterfield (1996) as cited in the Encyclopaedia of Human Disease and Conditions (2012:1-2) upholds the view that PTSD arises when individuals experience traumatic life experiences, causing them great harm and fear and leaving them defenceless and overwhelmed both physically and emotionally. The National Health Services, NHS, UK (2011:1-2) documents that people suffering from PTSD may in addition to experiencing recurring memories or flashbacks about the trauma further withdraw from people and develop excessive fear shortly after the event or several months or years later, leaving them distraught and severely disabled for prolonged time(NHS, UK 2011:1-2).

In addition to the symptoms of PTSD, anticipation of stigma and fear of rejection constitute two other major psychological implications of living with or in constant anticipation of life threatening illness. Link and Phelan (2006:528-529) contend that stigma in its true sense or the fear of stigma creates a considerable burden usually greater than the original illness, which necessitates early recognition and intervention. Barret and Brown (2008:34-36) declare that stigma may be linked to the public's fear

of infection as well as the projected scenarios of socioeconomic breakdown and its potential to destabilise people's established social order and the usual calm enjoyed.

This 'negative strength' of stigma is corroborated by Jacoby, Snape and Baker's (2005:171-8) assertion that social stigma, as felt or feared by the stigmatised person and enacted by the stigmatisers is both a cause of and a contributor to ill health. These negative consequences arise out of the attributes of stigma which Goffman (1963) as explained in Major and O'Brien (2005:394) claims discredits individuals reducing them "from a whole and usual person to a tainted, discounted person". This "change" has far reaching effects on them and their families. Crocker, Major and Steele (1998:395) remark that the discredit associated with stigma occurs when a person possesses or is believed to possess attributes that convey a social identity that is devalued or feared by the population. Link and Phelan (2001:363) add that stigma which is socially driven thrives where a dominant group labels, stereotypes, excludes and discriminates against a negated group because of their actual or perceived association with a devalued or feared attribute. These attributes thus reveal that stigma is a complex phenomenon uniquely experienced according to the social circumstances of the affected person or family (Fife & Wright 2000:50-54).

Furthermore, the fear of rejection, much like social stigma that results from survivors' association with life threatening illness creates in them a considerable feeling of threat and a disheartening imagination that they have an illness that frightens others. Link, Struening, Sheree Neese-Todd, Asmussen and Phelan (2001:1622-1625) maintain that individuals who are stigmatised often expect to be rejected by others, thus making them act less confidently, sometimes becoming defensive and choosing to avoid others. Butt (2008:719) adds that one major psychological outcome of stigma related to life-threatening illness is self-blame and the thought that the illness may be a punishment for their misdeeds. In the absence of support systems, the abandonment associated with stigma leads to needless dissipation of social, economic and healthcare relationships, further aggravating sufferers' already declining health and well-being including overall quality of life. The reduction in sufferers' status of wellness, Butt (2008:720) notes, may be partly attributed to their

refusal to access healthcare fearing it may further expose them to the ills of social stigma which in turn would only serve to increase their stress and the illness burden.

The negative consequence of life threatening illness is further illustrated by Drabe, Zwahlen, Buchi, Moergeli, Zwahlen and Jenewein (2008:199-204) who argue that the 'psychological burden' of life-threatening illness does not only stop with the sick person, but may result in increased prevalence of psychiatric disorders in the family. LeMaistre (1999:1-2) holds that the potential of life threatening illness to cause severe harm lies in their capacity to undermine affected persons' sense of well-being, competence and productivity. Ogden (2000:56-64) declares that if unchecked, survivors of life threatening illness may approach life from a defective and gloomy perspective of resignation, self-denial and helplessness and may begin to perceive their life after as meaningless and hence worthless. This view is further corroborated by Link et al (2001:1622-1625) who consider stigma as being harmful to a person's self-esteem leading them to withdraw from others. LeMaistre (1999:1-2) proposes that such resignation after life threatening illness or while anticipating a hurtful experience may be mitigated by helping affected persons adapt to their new realities.

### **3.5.3. Socio-economic effects of living in shadows of life threatening illness**

The social economic implications of living in the shadows of life-limiting illness relate more to the fear and panic it creates in populations. If widespread, such fear and panic results in social isolation, stigma, loss of relationships and loneliness. Waxler (1992:169-92) points out that the social stigma associated with serious infectious diseases such as Ebola is far worse than the disease itself and although the illness may be cured, the stigma often lingers on with the survivor for a long time, in some cases for a lifetime. This social mark of ostracism and the resultant stigma can motivate patients and their relatives to conceal new cases of the disease. This concealment may cause the illness to be '*silently*' perpetuated, thereby creating a possible "*epidemiologic catastrophe*" which undermines surveillance and health promotion efforts (McGrath 1993:63-65). Such practices threaten early case detection and treatment and have the potential to fuel epidemics particularly when affected persons refuse to seek health care because of their perception that the cost of social exposure resulting from seeking of health services is high in light of social stigma.

The damaging effect of social stigma, Goffman (1990:3-6) adds, relates to the undue labelling, rejection, disgrace and humiliation experienced by the stigmatised individual as well as being discriminated against by others including treating them inhumanely. This observation is further substantiated by Major and O'Brien (2005:393-421) who describe that stigmatisation transforms the stigmatised person from being a whole person to a tainted incomplete person, making them feel different and of less value than others. Such experience of stigmatisation may occur at workplaces, schools, healthcare environments or even at home within families. In educational settings, Major and O'Brien (2005:408) notes, students who belong to stigmatised groups tend to display lower academic performance and achievements compared to non-stigmatised groups, further underscoring the negative effects of stigma on groups.

In fact Major and O'Brien (2005:393-402) add that in the long run, stigmatised people tend to act in ways expected by those who stigmatise them especially by shaping their emotions and beliefs about their condition. This act of conforming to "*tormentors' expectations*" has a further negative consequence of lowering their self-esteem. The diminished self-esteem further alienates them from services, socio-economic, educational and welfare opportunities and prospects for gainful employment. The reduced opportunities further limit their social networks only to persons they think are sympathetic to them (Link, Cullen, Struening, Shrout & Dohrenwend 1989:400-402). In addition, Link (1982:202-205) and Rosenfield (1997:660-662) maintain that stigmatised persons also experience poor life satisfaction due to the possibility of remaining unemployed for a long time, isolating themselves and getting consumed by negative feelings of hopelessness and helplessness, further creating predicaments in their lives and in the lives of their close family members (Link & Phelan 2001:383).

A study carried out by Golden, Conroy, O'Dwyer, Golden and Hardouin (2006:3188-98) on stigma associated with Hepatitis C, showed that stigmatised individuals tended to underperform at the work place and had difficulties with social adjustment, in addition to experiencing greater impairment of memory and concentration. In view of these difficulties experienced, Barret and Brown (2008:34-7) conclude that stigma related to infectious diseases is a major barrier against health seeking behaviour and if left unchecked, has the potential to reduce early case detection and treatment

thereby increasing the risk for further infection. Barret and Brown (2008:34) also warn that if left unattended, social marginalisation may also lead to increased poverty and social neglect and this may in turn increase susceptibility to diseases. Another social consequence of stigma advanced by Barret and Brown (2008:34-37) is the potential to cause mistrust of health authorities with the potential to undermine cooperation with health officials during epidemics. Social stigma related to life-threatening illnesses also has a negative effect on resource allocation. Barret and Brown (2008:34-37) note that because stigma leads to exaggeration of potential of risk, the ensuing mass panic usually leads to overreaction, which in turn results in disproportionate allocation of financial resources by politicians and health workers for epidemic response thus compromising other equally vital areas of the public sector.

### **3.6. COPING STRATEGIES FOLLOWING LIFE-THREATENING ILLNESS**

The physical, psychological, social and economic consequences of living with or under the threat of life threatening illness create a burden that survivors have to withstand. This capacity to withstand these strains and stresses is what is broadly termed as coping, which according to Lazarus and Folkman (1984:141) is the constantly changing cognitive and behavioural efforts by the individual to manage specific external or internal demands that are perceived as taxing or exceeding a person's resources. Wright (2007:xi) explains that coping strategies provide individuals with possibilities to go through negative consequences. Coping is thus a stabilising factor, consisting of both cognitive and behavioural efforts that help individuals maintain psychosocial adaptation during stressful periods (Holahan, Moos & Schaefer 1996, in Livneh & Martz 2007:9). In fact, Livneh and Martz (2007:10) contend that during stressful situations, affected individuals make cognitive, emotional and behavioural adjustments so that they experience a decrease in the level of psychological distress in order to regain their state of psychological wellbeing.

#### **3.6.1. Social support and coping efforts**

In life-threatening illness, coping does not occur in isolation. Kosciulek (2007:72) declares that coping occurs in broader social contexts and draws in individual's families, members of their communities and healthcare institutions. Groves

(2008:338-40) explains that social support towards peoples' 'coping efforts' enhances their inner capacity to withstand stressors. Similarly, Folkman and Moskowitz (2004:745-60) observe that social support plays a significant role in minimising the negative impact of stressful situations, including lowering the risk of developing psychological disturbances. This is further affirmed by Ptacek and Pierce (2003:114-121) and Chronister (2005) as explained in Martz and Livneh (2007:79) who claim that social support not only reduces individual's susceptibility to illness, but it also promotes better coping during stressful circumstances. In view of these affirmations, it may thus be argued that social support makes coping much easier for the individual who is then able to reap the benefits, among them regaining a positive self-image and psychological well-being despite the presence of external challenges.

### **3.6.2. Goals achieved through coping efforts**

When effective, coping efforts should result in some benefits which are referred to as coping goals. These goals refer to the end product of the coping effort. Lazarus and Folkman (1984) as explained in Livneh and Martz (2007:13-14) propose that coping achieves two broad functional goals. The first helps the individual to deal with the source of distress, while the second helps them surmount emotions emerging from the situation. In dealing with the source of stress, the individual attempts to modify the situation to remove or lessen the magnitude of the stressor. The process of coping according to Perrez and Reicherts (1992) as explained in Martz and Livneh (2007:13-14) starts with assessing the complexity of the stressor to determine whether or not it is modifiable. When perceived as "*un-modifiable*", the individual's physical and emotional energies are re-directed towards adapting (coping) as a remedy to continue living with the stressor(s) in their everyday lives. A second explanatory model that explicates the goals of coping is proposed by Skinner, Edge, Altman and Sherwood (2003:216-218) who argue that coping is aimed at achieving three functionally derived adaptive processes to the stressor. The first process emphasises coordinating environmental actions to enable adjustment to the stressful situation. The second functional adaptation efforts help to integrate available social resources into coping efforts and whenever desirable to withdraw from relations deemed unsupportive to the person's coping efforts. The third process deals with coordinating

preferences and available options including new options to adapt to new realities. Livneh and Martz (2007:13-14) conclude that coping efforts are justified in the sense that they assist individuals to effectively withstand or transcend stressful occurrences.

### **3.6.3. Coping resources for effective adaptation**

In order to cope effectively, individuals require resources to adapt to stressors. These resources may be within or outside of the affected person and may be positive or negative depending on how they influence one's capacity to deal with challenging situations. Hobfoll (1998) explains in Livneh and Martz (2007:16) that internal positive coping resources are traits that result in positive psychosocial adaptation including attributes of mastery of self, positive self-esteem and sense of self-efficacy, personal control, hopefulness including optimistic disposition, problem-solving and interpersonal skills. The negative internal resources are those traits that result in poor psychosocial outcomes characterised by hopelessness, helplessness, pessimism and low self-esteem (Livneh & Martz 2007:16). External coping resources on the other hand include social linkages and tangible resources such as finances, network of colleagues, availability of time and existence of other stressors. These external coping resources influence individuals' response to stressful situations, meaning that individuals in possession of support structures tend to cope better than those with no or very limited external support mechanisms (Livneh & Martz 2007:16).

### **3.6.4. Coping strategies during and after life-threatening occurrences**

Individuals who encounter life-threatening and life-limiting illnesses have to adapt to the physical, psychological and socio-economic consequences of the illness, the details of which are explicated in section 3.5.1 for physical consequences; section 3.5.2 for psychological outcomes and section 3.5.3 for socio-economic concerns. Lain (2010:2-4) reports that when dealing with physical consequences of debilitating illnesses, systematically structuring one's day through appropriate planning and goal setting leads to rebuilding of the sufferers' self-confidence. This suggestion is supported by the affirmation that despite being handicapped, individuals experience a great sense of satisfaction if they are able to accomplish set goals. Lain (2010:2-4) explains that transcending illness through goal setting makes survivors attain peace

within themselves and in the long run this results in a positive outlook. This positive mentality enables individuals to regain control over their lives, which is critical to their recovery (Samson 2006, in Samson & Siam 2008:429). In addition, physical challenges of illnesses may be subdued through altering physical environments at home and at workplaces to facilitate accomplishment of tasks within one's limitations (Lain 2010:3). This alteration of the environment eases tasking and leads to emotional reward of *'feeling in charge'* and Cleveland Clinic Foundation (2009:1-2) asserts, through this alteration, the challenges such as those related to reduced range of motion of the affected person are addressed which enables better function.

Butler (2010:1-2) adds that another coping strategy that sufferers often use to adapt to the physical symptoms of serious disease involves educating themselves about the condition. In a study among cancer survivors, Heppner, Tierney, Wang, Armer, Whitlow and Reynolds (2009:331-332) found that a major coping strategy involved seeking out information about their illness from the internet, medical personnel and support groups. Such information, Lain (2010:4) clarifies helps sufferers to make decisions which make them to cope better. In fact, Samson and Siam (2008:426-8) maintain that through increased cognition, sufferers conceptualise the impact of a life threatening condition on their wellbeing and this in turn helps them to evaluate and utilise available resources for coping when facing life threatening illnesses. Furthermore, symptom management and heightened awareness about one's body are other coping strategies that have been utilised to adapt to the physical strains of serious illness. Lain (2010:2-4) explains that judicious symptom management is a positive health seeking behaviour and promotes early detection of complications. Also paying attention to one's body helps with understanding conditions that exacerbate the associated physical symptoms such as chronic pain and weakness. Therefore effective symptoms management ensures effective coping in the person.

When dealing with psychological consequences of life threatening illness or the aftermath of a condition that has altered their physical appearance or their social standing, Kosciulek (2007:79) discloses that affected persons usually develop coping abilities that enable them withstand inconveniences of second looks, prolonged stares or avoidance. When subjected to such situations, Wright (1983) as noted in

Kosciulek (2007:76) notes that stigmatised persons may respond by ignoring the stigma, or react with rage, retaliation and hostility or use humour to cope with or withstand the uncomfortable situation, although this often further demeans them.

In terms of social consequences of life threatening illness, Holmes and River (1998:231) illuminate that affected individuals often opt for various coping strategies among them social withdrawal, secrecy, indiscriminate disclosure, selective disclosure and social action. The first strategy, social withdrawal involves the affected individual retreating from social interactions to avoid the risk of being stigmatised. In other incidences they may cope by secrecy, which according to Holmes and River (1998:232) means hiding the illness from others. In contrast, others may choose indiscriminate disclosure which refers to deliberately disclosing to others that they have a particular illness. In some instances the affected person may chose selective disclosure where they open up only to persons they trust and believe will be supportive to their cause. The fifth coping strategy is adopted when affected persons lobby for change in the manner in which they and others with similar condition are treated. The fifth strategy of social action, Kosciulek (2007:76) affirms targets influential people, local communities and governments and is based on the assumption that involving such people lightens the burden of social stigma, thus making coping a tolerable affair eespecially when face with numerous consequences.

In order to retain their economic productivity including formal employment, Kosciulek (2007:81) states that stigmatised persons are often forced to go an extra mile to demonstrate their efficacy. This implies that at the work place, they have to overcome the view that they are less capable or unfit for their work. Szymanski and Trueba (1994) as expounded in Kosciulek (2007:82) affirm that stigmatised individuals cope by working extra hard, often beyond the call of duty in an attempt to demystify the illusion that they are incapable of performing assigned responsibilities effectively.

### **3.7. INDIVIDUAL HEALTH NEEDS AFTER LIFE THREATENING ILLNESS**

The healthcare needs of individuals living in the aftermath of life threatening illness depends on how they react to and cope with the illness as discussed in the previous section. These needs may increase if there is continuous deterioration of the

individual especially if they fail to adjust to their new realities and indulge in maladaptive behaviour such as refusing treatment, losing hope entirely or becoming unnecessarily dependent on others. When persons experiencing maladaptation do not receive extra attention, Andrykowski, Lykins and Floyd (2008:193-200) argue, they may not recover fully or could deteriorate further leading to their death. In contrast, others may experience enhanced psychological and social adjustment, transcending the traumatic experience and continuing in their upward journey of recovery. The health needs of such patients largely focuses on supporting them in this journey of recovery and identifying factors that contribute to their success in transcending circumstances related to the illness (Andrykowski et al 2008:193-98).

According to Doka (2009:82), individual's reactions to life-threatening illness may be broadly categorised into physical, cognitive, emotional, behavioural and spiritual wellbeing. The health needs of survivors of life threatening illness will thus depend on how well they adapt to each of these five dimensions. The caregivers' priority is to identify and address the unique health needs in each of the patients' five dimensions.

### **3.7.1. Healthcare needs related to physical effects of disease**

The experience of serious illness is associated with physical changes and challenges which may result from the disease and the treatment process. According to Knobf (2002:10-12) adapting to consequences of disease and the treatment regimen usually takes longer than anticipated and may cause untoward effect on affected persons. These consequences may be slight or severe. If the physical aftereffects are severe, the affected person may experience the sense of "loss of healthy self" which serves as an unwelcome reminder of the illness in survivors' lives (Odo & Potter 2009:24). The feelings of uneasiness and anxiety increase, particularly where the physical effects of the illness are visible, because they have to adapt to second looks and uncomfortable comments. In cases where no obvious physical consequences exist, affected persons still have to adapt to living with physical challenges such as sexual dysfunction, weakness and fatigue which in turn affect their self-image.

Doka (2009:82) claims that individuals and their families experience extraordinary levels of stress when a life threatening illness strikes. This stress begins with diagnosis, continues through to treatment and may extend well into the aftermath of the illness. The reasons for the stress are varied ranging from fear of death, treatment processes and other uncertainties related to the disease process and its aftermath. Goodman (2004:36) documents that the physical health needs usually relate to symptoms of insomnia, fatigue, headache, nausea, menstrual disturbances or loss of appetite, all due to the effect of stress or complication of the disease. Zebrack and Chesler (2001:248) add that the health needs of such persons should focus on resolving these physical manifestations through appropriate treatment.

### **3.7.2. Healthcare needs related to cognitive manifestations of disease**

The aftermath of life threatening illness is oftentimes characterised by cognitive responses such as shock, denial, egocentrism, perceived changes in body image, loss of self-esteem and sleep disturbances. Other cognitive disturbances include forgetfulness, inability to concentrate, mental confusion and psychiatric disturbances. Winiarski (1991) as cited in Doka (2009:92) explains that in other instances, suicidal thoughts and hopelessness may occur. The experience of shock is attributed to the expected outcome of the disease while the concept of denial relates to the difficulty of managing information about the illness (Grossman, Van Neste Kenny, Virginia & Chambers-Evans 1999:159-162). As a result of these cognitive challenges, Doka (2009:84) contends that sufferers frequently choose denial as a coping strategy, and in so doing, they may consciously suppress the facts of the illness, preferring to concentrate on less traumatic issues in their lives in order to adjust to the new reality.

When clients manifest egocentrism, available evidence suggests that caregivers should help focus their attention outwards, encouraging them to take more interest in other events and occurrences other than their illness. Bender, Ergun and Rosenzweig (2005:219-224) substantiate that caregivers are expected to exercise caution in dealing with such persons because their disengagement from others and constriction of interest about external occurrences may be evidence of depression. Other cognitive disturbances which members of the health team need to identify and

address through counselling and appropriate referral include suicidal thoughts, psychiatric disturbances and changes in clients' perception of their body image as explained in Knobf (2007:72-76) as well as Andrykowski and others (2008:193-195).

### **3.7.3. Healthcare needs related to sufferers' emotional responses**

The feeling of uncertainty and loss of control that characterises life threatening illnesses have far-reaching implications on affected person's self-image (Odo & Potter 2009:24). In the aftermath of serious illness, sufferers experience a wide range of emotional responses including a heightened awareness of vulnerability, resulting in decreased sense of wellbeing (Sammarco 2001:212-219); overwhelming fear of recurrence, resulting in numbing inability to move forward (Ganz, Greendale & Petersen 2003:4184-5) and mixed reaction of guilt, shame, anger, fear, anxiety, sadness, depression and resignation (Doka 2009:93-99). As a remedy, Bennet and Bennet (1984) as illuminated in Doka (2009:94) recommend that the health need of such sufferers is to help them cope with or overcome these negative feelings.

One of the commonest emotional reactions associated with life threatening illness is anger. This anger which sufferers often direct at caregivers, family members or friends may be due to the overwhelming burden of the illness, fear of untimely death, fear of the unknown, loneliness, loss of physiological and functional ability or the recurrence (Andrykowski et al 2008:194; Doka 2009:94). The responsibility of caregivers in such circumstances is to explore circumstances of the anger to help prevent more deterioration and decimation of supportive relationships and structures.

Doka (2009:99) explains that another emotional response in life threatening illness is resignation manifested by sufferers ceasing to fight for survival and accepting the inevitability of death. This emotional reaction occurs when individuals believe they can no longer conquer the impending death, leading to total collapse of other coping strategies (Roberts 1988, in Doka 2009:99). The caregiver in such circumstances is expected to understand reasons for their resignation and ensure they do not self-destruct any further to hasten their death including noncompliance to the medical regimen, refusing prescribed treatment or by committing suicide (Doka 2009:100).

#### **3.7.4. Healthcare needs related to sufferers' behavioural responses**

The commonest behavioural responses experienced during life threatening illness are hypersensitivity, disengagement and dependence (Doka 2009:102), which may affect the person either positively or negatively. They are considered positive if they help individuals cope with the demand of the illness and are negative if they lead to undesirable results. Usually such hypersensitive individuals often become extremely conscious of how their family, friends and caregivers respond to their demands.

Typically, they are suspicious and scrutinise all communication to such an extent that they may begin to annoy or embarrass those caring for them because their behaviour often projects the impression that others may be hiding vital information from them, thereby creating room for conflict. Caregivers are thus expected to encourage such sensitive clients to realise that their projected lack of trust in those caring for them could be counterproductive, which may lead caregivers and family to abandon them.

In addition to hypersensitivity, persons living in the aftermath of life threatening illness may also disengage and withdraw from others. Doka (2009:102) explains that people may withdraw from others due to anxiety, pain, egocentrism, depression or feeling of abandonment especially by those they consider close. Although this tends to occur frequently in the acute phase of the illness, it may also re-emerge in the aftermath of the illness. Hence, caregivers dealing with such patients need to explore reasons for their withdrawal and then attempt reintegration with significant others to foster coping.

Another emotional response that may occur in the aftermath of life threatening illness according to Doka (2009:103) is regression and overtly dependent behaviour. Such reactions are seen where individuals instead of being independent surrender all self-control to others under the pretext that the illness has diminished their ability for self-control, implying that they need others to “prop” and support them. This sense of hopelessness and refusal to take control of their own affairs exert immense pressure on caregivers. Health teams in such situations should persuade such individuals to regain their autonomy. Stewart, Wong, Duff, Melancon and Cheung (2001:537-40)

agree that facilitating client's journey towards autonomy promotes independence and a sense of wellbeing in such dependent persons, thus lessening the burden of care.

### **3.7.5. Healthcare needs related to clients' spiritual manifestations**

Life threatening illness often creates an existential or spiritual crisis in affected persons, leading them to question their faith, the quality of their lives and the fairness of the world (Doka 2009:105). Manning-Walsh (2005:120-130) explains that whether or not a survivor identifies with a particular religion, the aftermath of a life threatening illness presents an opportunity to explore spiritual and existential issues. This is because in the aftermath of serious illness, affected persons usually reflect deeply about their survival, prompting them to assign meanings to the illness experience.

The outcome of such questioning may lead to deepened faith, increased commitment to their faith or shattered faith, sometimes to the point of rejection. Manning-Walsh (2005:120-130) explains that if survivors experience renewed interest in religion, spirituality and the afterlife they may intensify their religious and spiritual activity including attending prayers and performing religious rituals. Conversely, those who experience spiritual crises may manifest signs of anger directed at God and other deities, at times resulting in rejection of previous spiritual practices such as prayers.

Although survivors of most serious illness are known to react differently, Clay, Talley and Young (2010:14-25) in a recent study found that individuals with a strong sense of spirituality tend to cope better with the aftereffects of life threatening illness, presenting with a lesser psychological burden than others. The implication of such research finding is that caregivers have to assess changes in their clients spiritual beliefs and practices to help identify the need for spiritual counselling and support especially for those sufferers perceived to be in a spiritual crisis (Doka 2009:105).

## **3.8. CONCLUSION**

The purpose of the preliminary literature review was to inform the researcher and the reader on the main issues linked with the experience of living with or in anticipation of

a life threatening and life limiting illness. The following were the four main themes that emerged from the preliminary review of related literature:

- nature of Ebola virus and the haemorrhagic syndrome.
- consequences of living with or in anticipation of life-threatening/limiting illness.
- coping strategies employed during the aftermath of life-threatening illness.
- healthcare needs of persons afflicted by life-threatening and life limiting illness.

In Chapter 4, the research design, data collection and analysis techniques, ethical considerations as well as measures to enhance the research quality are explicated.

## **CHAPTER 4**

### **RESEARCH DESIGN AND METHOD**

#### **4.1. INTRODUCTION**

The chapter briefly reiterates the research problem, study aim as well as grand tour question that guided data collection. Qualitative research paradigm is then discussed with emphasis on its attributes that justified its selection to guide this inquiry. The discussions are structured around the attributes of qualitative research, the phenomenological research method, research design, sample selection, data collection and data analysis. The ethical considerations that were employed in the study are articulated as well. The chapter ends with a dialogue on the elements of data quality and measures to enhance trustworthiness. The centrality of this chapter is based on the fact that it articulates the specific methods adopted in the study and provides the framework for data collection, including the form and quality of the data.

##### **4.1.1. Research Problem**

The impetus for this study is the widespread panic, ostracism and stigma that characterises outbreaks of life threatening illnesses and most importantly, the need to understand the basis for such unprecedented fear and rampant antisocial practices that threaten epidemic control. As new strains of lethal viruses such as H1N1 and Ebola continue to appear, the need for up to date scientific information is essential for effective response efforts during outbreaks (WHO 2007:1-2). As Boykin and Schoenhofer (2001:12-14) state, such evidenced based information obtained through appropriate research underpins competent and compassionate care for the affected.

##### **4.1.2. Aim of the study**

This study aims to gain a clear understanding of how people experience the phenomenon of living under a constant threat of Ebola, especially how they perceive Ebola, what their reactions towards Ebola symbolise, including their reactions towards affected individuals and families. The researcher aimed to propose

guidelines that health care workers and policy makers may use to address the human aspects of similar epidemics in future in Uganda and in the Africa region. The study explores the lived experiences of survivors and family caregivers who directly experienced the July 2012 Kibale Ebola outbreak and were aware of the August 2012 Ebola outbreak in neighbouring areas of Isiro and Viadana districts in Eastern DRC, as well as the November 2012 Ebola Sudan outbreak in Luwero, in Central Uganda, which was declared officially over by the MOH and the WHO on 16 January 2013.

#### **4.1.3. Grand Tour Question**

The researcher(s) asked every participant a single grand tour question and negotiated the data to illuminate their lived experiences and perceptions. The grand tour question was: *“What is the experience like to live under constant threat of an Ebola outbreak?”* The single grand tour question helped in exploring the perceptions and the meanings survivors and their family caregivers assigned to their lived experiences. Their perspectives related to the public’s response towards them and other affected persons were explored, using cues and hints provided by them during the interviews in line with the tenets of phenomenological research investigations.

## **4.2. THE RESEARCH METHOD AND DESIGN**

### **4.2.1. Research Design**

A research design refers to the overall plan for collecting and analysing data as well as requirements for enhancing the internal and external validity of the study (Polit & Beck 2010:74,567). Similarly, Loiselle and Profetto-Mcgrath (2004:204) explain the concept of research design as the researcher’s complete plan for answering research questions; including how they would like to test any hypothesis as well as make decisions during data collection and analysis. LoBiondo and Haber (2007:2002) further elucidate that a research design is a framework created to conduct a study. In essence, a research design is a framework that directs the researcher in planning and implementing a study in a way that is most likely to achieve its goals and objectives including assuring quality of data collected (Burns & Grove 2005:211-212).

In qualitative research, the defining characteristic of the research design utilised, as Denzin and Lincoln (2011:3) explain, involves using an interpretive, naturalistic approach where the qualitative researcher studies things (situations, phenomena) in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Creswell (2012:44) contends that qualitative research begins with assumptions and uses interpretive/theoretical frameworks to inform the study of the identified research problems and focuses on addressing the meaning individuals or groups ascribe to such social or human problems.

The qualitative researcher uses an emerging approach to inquiry, collects data in a natural setting, sensitive to the people and places under study, and employs an analysis framework that is both inductive and deductive and establishes patterns or themes. The final product of qualitative inquiry incorporates the voices of participants, the reflexivity of the researcher, a complex description and interpretation of the problem and its contribution to the literature or a call for change (Creswell 2012:44).

In affirmation, Polit and Beck (2010:259) state that the research design in qualitative research is “emergent” because the final design that guides the researcher in data collection and analysis arises during the course of data collection in the field. Within the qualitative research paradigm are various research methodologies (better known as designs) which share several similarities in their overall goals and techniques, although they arise from different theoretical and philosophical backgrounds. The commonest methods used include phenomenology, ethnography, grounded theory and discourse analysis among others (Polit & Beck 2010:263; Creswell 2012:42).

This study utilised the phenomenological method which falls within the qualitative research tradition rooted in the works of philosophers Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976) as discussed in section 2.4. I chose a qualitative research approach using the phenomenological method because it allows rich understanding and description of lived experiences related to Ebola outbreaks as experienced by survivors and their close family members, notably the caregivers. These experiences arose from various participant contexts (Polit & Beck 2010:260).

This choice of the phenomenological method is further supported by Brewerton and Millward (2001:223) who say its greatest advantage is allowing deep understanding of the *structure* or *essence* of people's experience in its rich immediacy and vibrancy (Manamela 2009:90). This is further supplemented by Cohen's (2004:402) declaration that the phenomenological method facilitates deep examination of the structures of an experience from many different angles, sides and perspectives.

#### **4.2.2. Assumptions underlying the design**

The design utilised is based on the following key methodological assumptions about the researcher and participants in addition to those explained in section 1.10.3:

##### **4.2.2.1. Assumptions related to the researcher:**

In regard to the researcher, it was assumed that:

- the researcher's consciousness and use of the open-ended questions are primary research instruments used during data collection (Creswell 2012:45).
- the researcher is inseparable from research process (Polit & Beck 2010:16).
- the reductive process (bracketing) should be integral (Polit & Beck 2010:268).
- the inquiry results in rich descriptive information which helps the researcher understand the meaning of lived experience (Streubert & Carpenter 2011:20).
- the outcome of qualitative inquiry is conveyed descriptively incorporating participant's words and from their contexts (Streubert & Carpenter 2011:22).
- the researcher best understands human experiences in their whole (entirety) rather than as interdependent variables of a situation (Creswell 2012:46).
- the researcher best articulates participant's lived experiences in a "*natural setting*", where the phenomenon occurs (Streubert & Carpenter 2011:22).

#### **4.2.2.2. Assumptions related to study participants:**

In regard to the participants, it was assumed that:

- participants are best suited to provide information about 'living under constant threat of Ebola' and assigned meanings to the experience (Parahoo 2006:66).
- participants do not need to understand the research process in entirety in order to contribute towards understanding of the experience (Witte 2007:102).
- the reality of a phenomenon exists as participants see it and the inquirer records them as seen from participants' eyes (Streubert & Carpenter 2011:21).
- the inductive nature of qualitative research means the researcher builds knowledge from observations and understandings gained from the study participants' narratives during the research process (Creswell 2012:46).
- the meaning obtained from the investigation results from co-creation between both the researcher and the researched (Wimpenny & Gass 2000:1485-1488).

#### **4.3. NATURE OF QUALITATIVE RESEARCH**

Qualitative inquiry is designed to understand and describe poorly understood phenomena and processes including peoples lived experiences (Alston & Bowless 2003:290). The researcher's aim in qualitative research is to focus on learning the meaning participants hold about the problem, not the meaning the researchers bring to the research or writers from the literature (Creswell 2012:47). The qualitative inquirer focuses on understanding phenomena from the perspective of those who have experienced it first-hand. In corroboration, Streubert and Carpenter (2011:3) claim that qualitative research methods are the best suited approaches to gaining knowledge about situations where there is human subjectivity and interpretation, especially where there is need to describe and interpret complex human phenomena.

Qualitative research approach is preferred when a poorly conceptualised phenomenon needs to be explored to generate detailed understanding of the issue (Creswell 2012:48). This is because the qualitative research approach allows in-depth explication of a phenomenon by providing the researcher the opportunity to talk

directly to those involved, by going to their homes or places of work and allowing them to tell their stories unencumbered by what the researcher expects to find or what is articulated in literature (Creswell 2012:48). This in-depth exploration is useful to study a group and to identify variables that cannot be easily measured, including “hearing silenced voices”. A key aspect of this research approach is its capacity to empower vulnerable individuals to share their stories within own contexts or settings.

Creswell (2012:48) adds that the choice of qualitative research is also warranted to develop theories when partial or inadequate theories exist for certain populations and samples or when existing theories do not adequately capture the complexity of the phenomenon. The qualitative research approach fits within the current research because quantitative measures and the statistical analyses simply do not fit the problem of understanding issues related to anticipating and experiencing the outbreaks including the meaning survivors and their family members assign to Ebola.

In the following section, the defining characteristics that make qualitative research appropriate for investigating lived experience such as the lived experience of living in constant anticipation of an Ebola outbreak (Mapp 2008:311-314) are articulated:

#### **4.3.1. Characteristics of Qualitative research**

Qualitative research as explicated by Patton (1990:40), Wiersma (1995:211), Polit and Beck (2010:259), Streubert and Carpenter (2011:20) and Creswell (2012:45) is characterised by:

- interplay of inductive and deductive reasoning.
- emphasis on the emic (insider) perspectives.
- reality as being subjective and multidimensional.
- capturing and discovering meaning and essence.
- developing concepts in the form of themes, categories and subcategories.
- emphasis on understanding of human phenomena.
- reporting of findings in a literary style rich with participants’ commentaries.
- use of multiple methods and data sources.

- flexible method to enrich deeper understanding.
- linguistic epistemology with unit of analysis as the words.
- holistic analysis emphasising the relationships between elements.
- openness to new perspectives that emerge from the field work.
- data collection occurring in natural settings, without manipulation and control.
- reliance on outcomes that emerge from the data rather than as predetermined.

In view of these, a descriptive, exploratory, and contextual qualitative research design was employed using phenomenological method since it allowed the researcher to:

- describe the essence of the experience of living in constant anticipation of Ebola as survivor and community member (Streubert & Carpenter 2011:21).
- collect data in the natural environment in which the phenomenon related to Ebola outbreak was experienced (Creswell 2012:45; Polit & Beck 2010:261).
- conduct the study in an unstructured manner allowing for flexibility during data collection (Polit & Beck 2010:259, Loiselle & Profetto-McGrath 2004:210).
- produce thick and vivid descriptions so that the reader can relate to them, projecting them in the moment (Polit & Beck 2010:267-8).
- present the data with an open mind, acknowledging that all data obtained from participants is valuable for the research outcome (Creswell 2012:48).
- adjust to the new realities that emerged during the data collection because of its inherent flexibility and elasticity (Loiselle & Profetto-McGrath 2004:209).
- explore meanings survivors and family caregivers assigned to their experience considering that reality is multiple and constructed by those who experience a given phenomenon in their own social worlds (Streubert & Carpenter 2011:20).

#### **4.3.1.1. Descriptive nature of qualitative research**

Qualitative research is useful to study phenomena about which little is known, and provides the opportunity to define such phenomena through description. Streubert and Carpenter (2011:21) explain that the in-depth, probing nature of qualitative research suits the task of answering questions such as...what is the nature of this phenomenon?. Thompson (2007:304) agrees that describing in qualitative research

is critical because it is through describing human experience as lived that we can understand the other. To Polit and Beck (2010:22), qualitative inquiry describes the dimensions, variations and importance of a phenomenon, thus helping to delineate, elucidate and classify the important aspects of the phenomenon. Creswell (2012:47) adds that the qualitative researcher develops a complex picture of the phenomenon by reporting multiple perspectives, identifying factors involved in a situation and sketching the larger picture that emerges by identifying and explicating complex interactions of factors in the situation. I utilised this descriptive attribute of qualitative research inquiry to classify the essential elements of the lived experience, later describing them in detail to facilitate deeper understanding (Manamela 2009:92).

#### **4.3.1.2. Exploratory nature of qualitative research**

According to Polit and Beck (2010:22), the exploratory nature of qualitative research is characterised by the researcher beginning with the phenomenon of interest and investigating it in its full breadth and depth including the manner in which it manifested itself including other factors that may influence the phenomenon. This view is supported by Manamela's (2009:91) affirmation that qualitative research allows exploration of new areas in order to gain insight into the phenomenon. Polit and Beck (2010:22) posit that qualitative methods are useful for exploring the full nature of a poorly understood phenomenon. Hence the exploratory nature of qualitative research allows researchers to shed light on various ways in which a phenomenon is manifested including underlying influences such as participants' cultural background. In this regard, I specifically explored the "*phenomenon of living under constant threat of Ebola*", including the *meanings* assigned to Ebola outbreaks.

#### **4.3.1.3. Contextual nature of qualitative research**

According to Polit and Beck (2010:15) human experience is best understood from the contexts of those who experience the phenomenon. The present study was conducted within a socio-cultural context awash with strict sanctioning and stigmatisation. The qualitative research design thus allowed me to explore survivors' and family caregivers' experiences within these unique contexts for the reader to

grasp essential elements and meanings of their lived experiences. The choice of the contextual aspect of qualitative research design was implored by the desire to present these experiences in the natural environment in which the strict social-cultural sanctioning occurred. As Bogdan and Bilken (2003:44) state, the research questions were carefully chosen so that the areas addressed also helped to contextualise the study findings to the realities of survivors and their family members.

#### **4.3.2. Limitations of qualitative research**

Although qualitative research design has a number of advantages due to its inherent flexibility and spontaneous nature, the researcher still noted the following challenges:

- Compared to the structured quantitative inquiry, the openness and emergent design that defines qualitative study resulted in the researcher needing direction on how to proceed at different stages of the research process. As a remedy, most times, I had to rely on my thesis advisor (promoter) for guidance and direction.
- Undertaking a qualitative study is more difficult than what it appears at first sight especially at the point of data collection where the interviews are driven by a grand tour question. The requirement for the researcher to adjust subsequent questions based on how participants navigate through the questions is complex.
- The detailed description of the data collection methods as well as the incorporation of verbatim quotes from participants to enhance the research quality proved all consuming. This requirement far exceeds the expectations within the quantitative tradition, where most research data is presented numerically.
- Conducting qualitative studies takes a long time. It took me several years to progress from identifying the focus of the study, to conducting a preliminary literature review, collecting data, analysing the data and presenting the findings. If it were quantitative research it would have probably taken a much shorter time.
- The data generation process resulted in a huge amount of unstructured descriptive data of over 100 pages single spaced, that needed to be coded and

organised into meaningful data units. I had to read and re-read the verbatim transcriptions several times to distil the themes, categories and significant statements. This process was exceedingly complex because it needed total immersion into the data, to make sense of the vast amounts of descriptive data.

- The ethical and scientific requirement for trustworthiness put me under a lot of pressure to ensure that the findings were presented in a manner that represented the true picture of the views of the survivors and caregivers. This requirement meant I had to adhere to all expected ethical and scientific standards of research.

In the following section, the various steps of the actual research activity are explicated, right from the point of identifying the population up to the point of delineating how ethical considerations were met to ensure the research findings were authentic and congruent with scientific and ethical standards of qualitative research.

#### **4.4. POPULATION AND SAMPLING TECHNIQUE**

The term “population” is defined by Polit and Beck (2010:563) to mean, the entire set of individuals and objects that have the characteristic or attributes in which the researcher is interested. To Parahoo (2006:471), a population consist of units as people, events, objects or institutions from which research data can potentially be collected. It is sometimes defined as target population. Sampling technique/method refers to how a sample is selected from within a target population. Whilst many options for sample selection exist, in phenomenological study, purposive sampling is often used to choose participants who have experienced the phenomenon first-hand and are suited to answer questions related to the experience (Parahoo 2006:274).

##### **4.4.1. Population**

The population consisted of all survivors and their close family members who anticipated and experienced the July 2012 Ebola outbreak in Kibale district. However for practical reasons, the investigation was limited to a smaller group of people who Brink (2006:123) terms, “study population”, which is a section of eligible population to

be included into a study. In this case, the study population comprised persons whose “*being-in-the-world*” was particularly disturbed by the 2012 Kibale Ebola epidemic as:

- survivors who contracted and survived the illness and are now living in the aftermath of this experience in constant anticipation of another Ebola outbreak.
- caregivers of patients and witnessed the illness experience, including the community’s reaction to patients and survivors during and after the epidemic.

The survivors’ perspective helped to bring to life the experience of living in constant anticipation of another outbreak at the backdrop of contracting and surviving a recent Ebola epidemic. The family caregivers’ accounts gave an indication of the experience of family members including the socio-cultural context from which these lived experiences should be understood by taking into account the perspective of the local community who sought to rid themselves of the infection. The rationale for explicating both views is underpinned on frequent occurrence of Ebola outbreaks and the continued stigma in the face of social-cultural sanctioning during such outbreaks.

#### **4.4.2. Sampling technique**

Sampling refers to selecting a portion of the population to represent the entire population (Streubert & Carpenter 2011:90). Norwood (2000:210) adds that the purpose of sampling in qualitative research is to identify information rich cases and explore them in-depth. Polit and Beck (2010:319) maintain that sampling in qualitative research involves selecting people who are knowledgeable, articulate, reflective and willing to talk at length with the researcher to meet the study’s informational needs.

I made a choice from the following applicable options: purposive sampling, network sampling, volunteer sampling, total population sampling, random purposeful sampling and convenience sampling whose salient characteristics are discussed in Table 4.1:

Table 4.1 Sampling techniques used in qualitative research studies

SAMPLING TECHNIQUES USED IN QUALITATIVE RESEARCH	
Technique	Purpose and Defining characteristics
Purposive Sampling	To select information rich cases for in-depth study of a phenomenon. Subjects are selected individually according to knowledge of the phenomenon and the study's informational needs. Several variations exist as presented hereunder:
	<b>Stakeholder Sampling:</b> Is useful in evaluation research and policy analysis and involves identifying stakeholders involved in designing, giving, receiving or administering a program or service being evaluated and persons affected by it (Given 2008:697-698).
	<b>Critical Case sampling:</b> Is used when a “decisive” case is required to help make a decision about a particular phenomenon. It is used to conform to recommendation by experts and it allows for generalisations to larger target populations (Given 2008:698).
	<b>Extreme or Deviant Case Sampling:</b> Chooses extreme cases which represent the clearest instance of a phenomenon by considering informants whose experience is beyond the norm (Given 2008:698). Such extreme cases illustrate a phenomenon more clearly than the norm (Østbye 1992, in Norwood 2000:212).
	<b>Typical Case Sampling:</b> Used when researcher is interested in describing typical cases as opposed to making general statements about a phenomenon (Patton 1990:182). The researcher or informants identify typical cases regarding the phenomenon and explore it further (Given 2008:697-698).
	<b>Politically important case sampling:</b> Occurs when the researcher selects high profile cases to increase visibility of a phenomenon (Norwood 2000:212). This sampling assumes that including prominent figures in a particular inquiry may help with adoption of the findings (Østbye 1992, in Norwood 2000:212).

<b>Purposive Sampling</b>	<p><b>Disconfirming or Negative Case Sampling:</b> Used when researcher is looking to extend the analysis by looking for cases that will disconfirm it, to arrive at the point where explanations are sensible. This technique is useful in theory testing and to find the point at which generalisability of findings stop (Given 2008:698).</p>
	<p><b>Theoretical Sampling:</b> Is used by researchers following a more deductive or theory testing approach such as in grounded theory research to find individuals or cases that embody theoretical constructs related to the phenomenon (Given 2008:697-698).</p>
	<p><b>Criterion Sampling:</b> it is used when researcher wants cases or individuals who meet a certain criterion, disease or experience. It is useful to assure quality of study findings (Given 2008:697-98).</p>
	<p><b>Maximum Variation Sampling:</b> The technique is used to obtain cases or individuals who cover the spectrum of positions and perspectives in relation to the phenomenon. It involves all different categories of people who have undergone the experience, so that the researcher is able to describe themes that cut across the different groups. It is vital in identifying the universally shared aspects of an experience (Patton 1990:182).</p>
	<p><b>Expert Sampling:</b> This sampling approach is used when the researcher is looking for individuals or cases who have particular expertise that is likely to advance the researcher's interests and to potentially open new doors in the inquiry, hence creating more understanding of the phenomenon in question (Given 2008:698).</p>
	<p><b>Homogenous sampling:</b> Used when there is need to describe the experience of a particular group in detail (Morse 1991:128). Consideration for sampling and investigation is based on variables such as gender, age or ethnicity because the phenomenon may be experienced differently by the various groups of people.</p>

<b>Purposive Sampling</b>	<b>Random purposeful sampling:</b> Helps the researcher to reduce potential purposeful sample to a manageable number, particularly when the potential purposeful sample is larger than what researcher can handle. The researcher chooses randomly from a group of informants to increase the credibility (Mongwe 2009:86).
<b>Network Sampling</b>	<b>Network sampling</b> is where support of a single informant is used to assist in selecting additional informants. It assumes that members of a group can identify others who meet the same criteria. It is useful where informants are difficult to identify. The approach is also termed snow ball sampling and is particularly helpful in the introductory phase of a study after the researcher gains participants' trust (Norwood 2000:212).
<b>Volunteer sampling</b>	<b>Volunteer sampling</b> involves soliciting participants through advertisements. Its advantage is that it helps to include informants with broader understanding of the phenomenon (Morse 1991:131). As quality measure, volunteer participants are pre-screened before enrolment to determine if they meet the inclusion criteria.
<b>Total population sampling</b>	<b>Total population sampling:</b> This sampling technique is used to identify potential informants with the attribute the researcher wishes to investigate. This strategy is reserved for situations where there is a relatively small number of potential informants and where excluding any one of them would be inappropriate or rude (Østbye 1992, in Norwood 2000:212).
<b>Convenience sampling</b>	<b>Convenience sampling:</b> This sampling technique is used to save time and money and the researcher targets those informants who are readily accessible, in other words, easily available. It may lead to information poor cases and low credibility of the study. It is considered poorest of sampling techniques (Mongwe 2009:86).

The present study adopted purposive, convenience and criterion sampling techniques to obtain study participants, the rationale and the method of which are now explained:

- **Purposive sampling**

Purposive sampling technique was used to select participants for the present study. This choice agrees with Streubert and Carpenter's (2011:29) affirmation that purposive sampling supports the qualitative researcher's goal of developing a rich or thick description of a given phenomenon. In support, Brink (2006:133) points out that purposive sampling involves consciously selecting certain participants from the target population whom the researcher believes will help them generate thick descriptions.

In this study where many individuals met the sampling criteria (refer to section 4.4.2.1), a random purposive sampling technique was used to arrive at a manageable number of participants. I selected the actual participants randomly from a list of *qualified* survivors and family caregivers (Mongwe 2009:86; Patton 1990:182).

- **Convenience sampling**

Convenience sampling entails inclusion as study participants, persons who are conveniently available at the time of data generation (Polit & Beck 2010:311). Convenience sampling according to Norwood (2000:428) involves selecting readily available participants that meet the inclusion criteria. Here it involved starting with participants who were "*at the right place at the right time*", especially at the beginning.

Although this sampling technique is often criticised for having low credibility, the *research team* ensured that all those who were sampled "*conveniently*" actually met the inclusion criteria of the study (refer to section 4.4.2.1). In the present study, *convenient sampling* was not a problem because the target population was relatively large and as Brink (2006:132) affirms, the conveniently sampled potential participant was either an Ebola survivor or a close family member who met the set study criteria.

- **Criterion sampling**

Patton (1990:182) explains that convenience sampling is where the researcher sets criteria (see section 4.4.2.1) and picks all cases that meet the inclusion criteria. The reason for choice of this sampling method is its strong impression on quality assurance. The research team selected participants based on the fact that they were *living in constant threat of an Ebola outbreak* as survivors or as family caregivers in the community, after witnessing the July 2012 Ebola outbreak. I came to know those who survived and witnessed the outbreak through information obtained from the District Health Office and after verification by members of Kibale District Ebola Task Force and Kibale Survivors Group members, before commencement of the study.

#### **4.4.2.1. Sampling criteria**

Christian (2000:291) and Polit and Beck (2010:321) assert that a key characteristic of qualitative research is that a variety of sampling methods are applicable. This implies that during sampling, the researcher employs a sampling technique that allows for careful selection of participants depending on the informational needs and the inclusion criteria. The eligibility to participate in this study was determined by:

- getting infected and surviving an Ebola infection and living in the community as a survivor and experiencing the aftermath and threat of Ebola outbreaks.
- caring for a close family member or family friend infected with Ebola and experiencing ostracism and social stigma by members of the local community.
- consenting to participate in the study as an informant.
- granting permission to be tape recorded during and after the interview.
- expressing readiness to share their lived experience with the researcher.
- demonstrating the ability to competently describe their lived experience.
- agreeing to validate themes and descriptions in other interviews if required.
- showing no signs of late complications of psychotic behaviour characterised by mental confusion, anxiety, depression, restlessness and aggressiveness.

Participants who satisfied these inclusion criteria were randomly chosen from a group of purposely chosen survivors and their family caregivers. As Patton (1990:169) suggests the logic and power of purposive sampling lies in selecting information-rich cases: those who witnessed the outbreak and the rampant social-cultural sanctioning.

#### **4.4.2.2. Sample size**

In qualitative research there is no rule regarding the sample size (Patton 2002:67), rather the size of the sample is determined based on the informational needs of the study (Polit & Beck 2010:321). However, Sandelowski (1995a:179-183) warns that the issue of sample size should not be misunderstood when dealing with qualitative research because adequacy of sampling is important in both qualitative and quantitative inquiry. Parahoo (2006:277) agrees that the qualitative researcher needs to make judgements to ensure that the number of participants is adequate to support a particular enterprise, warning that the sample should not be too large, so as to sabotage the deep case oriented analysis of the phenomenon, nor should it be too small so that the researcher fails to delineate the “*core*” essence of the phenomenon.

This is further validated by Punch (2004:117) who asserts that when the research sample is too large, certain responses of the participants may not be considered or not respected. LoBiondo-Wood and Haber (2002:126) also warn that researchers should avoid using too few participants arguing that such very small samples tend to be unstable, especially for nomothetic analysis. This view is similarly shared by Giorgi (2008:36) when he points out that larger samples help the researcher to more easily distinguish or discriminate a single individual’s particular way of living the phenomenon from a more general way that belongs to a type rather than to an individual. Hence, the number of participants should allow sufficient variation so that the researcher gets to ‘*general aspects*’ of an experience and ably arrives at the ‘*essential elements*’ of the phenomenon close to first-hand experience as possible.

Further, Polit and Beck (2010:321) point out that sample size in qualitative research is guided by the point at which data saturation and redundancy appear. In agreement, Streubert and Carpenter (2011:90) state that data generation in qualitative research

should continue until the researcher notes data saturation and when a sense of closure appears as additional interviews yield no new information and data are repeating. Data collection continued until the researcher was satisfied that the point of redundancy and saturation were attained (Robinson 2000:208; Streubert & Carpenter (2011:91). This point of data saturation was noticed with relative ease, because initial data analysis (initial reading) occurred alongside data collection.

In other words, I was careful to ensure that the sample size was small enough to facilitate idiographic analysis of each of the salient features within the phenomenon of inquiry and large enough to ensure nomothetic analysis so that the findings are sufficiently clear to apply to other survivors and their family caregivers who may experience similar phenomena during subsequent Ebola outbreaks in the near future.

#### **4.5. THE RESEARCH INSTRUMENT**

A '*research instrument*' refers to a tool or method that the researcher uses to collect or measure the concept or phenomenon being studied (Polit & Beck 2010:557). In qualitative inquiry, two types of tools are available: the researcher and the formal research instrument, as an interview guide or observation checklist, which guides the researcher in collecting the data required for answering the key research questions.

##### **4.5.1. The researcher as instrument**

The process of conducting qualitative research using the phenomenological method is characterised by a series of transformative steps which focus on the researcher as a central entity (Barrett 2007:417). Streubert and Carpenter (2011:22) point out that the 'researcher as instrument' notion is an important aspect of qualitative research because the researcher is intimately involved in research activities of data collection through observation, interviewing and interpreting results. The intimate relationship between researcher and participants enables researchers to add to richness of data collection and analysis and improve data quality (Streubert & Carpenter 2011:22).

As an instrument, the researcher presents to the world what the experience means for those who are undergo it. The researcher's role is thus to understand and evaluate the meanings participants attribute to their experience (Hoskins & Marino 2004:35). In order to present these views clearly, the researcher utilised a form of phenomenological reduction, also referred to as bracketing (refer to section 2.3.6.) which allowed the researcher to return to the original awareness of the phenomenon under investigation (Streubert & Carpenter 2011:76). This methodological process allowed me to convey to the readers, Ebola survivors' and family caregivers' lived experiences in a form *untainted* by prior undue influences (Giorgi 2008:41).

This concept of researcher as instrument is further illustrated by Reinharz (1983:78), Barrett (2007:418) and Streubert and Carpenter (2011:46-47) who explain that the researcher is involved in the transformation process through the following five stages:

- The first transformation occurs as participants described their experiences, transforming them into language during data generation phase. This is an 'active, creative, and improvisational process that creates representations of the phenomenon so that this experience may be shared (Graue & Walsh 1998:91). This transformation was enhanced by ensuring that the in-depth interviews took place in places recommended by the participants ensuring comfort, conduciveness and a non-threatening atmosphere (Barrett (2007:417).
- The second transformation occurs when the researcher transforms what is seen or heard into understanding of the original experience. Reinharz (1983:78) advises that since individuals can never experience what another person has experienced, researchers rely on participants' data to develop their understanding of the experience. This second transformation occurs as the in-depth interviews are shaped into data records (Barrett 2007:418). This transformation occurred as the raw data in form of interview notes and audio transcriptions were organised and reconstructed into permanent records, as evidence of the data generation process (Graue & Walsh 1998:142). This phase of transformation was achieved in the present study by exercising great loyalty when incorporating the interview notes and transcriptions into the data.

- The third step of the transformation process according to Barrett (2007:41) occurs as the researcher turns personal understanding of the narratives into conceptual themes and categories which define the essence of phenomena. These themes were generated as I immersed in the 'raw' data, and after reading developed patterns from the data. The thematic areas covered the participants' experience related to living in constant threat of Ebola as expressed by the survivors and family caregivers (Graue & Walsh 1998:143).
- The fourth transformation occurs as the researcher turns the themes, symbolising the essence of the experience into an initial written document that portrays the researcher's understanding of the experience (Reinharz 1983:78). This involves interpreting what the data means and relating the interpretations to other sources of insight about the phenomena in literature, including findings from related research, theoretical frameworks and common experience (Barrett 2007:418). The specific details of how this was achieved in the present study are found in Chapters 6 and 7. The credibility of the findings was enhanced by reaching agreement with the promoter as a form of "*member check*" to ensure that all the themes and categories were abstracted from the data and nothing significant was *left out or added* (McBride 2008:1287-1288).
- The fifth phenomenological transformation involves turning the initial written document into the final document, the exhaustive description, detailing the researcher's understanding of the phenomenon, from which all preceding steps can be clarified (Reinharz 1983:79). This final description as Graue and Walsh (1998:142-143) and Barrett (2007:418) explain reflects primary evidence of the phenomenon interwoven with researcher's reasoned interpretation. In other words, the exhaustive description of the phenomenon relied upon my logical interpretation and artistic presentation of the key findings (Barrett 2007:418), with the aim to get the feeling of "*phenomenological node*", which evidences the readers' affirmation that they could have had this very experience as well.

#### 4.5.2. The formal research instrument

In qualitative research, a variety of strategies can be used to generate data including interviews, observations, diaries, narratives and focus groups among others (Streubert & Carpenter 2011:33). I chose in-depth interviews conducted with the aid of an interview guide as the formal research instrument (Robinson 2000:18) for the data generation because of the need to understand survivors' and family caregivers' experience of Ebola in-depth. Gillis and Jackson (2002:466) define an interview as a face to face verbal interaction in which the researcher elicits information directly from participants through direct questioning. Interviews are highly cherished in qualitative research as substantiated by Creswell (2007, in Elmir, Schmied, Jackson & Wilkes 2011:13) who affirms that face-to-face in-depth interviews result in exchange of information that would otherwise be difficult to obtain through other methods of data collection such as questionnaires or even surveys given their "*personal*" nature.

The choice of in-depth unstructured interviews using open ended questions was based on the understanding that it would provide participants the opportunity to fully describe their experience (Streubert & Carpenter 2011:35). In addition to providing a platform for participants, an in-depth interview was chosen because it yielded rich and detailed information that enabled the researcher to understand the meaning of the phenomenon, from the view point of survivors and their close family members (Streubert & Carpenter 2011:35). As Flood (2010:11) observes, in-depth interviews within phenomenological inquiry usually start by the researcher asking a general question, the grand tour question, which is used to drive the conversation to deeper levels, through the following three stages: first establishing the context of the experience, then moving to construct the lived experience, and then moving to reflect on the meanings interviewees assign to their experience, the result of which is a detailed explication of the essence and meaning of the lived experience in question.

A key aspect considered during the interviews was the level of trust that existed between me and the participants. Perry, Thurston and Green (2004:140) state that the nature and quality of communication and relationship between the researcher and interviewees greatly influence the richness of the data generated because as Denscombe (1998) as cited in Perry and others (2004:140) contends that,

interviewees are more likely to respond according to their perceptions of the interviewer. Cognisant of this fact, I and the other interviewers ensured that a good relationship existed between the interviewing teams and the participants, facilitated by continually assuring informants that the confidentiality of their data would be kept as advocated by Streubert and Carpenter (2011:35) and Perry et al (2004:140). Also employing unstructured in-depth interviews using open ended questions provided participants with an opportunity to respond to research questions, including probes and clarifying questions that interviewers asked as participants navigated through their lived experiences. These allowed survivors and family caregivers to share their lived experiences and life stories and the meanings thereof in their own words, thereby making them more authentic and believable by others (Rosen 2006:310-11).

In order to facilitate the in-depth interviews, an interview guide was utilised (refer to Annexures H and I) as recommended by Robinson (2000:18) consisting of three sections namely: introduction, questions and conclusions as explicated below:

- **Introductory section**

This is the climate setting part aimed at creating an environment that facilitates data collection. In keeping with the recommendations of Qu and Dumay (2011:239) and Perry et al (2004:140), a good relationship ensured successful interview outcomes by allowing survivors and caregivers to share closely held information with interviewers (Streubert & Carpenter 2011:35). The introductory part consisted of congenial elements like greeting, welcome and appreciation remarks, introductions of researcher and the assistants and then explaining the study objectives and ground rules for the interviews as detailed in the interview guide (refer to Annexure H and I).

- **Questions section**

The question section consisted of a single grand tour question explored through related thematic questions aimed at aiding the journey of exploring survivors' and family caregivers' lived experiences in various contexts. The grand tour question was:

- “What is the experience like to live under constant threat of Ebola outbreak?”

Whenever necessary, for purpose of clarity, the grand tour question was re-stated as:

- How do you experience living under a constant threat of Ebola?
- How do you experience the constant threat of Ebola?

The single grand tour question was negotiated and explored with every participant to ensure the questions were well understood using applicable thematic questions:

- What was the experience like to anticipate Ebola infection?
- What was the experience like to be infected with Ebola?
- What is it like to survive an Ebola infection?
- What is it like to live in this community as an Ebola survivor/caregiver?
- How did the public relate to you before, during and after the outbreak?
- What are your feelings about how the public relates to you?
- What does having been infected with Ebola mean to you?
- What does the public's reaction towards you symbolise?
- What do you think causes Ebola/what have you heard about causes Ebola?
- What does caring for a close relative/friend with Ebola mean to you?
- What cultural/religious beliefs and practices influenced public's reaction?
- How have you managed to cope with life as an Ebola survivor/caregiver?
- How did you feel when Ebola broke out in the DRC and in Luwero district?

These thematic questions facilitated deep exploration of perceptions and meanings of lived experience and were enhanced by cues and hints that emerged during the interviews. Probing and clarifying questions were also used to explore unclear areas.

The probing questions utilised included questions such as:

- "Could you say something more about that...?"
- "Can you give a more detailed description of...?"
- "Do you have further examples of this...?"

While the clarifying questions utilised were questions such as:

- “What did you think then...?”
- “What did you actually do when...?”
- “What did you actually do when you felt...?”
- “How did your body react...?”

The use of a single grand tour questions is supported by Fontana and Frey (1998:64) who infer that investigating experiences using unstructured interviews enables researchers to understand complex issues related to people’s experiences without imposing strict categories that may limit the scope of the inquiry. The ‘thematic questions’ and ‘emerging probes’ facilitated navigation through participants’ experiences which allowed deep exploration of their worlds (Qu & Dumay 2011:239).

#### **4.5.3. Pretesting research questions**

The formal research instrument was pre-tested prior to commencing data generation. Polit and Beck (2010:75-76) consider a pre-test as a trial administration of a newly developed instrument to determine whether it meets the desired adequacy, including generating desired information. The pre-test involved administering the draft interview guides to two survivors and two family caregivers to determine the clarity of the interview questions and whether the time allotted was adequate. After the pre-test the research team revised the thematic questions as *a quality control* intervention.

#### **4.6. DATA COLLECTION**

Data collection is defined by Gillis and Jackson (2002:424) as gathering information from identified subjects to answer a particular research question. In qualitative studies, the researcher is expected to describe in sufficient detail the data collection process for others to “see” how the research progressed, thereby serving to enhance the trustworthiness of the study findings. Another rationale for explicating the data collection process is that it helps the researcher show evidence that the data collection process occurred in a systematic manner in line with the chosen research paradigm and the associated epistemological assumptions (Solomon 2001:229).

#### **4.6.1. Data collection using in-depth interviews**

In line with the phenomenological research tradition, in-depth unstructured interviews were conducted using an interview guide that consisted of a single grand tour question, but navigated through several closely related thematic questions. This approach was chosen because of its inherent capacity to enable interviewers to gain entrance into participants' world in order to have full access to their experience. In the words of Polit and Beck (2010:341), interview guides are helpful in ensuring that all the main questions are covered during the interview and that no area gets missed out. McNamara (2009:2-3) points out that another strength of the interview guide is that it helps the researcher to ensure that similar general areas are covered or similar information is collected from each interviewee in addition to allowing the researcher some freedom to adapt the thematic questions to get desired research information.

Each participant was allowed time to describe their experiences in full without the researcher leading and interrupting them needlessly. However, whenever the need arose, probing and clarifying questions were used from the hints and cues noticed during the interview to explore aspects of the lived experience much deeper. This approach permitted participants to describe their experiences freely until they felt they had exhausted their experiences. The interview was facilitated by navigating with each participant the thematic questions in an exploratory manner that did not limit participants' answers only to pre-established alternatives (Norwood 2000:247-248).

#### **4.6.2. Motivation for selecting in-depth interviews**

In-depth interviews were chosen as the primary data collection method because:

- unstructured in-depth interviews allowed participants to describe their lived experience in detail in a free and non-restrictive manner. This allowed me to grasp the essence of each of their lived experiences (Parahoo 2006:66).
- the data collection approach provided me with flexible, creative and penetrative methods and a window for exploring each participant's lived experience in a manner unique to their situation (Polit & Beck 2006:220).

- the method also allowed me to gain entrance into participants' personal (or inside) emic view, the intimate and private world, critical to explicate their lived experiences and associated meanings (Streubert & Carpenter 2011:22).
- the method allowed participants to share their experiences in their own words rather than through pre-established lines of thought, as would have been with structured interviews as in quantitative research inquiry (Norwood 2000:247).
- the approach created the opportunity to intuitively follow participant's leads by asking probing and clarifying questions, leading to exploration of various cues and themes into more complete lived experiences, thereby preventing misinterpretation of their lived experience accounts (Qu & Dumay 2011:239).

#### **4.6.3. Principles that guided in-depth interviews**

The following principles were observed to ensure data quality during the interviews:

- I remained open to the ideas that emerged from the interviews and remained focused on conceptualising them from each participant's "eyes", without undue influence from my pre-understandings and imposing any of my personal perspectives on them (Jonker & Pennink 2010:77) by exercising *reflexivity*.
- I maintained the flow of participant's stories by avoiding unwarranted interruptions and only re-directing participants when they completed their sentences. The thematic questions were phrased in a simple way and as the interviews proceeded, unclear areas were clarified to ensure the interviews did not stall and remained freely open flowing, exploring thematic areas (Qu & Dumay 2011:248).
- Each interview was sustained by maintaining a positive relationship with the interviewees by not offering opinions about responses and avoiding non-verbal indications of surprise or shock. Using non-verbal cues such as nodding to indicate approval or a correct answer were kept minimal. The interviewers also desisted from leading questions, ensuring that all cues and new areas introduced during the interviews were followed through to the end (Qu & Dumay 2011:248-9).

#### 4.6.4. Interviewing skills used during in-depth interviews

In addition to principles of phenomenological interviewing used, the research team followed interview skills recommended by Hannabuss (1996:26), Field (1996:133), Polit and Beck (2010:79) as well as Qu and Dumay (2011:250) in order to avoid limitations inherent during data collection during face to face interviews by:

- Establishing and maintaining rapport with interviewees before and after commencement of data collection. The research team established rapport with participants by welcoming them and engaging them in a “*small talk*” prior to proceeding to the main interview as an ice “*breaker*” to start the process of building trust and to inform interviewees about the purpose of the interview and then to get them talking freely (Mellon 1990, as cited in Qu & Dumay 2011:250).
- Keeping the discussion going and easy flowing by encouraging each participant to talk freely without guiding their responses unnecessarily and avoiding close ended questions as well as jargons that would dampen the free flow of information, ideas or puzzle or even annoy them (Polit & Beck 2010:79; Qu & Dumay 2011:250).
- Focusing and pacing the interview through tactful interruption and guidance of the interview sessions (Hannabuss 1996:26). This was done by using structuring questions which helped the researcher to move from one part of an interview to the next, especially after exhausting such previous areas. As Kvale (1996:134) advocates, the researcher incorporated questions such as “I would now like to introduce...”, and ... “I would like us to talk a bit more on...” to pace the interview.
- Fostering patience and using the moments of silence during the interview to work positively towards the goal of the interview (Qu & Dumay 2011:248). The pauses that arose during the interview were used to give interviewees time to reflect and gather energy for more disclosure. As Doyle (2001:11) advocates, the interviewers tolerated the silence that emerged and desisted from looking impatient, instead we chose to give participants the time and chance to think about what they wanted to say without hurrying them. Giving participants time to think and

recollect their views resulted in the interviewees filling the silence with more information and this kept the conversations 'alive' and rewarding to both parties.

- Adopting a non-judgmental attitude and listening actively and empathetically to participants while avoiding being overtly involved with the topic (Field 1996:134). This potential pitfall was overcome by remaining calm and showing no direct involvement or association with the participant's experiences by maintaining balance and impartiality in the discussions. This impartiality allowed participants to spontaneously express their views without undue influence from the interviewers.

#### **4.6.5. Initiation of the research process**

Initiation of the research process consisted of three main phases: obtaining formal approval from relevant authorities; obtaining potential participants; and preparing for formal interviews in the community setting as described in the subsequent section:

##### **4.6.5.1. Approval Processes**

Approval to conduct the study was sought from the University of South Africa (UNISA) Department of Health Studies Ethics and Research Committees. This was followed by approval from Mildmay Uganda, a Ugandan based Institutional Review Board, and later, Uganda National Council for Science and Technology (UNCST), the national research clearance agency. After the UNCST approval, the researcher was advised to seek further clearance from Office of the President, Uganda. This was then followed by authorisation by the Kibale District Resident District Commissioner (RDC). Scanned copies of these approval letters are enclosed (see Annexures A-F).

##### **4.6.5.2. Selection and training of Research Assistants**

The researcher recruited and trained seven (7) research assistants involved in the data generation. One of them functioned as a translator and three (3) accompanied the researcher during data collection. In addition, the researcher also recruited three (3) transcriptionists. The translator had masters training and the three (3) data collectors were health professionals (1 masters and 2 diploma holders), all fluent in

both Rutoro and Runyoro, the dialects of Kibale district. They were knowledgeable about the local geography and had experience in conducting qualitative interviews. In order to further enhance their capabilities, I re-trained them to ensure that they:

- talked to the “local gatekeepers” to ensure that the researcher was accepted.
- guided the researcher to the various villages and homes of the participants.
- translated the consent form and other related documents into the local language.
- translated the interview questions for participants who do not speak English.
- participated in follow up interviews whenever the researcher deemed fit.

The masters trained research assistant, translated the consent form and the interview guides into Runyoro-Rutoro (see Annexures G, H, I) and also transcribed the interviews that were conducted in the local language into English. The remaining three (3) were bachelors trained and they served as transcriptionists to aid the research process and ensured that the researcher had speedy access to the data.

#### **4.6.5.3. Obtaining potential participants**

- Selection of participants was based on the sampling criteria (refer to section 4.4.2.1) following securing of authorisation letters and the list of survivors from the Kibale District Ebola Task Force Office and Resident District Commissioner, RDC.
- The potential participants were selected from the list of adult survivors and caregivers obtained from the Kibale District Hospital where Ebola patients and contacts, including family caregivers were isolated and treated. A member of the Kibale District Ebola Task Force, a health worker at Kibale district hospital and who also had participated in the epidemic response efforts was requested to link the researcher and his assistants to the Ebola survivors and family caregivers.
- The most credible potential participants were selected based on the understanding that they would be in the best position to describe their lived experiences in-depth as required for qualitative investigations. These potential participants were selected using the set sampling criteria (refer to section 4.4.2.1).

- The selected survivors and family caregivers were then contacted either through telephone or through home visits and appointments were sought with each one of them at their convenient times to participate in the interviews as earlier scheduled.
- The member of the Ebola taskforce accompanied the research team during the home visits and also helped in scheduling appointments with the participants. When the research team met the potential participants, the study purpose was explained and preliminary consent was sought prior to the scheduled interviews.
- This prior preparation was aimed at ensuring that the potential participants had been given sufficient time to reflect on their experiences so that they were better prepared to describe their lived experiences freely during the in-depth interviews.

#### **4.6.5.4. Physical Environment for in-depth interviews**

According to Elmir and colleagues (2011:14) the researcher conducting in-depth interviews must give a thorough thought about the venue of the interviews. A key consideration is that both researcher and participant must feel safe in the venue. To reduce participants' sense of vulnerability, each participant chose suitable venues where they would feel comfortable as acclaimed by McCosker, Barnard and Gerber (2001) and cited in Elmir et al (2011:14). It turned out that most preferred their homes because as qualitative research necessitates, participants should be interviewed in familiar settings where they feel comfortable. Betterstill, the interview venue should be the natural setting in which the experience occurred so as to generate rich data.

As Becker (1992:39) recommends, the interview venues were private, free from interruptions and where participants felt relaxed and comfortable. The justification for a comfortable venue lies in the observation that personal experiences such as lived experiences are best shared when a person feels safe and secure as provided by a homely environment. This notion is further supported by Streubert and Carpenter (2011:36) note that the more secure and comfortable a participant is, the more likely they will share important information about themselves such as lived experiences.

#### **4.6.5.5. Obtaining consent from potential participants**

The research team used a consent form to obtain written permission from potential participants. Polit and Beck (2010:127) explain that consent is an ethical requirement that researchers are required to secure before conducting a study, because it indicates the terms and conditions of a person's voluntary participation in a study. Informed consent means participants have adequate information regarding the study, comprehend the information, and have the power of free choice, enabling them to consent to or decline participation. The research team implemented the informed consent process by ensuring every participant signed the consent form (refer to Annexure G). The consent process form was translated into the local dialect to ensure it met the needs of those participants who did not understand English well.

The research team prior to all interviews, provided ample information about the study to the participants, including the purpose and scope of the study, the type of questions, how the results would be used including protection of their anonymity (Richards & Schwartz 2002:137). The participants were also given time to consider their participation and to ask clarifying questions before the formal interviews began.

Consent was also obtained from participants to audio record the interviews to ensure that no data was lost during this data generation. This also helped to relieve the researcher and the research assistants from writing large amounts of notes and instead the team concentrated on participants and the cues and leads in their interviews and only took field notes to support significant verbal cues that would not be captured by the digital audio recorder. The consent process ensured that the voluntary participation in the study was achieved prior to the commencement of the interviews. The detailed consent process is described in section 4.8 under ethics.

#### **4.6.5.6. Seating arrangement during interviews**

The seating arrangement was such that the researcher, the research assistants, and participants sat comfortably in a circular manner facing each other with a table between them. The digital recorders were placed on the table in between the research team and the participants to ensure that all the proceedings were accurately

recorded. This seating arrangement helped to create a comfortable environment for personal conversation with the informants and encouraged free communication between the participant and the interviewers. The seating arrangement further provided the research team the opportunity to maintain “good” eye contact and observe the non-verbal expressions of the participants as the interviews progressed.

#### **4.6.5.7. Recording of the in-depth interviews**

To ensure good quality recording and data security, a high quality portable digital MP3 player was used to record the proceedings as suggested by Fernandez and Griffiths (2007:10). This technology is based on a patented audio-specific format that was designed by the Moving Picture Experts Group (MPEG). It combines excellent audio quality and small size enabling audio files to be shared easily including by email (Fernandez & Griffiths (2007:11). The use of good quality recorders during qualitative interviews is supported by Burns and Grove (2005:540) who infer that poor recording may be so faint or so much distorted that transcription becomes impossible.

Aware of this expectation, high quality digital recorders were always at hand and this allowed the research team to concentrate on the interview process, asking questions appropriately and clarifying any unclear areas without having to worry too much about the recording, which would have been the case if tape recorders were used. The team was thus relieved of “*tape anxiety*”. This allowed us to concentrate on the interview instead of worrying about batteries and tapes running out. Besides, we had a third backup recorder, a Samsung (s-3) smart phone voice recording application.

In addition to digital recording, field notes were taken to capture the context of the descriptions. This was used to describe participant’s expressions, changes in their position and other observations such as emotions that could not be captured by voice recordings. Streubert and Carpenter (2011:43) assert that incorporating field notes during data analysis helps to achieve a more contextualised description of lived experience. These field notes became important additions during data analysis because they were used to validate important points made by the participants and they proved essential to lay emphasis of emerging thematic areas. Enhancing data

safety is further recommended by Flood (2010:11) who maintains that extra care is required especially when the interview is the main source of data as in this study.

#### **4.6.5.8. In-depth unstructured interviews**

The interview process was shaped by the views of Hannabuss (1996:22-25), Field (1996:136) and Qu and Dumay (2011:245) who advocate for each interview to be adapted to the individual situation and context while ensuring participants comfort. Participants were made to feel at ease and a good sense of rapport was created by engaging them in a 'small talk' before every interview. This helped to allay the participants' anxiety and readied them for the interview which proceeded as follows:

- The research team explained the purpose of the study, issues related to confidentiality and anonymity, requested participants' collaboration and obtained their formal consent. Permission was also requested to audio record the interview proceedings. Participants were asked if they had questions after assuring them of confidentiality, emphasising that no identifying information such as their names would be used, instead acronyms SVR (for survivors) and FCG (for family caregivers) (refer to Annexure K) were used instead as identity markers. All the participants accepted to have their interviews recorded. The details of ethical considerations are in section 4.8 and in the consent form (refer to Annexure G).
- The interviewer started each interview by posing the grand tour question: "How do you experience living under a constant threat of Ebola?" Or, "How do you experience the constant threat of Ebola?" As Creswell (2012:54) notes, beginning a qualitative interview with exploration of a single idea allows the interviewer to first understand the phenomenon in sufficient detail. As the interviews progressed, thematic and follow-up questions were tactfully introduced to further explore aspects of their lived experience which had not been relayed up to this point. The interview guide provided useful directions and focussed the interview. I assumed a stance of self-reflexivity, becoming aware that my pre-understandings about participant's experiences could influence interpretation of their experiences. This self-awareness readied me for data generation (Streubert & Carpenter 2011:34).

- I ensured that unnecessary interruptions were avoided during the interviews. Participants were asked to relay their lived experiences by elaborating on their feelings, memories, meanings and thoughts that have continued to linger in their minds as they reflected about the outbreak. The responses were approached with an open mind and obscure areas were carefully probed (Patton 1990:324). Participants were asked to describe what the experience meant to them. As Becker (1992:38) posits, clarifications were sought until participants' experiences were exhausted or when they said they were not willing to explore an area further.
- I also adopted a flexible approach, of "not using a preconceived framework", but rather allowing to be led by the unique realities of the research situation (Grbich 2013:Loc2278). In fact I either played a passive or active role during data collection. This flexibility was essential for entering participants' worlds and to adequately elicit their story to enable me better understand the meanings of lived experience from the participants' perspectives (Wall, Glenn, Mitchinson & Poole 2004:32). I avoided leading questions and giving personal views during the interviews, ensuring that all that was described were mostly participants' views.
- I also remained centred on the data as participants' experiences were explored, listened attentively and followed each participant's story keenly. I remained calm and focused as recommended by Dickson-Swift, James, Kippen, Liamputtong (2007:330). Interrogating participants was also avoided, instead participants were treated with the greatest respect and made to feel respected and valued by showing genuine interest in their life stories during all the participant interviews.
- The research team encouraged participants to continue talking by using culturally acceptable affirmation sounds that encourage people to talk, while taking care not to portray a sense of approval or disapproval of what was being said. Clarifying and probing questions helped to elicit more information in obscure situations. The interviews continued until data redundancy was attained and participants exhausted their lived experiences. At this point the interview ended with a request for a follow up interview if any obscure areas emerged (Van der Wal 1992:115).

#### **4.6.5.9. Follow- up interviews**

The research team listened to the recorded interviews immediately after every interview, checked whether the interview made sense and determined the need for follow-up interviews with the same participant. Paterson (1997:199) maintains that a follow up interview is essential especially when participants are required to expound on some of their previous descriptions. In affirmation, Streubert and Carpenter (2011:91) declare that a second interview is required to give the researcher the opportunity to expand, verify and add more descriptions about the phenomenon being studied, and assisting participants to clarify and expound on inadequate areas.

#### **4.7. DATA ANALYSIS**

Details of data analysis highlighted here are presented in Chapter 6. As expected in qualitative analysis, I immersed in the data and committed fully to the project with significant degree of dedication to reading, intuiting, analysing, synthesising and reporting the results (Giorgi 2009, in Wertz 2011:131; Streubert & Carpenter 2011:45). Data analysis was informed by Wertz's (1983, 1985, 2005, 2011) Empirical Psychological Reflection (EPR) research approach. Whilst this analytical approach is linked to the Duquesne tradition and inspired by Husserlian phenomenology, the method shares features with general interpretive phenomenological research inspired by Ricoeur's (1976) Hermeneutic-phenomenological philosophy (Lindholm, Udén & Råstam 1999:103-104; Lindseth & Norberg 2004:149-150; Van der Wal 2013:1-2).

This analytical framework was chosen because it's detailed and yet flexible approach allowed me to capture both "unique individual" experiences and "general aspects" of survivors' and their family members' lived experiences (Wojnar & Swanson 2007:177; Wertz 2011:131). An important feature of this approach is the flexibility of "not using a preconceived framework" (Grbich 2013:Loc2278). At the same time, it allowed me to examine key elements of participants' lived experiences including embodied selfhood, emotionality, social relations, and temporality, in order to better understand their unique life experiences (Koch 1999:21; Benner 2001:40; Wertz 2011:133).

Wertz's (1983/2011) data analysis framework consists of three specific phases of analysis and one phase of describing the "themes" to obtain a holistic understanding of the phenomenon, termed as phenomenological description or writing (Wertz 2011:131). To carry out the three stages of reflection well, specific attitudes or stances and methodological procedures or research activities are required (Giorgi 2009, cited in Wertz 2011:132; Wertz 2011:131) as further described in section 5.4.

DeSantis and Ugarriza (2000:362) affirm that a theme is "an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations, and captures the nature of the experience into a meaningful whole. Themes enabled the researcher to decipher hidden meanings in the stories and were used during the phase of "phenomenological writing" to articulate the "unique individual" and "general essences" of the phenomenon, including meanings and structure of survivors' and family caregivers' lived experiences, interspersed with verbatim expressions to enhance the study's credibility (Polit & Beck 2010:503; Wertz 2011:161; Van Manen 2011:2) and also to help the reader get a "near first-hand" feel of these experiences.

#### **4.8. ETHICAL CONSIDERATIONS**

Ethics in research refers to a system of moral values concerned with the degree to which a researcher adheres to professional, legal and social obligations during the research process (Polit & Beck 2010:553). In the present study, the key ethical considerations lay within three broad areas: participants; institutions and scientific integrity of the entire research enterprise. Norwood (2000:57) advocates that researchers should commit to addressing anticipated as well as emergent ethical issues from the time the research problem is identified up to the final stages of communicating the findings. As Streubert and Carpenter (2011:60) counsel, I was conscious that ethical standards of qualitative research arise out of the dynamic and evolving nature of the research process, meaning that unanticipated ethical concerns could arise anytime. Hence, in addition to adhering to the ethical issues grounded in the ethical principles of autonomy, beneficence and justice, I remained open to the possibility of new and unexamined ethical concerns, especially during data collection.

The details of how ethical considerations were adhered to in regard to participants, institutions involved in the study as well as the scientific integrity of the study follow:

#### **4.8.1. Ethical issues related to participants**

In qualitative research, participants are the researchers' primary concern in terms of ethical considerations. Whilst it was clear that participants would not suffer any physical injury, I was aware that the sharing of sensitive experiences may lead to experience of psychological and emotional trauma. Consequently, I ensured informed decision making, observance of anonymity, privacy and confidentiality, prevention of harm and discomfort as well as fairness in treating participants as explicated:

##### **4.8.1.1. Informed Consent**

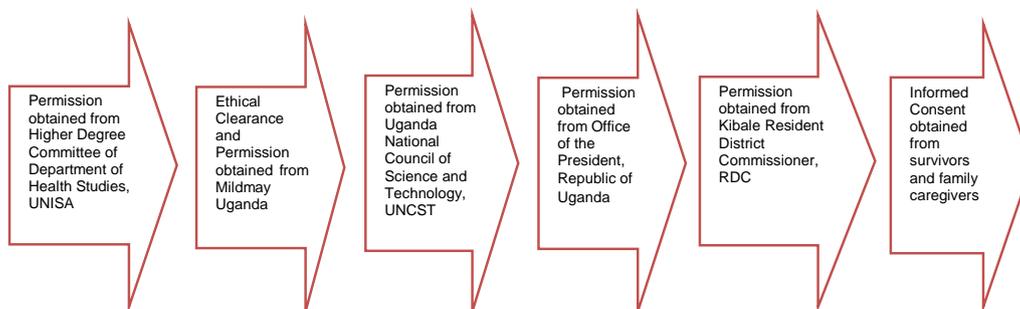
Informed consent is a critical part of research and signifies that the researcher upholds participants' right to self-determination. According to Streubert and Carpenter (2011:61) informed consent is a prerequisite for all research involving identifiable subjects and requires of participants to have adequate information about the study. Polit and Beck (2010:127) explain that informed consent means participants have been provided with ample information and have the power and freedom to voluntarily accept or refuse participation and signifies researcher's efforts to establish and maintain participant's autonomy. In keeping with this requirement, we always obtained informed consent at the start of the study (Hamersley & Atkinson 1995:264).

I addressed participants' right to self-determination by providing a written explanation along with an informed consent form to explain the study purpose, nature of participation including potential risks and benefits to participants as well as reasons for their participation. Participants were also informed that they had the right to terminate participation and to refuse to give information or seek clarification during the interview (Burns & Groove 2005:192-195). Methods and procedures to be used in the research were also explained and doubts arising thereof were clarified. The informed consent process also involved obtaining permission to digitally record the interviews. My role as researcher was also clarified as being an independent person with no ulterior interests. Participants were also informed that the data would be used

for scholarship purposes only and to recommend strategies to improve the wellbeing of those who contract Ebola in future. This role clarification enabled participants to see me as a neutral person, reducing chances of obtaining biased or fabricated information, which could have occurred if I was seen as representing the government.

The informed consent was authenticated by participants signing an official consent form (refer to Annexure G) as depicted in figure 4.1 which details the various steps the research team took to arrive at a signed consent form. This process was essential for informed decision making as well as in preventing avoidable harm and discomfort.

**Figure 4.1. Flow diagram showing the informed consent process**



The research team upheld the ethical principle of beneficence, ensuring that participants were free from physical or psychological harm by timely addressing any issues that would harm or cause discomfort during the interviews (Streubert & Carpenter 2011:61). Participant's dignity and autonomy was also maintained by ensuring voluntary participation after obtaining written consent. In addition, thematic and related questions were framed in a manner that would not threaten or corner participants, but rather encourage them to share their experiences with the inquirer.

#### **4.8.1.2. Confidentiality**

A critical component upheld throughout the research process was confidentiality. Polit and Beck (2010:129) point out that confidentiality is a pledge that any information participants provide will not be publicly reported in a manner that identifies them and will not be made accessible to others. I was acutely aware that the in-depth nature of qualitative inquiry meant that participant's privacy was critical and had to be protected

throughout the research period. Participant's right to privacy is based on the ethical principle of justice which states that individuals have the right to determine the time, extent and general circumstances under which personal information including beliefs, practices, opinions, and records will be shared with or withheld from others (Burns & Groove 2005:186). I secured participants' right to privacy by asking them to choose the venue for the interviews. Most participants chose to be interviewed from their homes. I ensured that participant information was not made accessible to persons other than the research team by using password protection and by using identification codes instead of actual names. Also direct quotes used in the final report would not reveal participant's identity, which were disguised in codes (Polit & Beck 2010:129).

#### **4.8.1.3. Anonymity**

Anonymity is closely related to confidentiality and is the most secure means of protecting confidentiality. Strict anonymity occurs when the researcher cannot link a participant with particular data (Polit & Beck 2010:129). As Burns and Grove (2005:194) maintain, confidentiality warrants that any information participants provides will not be made accessible to parties other than those involved in the research, whilst anonymity ensures that revealing information about participants' identities are not declared during presentations, reports and in ensuing publications.

The research team constantly reminded and assured the participants as Norwood (2000:68) recommends that their personal information will not be handled carelessly. I was aware that if any worry of breach of confidentiality lingered in participant's minds, they could advertently withhold vital information or could decide to provide inaccurate information deliberately. To allay their anxiety, participants were told that the findings would be reported from the nomothetic (generalised) perspective rather than from the idiographic (individualised) descriptions. This aggregation helped to ensure anonymity of participants and reduced the possibility of linking a particular individual to a specific verbatim expression in the final report (Polit & Beck 2010:130).

#### **4.8.1.4. Fair treatment of participants**

Participants were treated fairly, aware that the close and private nature of relationship with participants raises peculiar ethical concerns. Streubert and Carpenter (2011:65) warn researchers to be aware that being the research instrument, means the researchers come to know participants in a personal way, some times to the extent that a blurring of responsibilities arises. As Ramos (1989:57) advises, I was conscious of this blur and so remained steadfast in the “*instrument*” role instead of assuming the “*therapist*” role. Hence to be fair to participants, I guided the interview process and maintained the focus of the interview keeping clear that the interview was not a therapeutic event. We desisted from asking questions that would result in more answers than they originally agreed. At the end of each interview, the team reiterated issues that needed further clarification (Streubert & Carpenter 2011:65).

#### **4.8.2. Ethical issues related to institutions**

Van der Wal (2005:154) advises that research related institutions should be treated as though they were individuals. The implication of this declaration is that the researcher has to obtain informed consent from these institutions as well as ascertain a level of anonymity so that names and specific identifying information about them that may have ethical implications are left out to ensure their privacy. I protected the rights of institutions by adhering to their guidelines ensuring that data collection, analysis and reporting occurred in ethical and scientific manner (Norwood 2000:72).

##### **4. 8.2.1. Informed consent and permission**

Data collection commenced only after permission was granted by various institutions, including the Department of Health Studies, UNISA; Mildmay Uganda; Uganda National Council for Science and Technology; Office of the President, Uganda, and Kibale Resident District Commissioner. As an ethical requirement, I dutifully followed the advice and guidelines and the recommendations of the various IRBs and related institutions during the data generation and dissemination phases of the research.

#### **4.8.2.2. Anonymity and confidentiality**

In order to comply with the principle of anonymity at the institutional level, names of health facilities linked to the survivors who participated in the study were omitted. Similarly, names of survivors and hospitals and health centres they were associated with were left out to further ensure anonymity and confidentiality (Norwood 2000:72).

#### **4.8.3. Ethical issues related to research integrity**

A high standard of scientific and personal honesty was upheld throughout the study. Scientific integrity refers to researcher's competence in all aspects of the research activity, particularly how well they adhere to the ethical and scientific expectations of the study at every stage. I demonstrated ethical and scientific integrity by respecting the rights and dignity of the participants and institutions involved in the study and avoided any form of malpractice. In observing ethical requirements and judicious execution of scientific rules, the scientific integrity was assured (Mongwe 2007:109).

##### **4.8.3.1. Researcher competence**

My capacity to conduct this research study was acknowledged by the Department of Health Studies Higher Degrees Committee, UNISA through their approval of the research proposal. This competence was also affirmed by other institutions that provided similar ethical clearance to conduct this study. My competence to assure the study's scientific integrity was also bolstered through the guidance of the theis promoter, himself a seasoned qualitative researcher who constantly supported me at every step of the research process. As Van der Wal (2005:15-19) advises, I was mindful that the study outcome needed to meet ethical standards required for educational, clinical and scientific research if the findings were to be utilised in care.

##### **4.8.3.2. Researcher integrity**

I demonstrated personal integrity by avoiding deception of participants and institutions involved, including the public who receive the results. Struwig and Stead (2001:69) consider deception as misrepresenting facts to intentionally mislead

participants in such a way that if, they were aware of the nature of the study, they would have declined to participate. Polit and Beck (2010:123) add it may involve withholding information from or providing false information, to interfere with participant's right to make truly informed decisions about costs and benefits of participation, exposing them to situations different from what they earlier consented.

I avoided deception by providing accurate information to all those involved notably participants, institutions and the public. I also desisted from fabrication, falsification and manipulation of data and data generation and analysis procedures as affirmed by Cohen and Ciocca (1993:95). I also avoided all forms of plagiarism, which implies, presenting as own, ideas of others through inappropriate referencing as explained by Polit and Beck (2010:134). As Struwig and Stead (2001:69) point out, I avoided deception thereby preventing embarrassment, anger and humiliation for all those involved in the study, and ensured the research report meets the highest standards.

#### **4.9. CRITERIA TO ESTABLISH QUALITY AND TRUSTWORTHINESS**

Standards of quality in research emphasise concepts of objectivity, validity, reliability, rigor, open mindedness and honesty through reporting of research findings (Focus 2005:1-2). Research quality as defined by Meulenbergh-Buskens (1997:111) refers to the degree to which the work conforms to methodological expectations of the study. Trustworthiness in research, Lablanca (2010:1) describes is the "demonstration that a study and the argument based on its results are strong and verifiable. In order to ensure quality, Mauthner and Doucet (2003:413-415) advocate that researchers should show how they arrived at and interpreted the findings. It follows that in all studies, whether qualitative or quantitative, the central elements of reliability and validity need to be met. In qualitative studies, Morse, Barrett, Mayan, Olson and Spiers (2002:17) maintain that data reliability and validity can be achieved through an in-built verification process. This process they affirm entails checking, confirming, making sure, and being certain that the researcher can incrementally ensure reliability and validity and consequently rigor of the study. They argue that by incorporating verification strategies in the research process, reliability and validity are attained, rather than waiting for external reviewers to declare as such at the very end.

To Random House College Dictionary (1980:1114), reliability is being...“authentic, consistent and trustworthy and being able to depend upon with confident certainty”. Reliability deals with accuracy and consistency of information obtained in a study (Polit & Beck 2010:373). The concept of ‘validity’ on the other hand refers to “being sound, just and well-founded” (Random House College Dictionary 1980:1453). Likewise, Polit and Beck (2010:377) refer to validity as the degree to which an instrument measures what it is designed to measure”. An account is valid if it represents accurately features of a phenomenon it is intended to describe, explain or theorise (Hammersley 1987:69). The centrality of these concepts implies that a researcher should demonstrate how these concepts have been addressed in a study.

In quantitative research that is underpinned on positivism, reliability is ascertained by ensuring the research tool is consistent, stable, predictable and accurate (Kumar 2005:156), implying that the greater the degree of consistency and stability of an instrument, the greater its reliability. The opposite of reliability is a measurement process that yields erratic, unstable or inconsistent results (Neuman 2006:188). In a research study, the researcher is expected to ascertain the reliability of the instrument by pre-testing the questionnaires in a pilot study and then making necessary adjustments to assure its consistency and stability over varying conditions.

On the other hand, validity is achieved by ensuring that the study’s instrument is valid and measures what it is supposed to measure (Gray 2004:206-210). Accordingly, the researcher assures the validity of the research instrument by ensuring that the contents covered; including the questionnaire reflect variables to be measured. Like in reliability, Mpisi (2010:196) advises researchers to test and improve the validity of their research instruments using pilot studies and then make required adjustments.

In qualitative research that is underpinned on human science paradigm, the concepts of reliability and validity as overarching constructs are still relevant because as Kvale (1989, in Morse et al 2002:19) states, validation is an important element in all research, requiring checking and questioning various aspects to ensure quality. The goal of quality control or rigor in qualitative research is to accurately represent participants’ experiences. To ensure that qualitative researches such as the present

meet quality standards, Krefting (1991:215) advises use of models that appropriately measure rigor without sacrificing the relevance of qualitative research tradition.

In view of this expectation, I settled for the “gold standard” quality criteria outlined by Lincoln and Guba (1985) and later augmented by Guba and Lincoln (1994) based on five aspects of trustworthiness relevant to both quantitative and qualitative studies namely truth value (credibility), applicability (transferability), consistency (dependability), neutrality (confirmability) and authenticity (Polit & Beck 2010:492). The rationale for these criteria is the fact that when meticulously observed, they result in achievement of quality control and trustworthiness of the research findings. A pertinent discussion on how these criteria were utilised for quality control now follows:

#### **4.9.1. Credibility**

Credibility refers to the confidence participants have in the truthfulness of the findings of a particular study (Polit & Beck 2010:492). Krefting (1991:218) argues that qualitative research study is considered credible when it portrays an accurate description of the human experience that people who also share the same experience would immediately recognise and find believable. Credibility was established in this study through prolonged engagement with the study participants; incorporation of method and data triangulation; consensus building with a research expert; and researcher authority and capacity for such inquiry, as explicated below:

##### **4.9.1.1. Prolonged engagement**

In qualitative inquiry, prolonged engagement according to Polit and Beck (2010:495) is the investment of sufficient time collecting data to have an in-depth understanding of the phenomenon so as to test for misinformation and distortions and to ensure saturation of important categories. In addition to being able to gather in-depth information, prolonged engagement also results in building of rapport and trust with study participants. I spent sufficient time with each survivor and family care giver so that useful, accurate and rich data would be obtained from them, to better understand the phenomenon. Prolonged engagement was fortified with some follow-up interviews.

#### 4.9.1.2. Triangulation

Triangulation refers to use of multiple reference points to draw conclusions about what constitutes truth (Polit & Beck 2010:497) aimed at capturing a more complete and contextualised portrait of the phenomenon. Triangulation was achieved by the use of multiple methods and perspectives during data collection and interpretation. The impetus for triangulation lay on the desire to ensure a convergence point, where reality as manifested by participants would be accurately reflected in the researchers' representation of their lived experiences (Krefting 1991:219). Triangulation was achieved in the present study by engaging in both method and data triangulation:

- Method triangulation was achieved by using both the initial in-depth phenomenological interviews and follow-up interviews which are two different data gathering methods (Thomson & Jolley 1997:187). These two approaches ensured data gathering from two different viewpoints and prevented biases and deficiencies usually associated with using a single data collection method. The preliminary literature review also helped to set guidelines for the entire interview process.
- Data triangulation was achieved through extensive review of relevant literature before and after the study. Furthermore, data triangulation was attained by collecting data from both survivors and family caregivers. These two different perspectives facilitated the researcher have a more complete understanding of participant's lived experiences as they described them (Krefting 1991:219-220).

#### 4.9.1.3. Consensus with expert reviewer

Using peer or expert evaluation is credited by early phenomenologists such as Van Kaam (1966, cited in Beck 1994:260) who justify the practice as providing an opportunity for critical comparison of results between at least two phenomenologists to ensure data validity. I passed all the raw data to the promoter, to carry out independent checking during data analysis. The promoter helped to ascertain the themes and categories I obtained and any discrepancies were subjected to thorough debate and resolved after achieving what Mongwe (2007:115) terms as '*intra-participative*' agreement with my thesis promoter. He thus served both as independent

expert coder as well as an analyst to verify and authenticate the various themes, categories and sub-categories, which then formed the basis of the research findings.

#### **4.9.1.4. Researcher's authority and capacity**

My authority and capacity to conduct this study are underpinned on previous experience with conducting similar qualitative studies. The importance of investigator experience is based on the fact that the researcher is the main instrument in qualitative inquiry (Patton 1990:427); as such the experience of a qualitative researcher contributes substantially to the outcome of a study. My experience with qualitative research started when I was trained and participated in conducting qualitative research within phenomenology during my master's education.

This exposure to researching lived experience dates back to year 2000 when I encountered two "suspected Ebola patients", one of whom was my student and another a fellow lecturer and colleague during the 2000 Ebola outbreak in Mbarara Hospital. At this time, I worked as an Assistant Lecturer of Nursing at Mbarara University of Science and Technology in Uganda. This exposed me indirectly to clinical care of Ebola patients while becoming directly involved in epidemic control activities of health education of the population. This experience motivated me to take part as a co-investigator in a formal research study, entitled: "*The Lived Experience of Waiting-to-Know: Ebola at Mbarara, Uganda- hoping for life, anticipating death*", which was published in *Journal of Advanced Nursing* under the names, *Locsin, R., C & Matua A, G. (2002). Journal of Advanced Nursing, Volume 37, Number 2, 173-181.*

I participated in a second study entitled: *Surviving Ebola: Understanding the experience through artistic expressions*, published under the names, *Locsin, R.C, Barnard, A., Matua, A., G., Bongomin, B., (2003). International Nursing Review, Volume 50, 156-166.* My third exposure to lived experience research was during the master's thesis on Ebola survivors, entitled: *Conquering Death from Ebola: Living the Experience of Surviving a Life-Threatening Illness*, published as a book chapter as: *Matua A, G. & Locsin, R., C. (2005) in the book, Coping with Disease", edited by Lee, Annette, by Nova Science.* These three major hands-on research experiences taught and grounded me firmly in lived experience investigations within phenomenology.

These credible experience made me feel well qualified to carry out the present study into survivors' and their close family members' lived experiences with Ebola outbreak.

#### **4.9.2. Transferability**

Transferability is the second criterion for establishing trustworthiness in qualitative research. According to Krefting (1991:216), transferability refers to the degree to which the findings of a study can be applied to other contexts. This according to Lincoln and Guba (1985:290) is equivalent to quantitative research's external validity and refers to whether a study's findings also apply in other settings. Polit and Beck (2010:492) are also of the view that transferability entails the extent to which findings of study may be "generalised" to other settings or groups. Streubert and Carpenter (2011:49) similarly consider transferability as referring to the probability that the findings have meanings to others in similar situations. Whereas I was acutely aware that the expectation of determining whether the findings fit or are transferable rests, with potential users, I complied with Lincoln and Guba's (1985:316) criteria of providing the basis for making transferability judgment possible for potential users.

Plans for transferability were enhanced by careful selection of participants and by providing sufficient descriptive data in the final report so that the consumers of the study may ably evaluate applicability of the findings to other circumstances, through:

##### **4.9.2.1. Careful sample selection**

I ensured careful selection of participants by using only the approved sample criteria to select the best possible sample. Krefting (1991:220) defines a nominated sample as the use of a panel of "judges" to help in the selection of participants experienced in a phenomenon. Field and Morse (1985, cited in Krefting 1991:220) also refer to a nominated sample as using one or two long-time members of a group to identify persons who are typical of the membership. In the present study, the lead member of the Kibale Ebola Task Force Team who was involved in follow up care of survivors in consultation with the researcher and the research assistants carefully selected the most eligible survivors and their corresponding family caregivers using purposive, convenience and criterion sampling techniques where applicable. The details of the sampling techniques are described in section 4.4.2 to allow for external verification.

#### **4.9.2.2. Thick Descriptions**

I enhanced transferability of the study findings by including in the final report as much of direct quotes from participants as possible. The details of the dense (thick) descriptions that capture the vivid experiences using survivors' and family caregivers' words are given in Chapter 6. In support, Whittemore, Chase and Mandle (2001:531-533) supplement that vivid description of participant's experiences enables consumers of research to have a '*near-real mental*' experience which enables them to better 'understand' the experience as described. In the current study, in addition to using verbatim quotes, I described the research setting as well as the transactions and processes that characterised the entire investigative process. This clarification aims to facilitate better understanding of the findings, including users' decisions for transferability of the study findings to other practice settings (Sandelowski 1986:28).

#### **4.9.3. Dependability**

The third criterion for establishing trustworthiness in qualitative research is dependability which means data stability over time and over conditions (Polit & Beck 2010:492). In the opinion of Thomas and Magilvy (2011:152), dependability concerns with whether the study process is consistent and reasonably stable over time and across researchers and methods. I assured dependability of the study findings by ensuring that all the processes within the entire research process were consistent with the philosophical and methodological precepts of phenomenology (Rose, Beeby & Parker 1995:1126) and that methods of data gathering, analysis including interpretation were explained clearly for others to verify (Lincoln & Guba 1985:290).

The first requirement of methodological consistence was boosted when I first acquainted myself with general principles of qualitative research methodology and the phenomenological method prior to commencing this project. The second strategy was to overcome inconsistencies in the research process by describing in meticulous detail the various steps of data generation, analysis and interpretation. Importantly, the details of data generation are contained in chapter 4, data analysis in chapter 5, findings in chapter 6 and interpretation in 7 and recommendations in chapter 8. In each section, the researcher's role is articulated for others to make judgements.

In specific terms, data collection occurred in settings and during times consistent with the study's design and the research question. Coding checks were made by both the researcher and the supervisor and they showed adequate agreement. Quality checks were made for any bias and misinformation in the data. These various processes led to a data trail that a reader wishing to conduct a data audit or secondary analysis or verify data consistency may use as recommended by Lincoln and Guba (1985:290). In view of these, I assured myself that the findings could be similar if the study was repeated with similar participants in similar context by a similarly trained researcher.

#### **4.9.4. Confirmability**

The fourth criterion for trustworthiness, confirmability refers to objectivity or neutrality of the research data. According to Polit and Beck (2010:492) objectivity refers to the potential for congruence between two or more independent people about the data's accuracy, relevance and meaning. A closely related concept of neutrality according to Lincoln and Guba (1985:290) is the criterion that the reader can use to ascertain the degree to which the findings of a study are determined by the actual views of participants and not that of the researcher's imaginations. Consistent with Polit and Beck's (2010:492) position, I was conscious that the findings had to reflect participants' true voice and conditions and not my uninformed biases and views. I demonstrated full objectivity through reflexivity, auditability and flexible coding system:

##### **4.9.4.1. Reflexivity**

I was conscious of the role my pre-understandings about Ebola would have on the findings. In remedy, I remained open to mechanisms that would enhance the self-reflective stance required to enter the "field" with an open mind set (Streubert & Carpenter 2011:34). This openness was achieved through the process of reflexivity which Finlay (2008:15-17) compares to Husserl's reduction. Like Heidegger and Gadamer, Finlay (2009:12) maintains that the researcher's fore-structure cannot be fully bracketed out, but rather needs to be acknowledged and placed in the foreground to separate out what belongs to the researcher from that of the participants. This process described as a dialectic tension between 'striving for reductive focus and reflective self-awareness; between bracketing out researcher pre-understandings and exploiting them as a source of insight' (Finlay 2008:17-18).

Polit and Beck (2010:110) maintain that a researcher's reflexivity is critical in qualitative research because it is what qualitative researchers rely on to guard against personal bias in making judgements during the research process. They consider reflexivity as the process of reflecting critically on self and of analysing and making note of personal values and views that could affect data collection and interpretation. Jootun, McGhee and Marland (2009:42) explain that the process of reflecting on one's research and trying to understand how one's own values and views may influence the findings adds credibility to the study findings. In the present study, I used the process of self-reflexivity to accurately portray the lived experiences and meanings the survivors and their family caregivers assigned to their experiences.

Reflexivity was thus accomplished by recollecting and keeping in mind, what I already knew about lived experience of survivors and family caregivers through prior research experience and preliminary literature review (refer to chapter 3). I enhanced self-reflection by consciously checking to ensure that my prior experiences and biases did not skew the research data. This required me to be consciously aware and remain open to participants' views regardless of whether they were in agreement or divergent from all prior learning, considering them "*authentic*" since they came from participants.

#### **4.9.4.2. Auditability**

Lincoln and Guba (1985:319) contend that a study may be considered objective by means of an audit trail, which refers to the way the researcher documents the findings. Polit and Beck (2010:547) consider an audit trail as systematic documentation of materials that allows an independent auditor of a qualitative study to draw conclusions about the trustworthiness of the findings. Glaser and Strauss (1967) and Guba and Lincoln (1989), as cited in Cutcliffe and McKenna (1999:377-78) recommend that to increase confirmability (objectivity) of the findings, the researcher should leave an 'audit trail' or 'decision trail' so that their "pathway" of the decisions made during data analysis can be checked or verified by other researchers.

The researcher enhanced the auditability of the study by adopting Halpern's (1983) criteria as cited in Lincoln and Guba (1985:319) for creating an audit trail by keeping:

- interview guide development information including amendments.
- raw data, including digital recordings, field notes and transcripts.
- data reduction and analysis products, such as codes or summaries.
- review notes and mails from the thesis promoter who performed 'expert' reviews.

In addition to these strategies, I used '*memoing*' throughout the data generation process as '*credible*' audit trails and made notes of key thoughts and '*felt sense*' that other researchers may choose to follow. In chapter 6, codes were used to accompany every data unit in the data analysis and presentation phase. These codes are points of evidence within the transcripts and facilitate location of evidence whenever it is required. The codes provide the opportunity for the reader to conceptualise the data units in the context of the transcripts should there be need to audit the study findings.

#### **4.9.4.3. Flexible coding system**

As a further procedure to ensure auditability, a flexible coding system was adopted as part of the consensus discussion between the researcher and the supervisor, who served as an independent expert. The supervisor and I agreed on all the codes as well as the categories and themes up to the present final product. The adoption of a flexible coding system meant that I remained open to new ideas, considering that themes and categories were tentative and open to re-coding and restructuring as and when the need arose. Hence, the '*malleable*' code and recode procedure enabled me as *researcher* and the supervisor as *check* to arrive at the most acceptable and complete description of survivors' and family members' lived experiences. This consensus process was in consonance with the recommendation of Krefting (1991:219) who declares that triangulation of investigators is critical because through consensus, the researcher is afforded a chance to clarify and improve the findings.

#### **4.9.5. Authenticity**

The fifth criterion for establishing trustworthiness of a qualitative study espoused by Guba and Lincoln (1994) relates to authenticity. Polit and Beck (2010:493) refer to authenticity as the extent to which researchers fairly and faithfully show a range of different realities about the phenomenon being investigated. An account becomes

authentic if it conveys the feeling tone of the participants' lives as they are lived (Polit & Beck 2010:493). A phenomenological account is thus authentic if it enables the reader to re-live the experience being described. This is what Van Manen (1990:27) terms as "phenomenological nod", when a person after reading a lived experience account says..."this is the experience I could have had..." This supports the claim that a good phenomenological description is validated by lived experience, as much as it validates lived experience (Van Manen 1990:27). As Polit and Beck (2010:493) posit, a truly authentic text invites readers to develop a heightened sensitivity to the issues portrayed in the research narratives through appropriately incorporating aspects of mood, feelings, experiences and contexts to allow better understanding.

By documenting the "hard facts" about the Ebola experience in a language that is evocative, expressive, transcendent and poetic, I allowed the emotional aspects of the lived experiences to create in the reader a 'phenomenological reverberation' or 'resonance'. This enables the reader to "experience" Ebola through the "eye, "skin" and "heart" of survivors and caregivers who went through the experiences (Van der Zalm & Bergum 2000:212). As Van Manen (2011:1) posits, the expressive manner with which the findings were reported hopefully allows readers to better feel and deeply understand the survivors' and their family members' everyday life. I was motivated to make the work '*authentic*' through the imagery power of language, so that readers of this account would be "*touched*" and become more thoughtful about what it means to experience constant threat of Ebola outbreaks (Van Manen 2011:2).

#### **4.10. CONCLUSION**

In Chapter 4, operationalisation of a qualitative research design using the phenomenological method was explicated. The chapter discussed in detail the sampling procedure, data collection method, and the researcher's adherence to ethical requirements. In addition, strategies of ensuring data trustworthiness were discussed. In chapter 5, steps and various processes involved in data analysis follow.

## **CHAPTER 5: DATA ANALYSIS**

### **5.1. INTRODUCTION**

The purpose of data analysis according to Polit and Beck (2010:463) is to organise, provide structure to and elicit concrete meaning from narrative data. It is a “data reduction” and “sense-making” effort that takes qualitative material and attempts to identify core consistencies and meanings therein (Patton 2002:453; Wertz 2011:161). Qualitative data analysis is an analytical process designed to condense raw data into categories or themes based on valid inferences (Zhang & Wildemuth 2010:2). This process relies on inductive reasoning and entails the inquirer creating generalisations from specific observations; beginning from specifics and then moving to general aspects of the experience (Polit & Beck 2011:10; Streubert & Carpenter 2011:10)

The need for meaning making from qualitative materials is corroborated by Polit and Beck (2010:464) who declare that qualitative data analysis is an active and interactive process that results in search for meanings and deeper understandings from conversations following a very careful classification and analysis process (Jonker & Pennink 2010:87). Data analysis is an important part of the qualitative research process, because it allows the researcher to fit data together, make the invisible, obvious and draw general conclusions about the phenomenon (Morse & Field 1996:126; Polit & Beck 2010:79). Qualitative data analysis helped the researcher interpret data and explain the essence of the Ebola experience. A key notion of qualitative data analysis is dwelling with and becoming fully immersed in the data through prolonged engagement and deep reflection (Polit & Beck 2010:464; Streubert & Carpenter 2011:92). In the present study, the desire to obtain a comprehensive picture of the experiences necessitated data analysis from both “descriptive” and “interpretive” perspectives. This allowed the researcher to capture the “essence” of the Ebola experience including the contextual features and meanings assigned to these experiences. The findings were articulated using concrete data and lifeworld situations and entailed incorporating direct quotes to provide readers with an intuitive understanding (Benner 2001:4-42; Wertz 2011:161).

## 5.2. GENERAL PRINCIPLES OF QUALITATIVE DATA ANALYSIS

In qualitative research, although “initial” data analysis occurs simultaneously with data collection to assist the researcher determine when to stop data generation, “real” in-depth analysis begins when the researcher starts listening to the recordings and reads through the verbatim transcriptions to get a sense of what the data “says”. This process is then followed by a thorough “reduction” of data into chunks, termed as “meaning units,” whose contents convey specific information about the lived experience and lend themselves well to meaningful and fruitful analytical reflection, to answer the research questions posed (Burns & Grove 2005:548; Wertz 2011:131).

According to Sandelowski (1995b:373) and Streubert and Carpenter (2011:45), this process of “reducing” data into meaning units begins with immersing in and dwelling with the data and repeatedly reading the transcripts, alongside field notes and recalling the observations and occurrences recorded during the interviews. This process helps the researcher identify and extract significant statements from the data. As Burns and Grove (2005:547) recommend, immersion was enhanced by underlining key phrases, highlighting words, sections and paragraphs and inserting comments next to the data sets or texts that triggered them, to ensure that the researcher’s psychological processes that identified them would not get lost during further readings of the transcripts (Van Manen 1990:92) and this proved critical in helping the researcher to arrive at evidence-based conclusions (Wertz 2011:160).

To achieve quality data analysis, one principle embraced was committing to a structured analytical process to achieve in-depth understanding of what the data communicated (Basit 2003:143). Miles and Huberman (1994:10) and Wertz (2011:132) observe that structured analysis requires prolonged in-depth reading, intuiting, analysing, synthesising and ordering to enable the structure and meaning of the lived experiences to be portrayed accurately to create new knowledge and signal call for action (Creswell 2007: 37). A second principle adhered to during data analysis was embracing a form of “phenomenological attitude,” a vital methodological procedure by engaging in two methodological processes, termed “epochés” by Husserl and described by Wertz (2011:125) as abstentions; the first being the

“epoché of the natural sciences”, and the second, the “epoché of the natural attitude”. The epoché of the natural sciences according to Husserl (1901/1970, as explained in Wertz 2011:125) involves putting aside the natural scientific and other knowledge including theories, hypotheses, prior research information about the phenomenon to “return to the things themselves” (*zurück zu den Sachen selbst*)” as Husserl noted.

The epoché, of the natural attitude also referred to as “phenomenological reduction” by Husserl, required researchers to abstain from the natural tendency of consciousness to unreflectively posit and focus on the existence of objects independent of experience, while emphasising transcendence as in most philosophical inquiry (Husserl 1936/1954, in Wertz 2011:125). Instead of “bracketing” prior knowledge about Ebola and emphasising transcendence by focusing on the existence of objects independent of lived experience; I deliberately embraced the methodological procedure of “openness”, “empathic immersion” and “reflexivity” (Finlay 2003:108; Wertz 2005:172-173; Finlay 2008:15-16; Van Manen 2011:1-2).

This decision was influenced by “interpretive” perspectives upon which the study is partly hinged, because within this framework, the inquirers’ pre-understandings are not entirely “bracketed”, but rather delicately used to guide the findings. This decision is underpinned on Heidegger’s (1929/1962, in Finlay 2008:8) declaration that interpretation is an inevitable and basic structure of our being-in-the-world. This implies that whenever an “object” is interpreted as “something”, such an interpretation is grounded upon the interpreters’ pre-understandings. Interpretation is therefore never a “presuppositionless” apprehension of something presented to us, instead it always pertains to the whole of being-in-the-world”, meaning it is impossible to forget or transcend one’s pre-understanding (Heidegger 1929/1962, cited in Finlay 2008:8).

These methodological procedures, necessitated that the researcher identifies prior knowledge, also termed “fore structures” about the Ebola experience and attempts to put them out of play as much as possible so as to attend genuinely and actively, to participant’s experiences while listening to, interacting with and analysing their stories as Giorgi (2008:41) and Finlay and Eatough (2012:70-71) advocate. The pre-understandings I “entered” participants world’s with during data analysis arose from

my field experience of interviewing contact persons and survivors respectively during the 2000/2001 Ebola outbreak in Mbarara and Gulu Districts and from literature reviews during the master's and the current doctoral studies. It may be argued that this prior knowledge poses a "potential danger" for data analysis because it may "influence" me to impose my own interpretation onto participants' stories, creating wrongful understanding of their lived experience (Parsons 2010:63; Hinds 2011:193).

In recognition of this "potential error", I made the pre-conceptions about the Ebola and related experiences explicit and guarded against their imposition on my interpretations. The support for such "*methodological guard*" arises from Finlay's (2008:2) and Hinds' (2011:192-3) declaration that the phenomenological process of "reflexivity", when properly done allows researchers to "restrain" pre-understandings from unduly influencing interpretations of the findings, ensuring unbiased interpretation of the findings. Additional "researcher restrain" arose from the methodological procedure of "empathic openness" which challenges the researcher to remain open to participants' ideas and to conscientiously contemplate and reflect upon them to apprehend their hidden meanings (Finlay 2008:29; Wertz 2011:125).

This methodological procedure which Wertz (2005:168) calls "empathic immersion" into research data was facilitated by adopting an attitude of "genuine care" and concern and in a meditative way moving back and forth between different aspects of the data and the whole experience, which Finlay (2008:3) describes as "intertwining reduction with reflexivity" which is comparable to "a dialectical dance" movement. It involved moving between striving for reductive focus and being reflexively self-aware; between bracketing pre-understandings and exploiting them for insight; between naïve openness and critical reflection (Grbich 2013:74-75). The "phenomenological attitude" did not simply involve "suspending" the researcher's presuppositions, but rather, it involved carefully utilising reflection, openness and empathy to get to hidden meanings and structures (Finlay 2008:3; Hinds 2011:193).

Finlay (2008:3) explains that this methodological procedure of reflexivity enabled the researcher to remain open to being "moved by another", in this case survivors and their family caregivers and this openness allowed the evolving understandings to be

managed in a relational context as the researcher senses, moves, empathises, responds to and resonates with, “re-lives” and re-embodies, each participant’s unique experiences of the phenomenon (Finlay & Eatough 2012:72). As I deeply reflected and pondered upon survivors’ and family caregivers’ lived experiences, the “*essence*” of their experiences manifested (Dahlberg 2006:16) and by “*interpreting*” these essences from the participants’ various contexts, the “*meanings*” that lay hidden in participants’ lived experience texts became *visible* (Lindseth & Norberg 2004:148-49). As Streubert and Carpenter (2011:92) and Polit and Beck (2010:93) posit, the themes that emerged from the “descriptive” and “interpretive” processes were used to explain the themes related to what it is like to anticipate and experience an Ebola outbreak from the perspective and context of the survivors and the family caregivers.

### **5.3. FUNDAMENTALS OF PHENOMENOLOGICAL DATA ANALYSIS**

The phenomenological data analysis framework of Wertz (1983/2011) was used because at its core is description of “things” as they appear in peoples’ lived experiences (Finlay 2009:6; Wertz 2011:132), essential to arrive at “unique individual” and “universal essence” of lived experience. This approach shares features with works of Duquesne scholars among them Van Kaam (1966), Giorgi (1975) and Colaizzi (1978), all grounded on Husserl’s (1962) descriptive phenomenology at the core of which is arriving at a “description” of the “universal essence” of the lived experience. The details of these analytical frameworks are summarised in Table 5.1.

Table 5.1. Summary of Descriptive Phenomenological Data Analysis Methods

SUMMARY OF PHENOMENOLOGICAL DATA ANALYSIS APPROACHES ACCORDING TO HUSSERL (1913/1962), VAN KAAM (1966), GIORGI (1975), COLAIZZI (1978) AND WERTZ (1983/2005/2011)					
(Source: Husserl, E & Gibson, WRB (trans) 1962; Polit & Beck 2010: 474; Streubert & Carpenter 2011:79; Wertz 2011:131-161)					
STEP	HUSSERL (1913/1962)	VAN KAAM (1966)	COLAIZZI (1978)	GIORGI (1985)	WERTZ (1983/1985/2005/2011)
1	Explore diversity of one's consciousness	List and group preliminarily the descriptive expressions, which must be agreed upon by expert judges. Final listing presents percentages of these categories in that particular sample	Read all protocols to acquire a feeling from them	Read the entire set of protocols to get to a sense of the whole	Read the Individual Phenomenal Description (IPD) of the phenomenon, which is a comprehensive and faithful description of how the event (the experience) was originally lived.
2	Reflect on experiences: ✓ choose an experience to study ✓ develop a phenomenological framework ✓ specify a research problem	Reduce the concrete, vague, and overlapping expressions of the participants to more descriptive terms. Intersubjective agreement between judges is necessary	Review each protocol and extract significant statements	Reread the description	Think through each IPD psychologically to articulate the immanent significations (meanings) both explicit and implicit to the study participant
3	Perform phenomenological reduction	Eliminate elements not inherent in the phenomenon or two related phenomena	Spell out the meaning of each significant statement by formulating their meanings	Identify the transition units of the experience	Articulate psychologically the structural unit (the interrelations of the immanent meanings) of each of the participants narrative accounts
4	Explore the participants' life world	Write a hypothetical identification and description of the phenomenon being studied	Organise formulated meanings units into clusters of themes: ✓ Refer these clusters back to the original protocols to validate them ✓ Note discrepancies among or between various clusters. The researcher should avoid temptation of ignoring data themes that do not fit	Clarify and elaborate the meaning by relating constituents to each other and to the whole	Adopt a phenomenological "attitude" or "stance" consisting of five (5) components, dwell with the data, and grasp the "essence" of the descriptions during the idiographic level of analysis.
5	Intuit the structures through descriptive analysis: ✓ Perform the eidetic reduction ✓ Create a taxonomy for the experience ✓ Create a taxonomy of the context of the experience	Apply hypothetical description to randomly selected cases from the sample. If necessary, revise the hypothesised description, which must then be tested again on a new sample	Integrate result into an exhaustive description of the phenomenon under study	Reflect on the constituent parts in the concrete language of the participant	Engage in eleven (11) active operations or specialised activities of psychological reflection and dwell with the data to allow insight to emerge during idiographic level of analysis
6	Engage in intersubjective dialogue about the phenomena and contextual features	Consider hypothesized identification as a valid identification and description once preceding operations have been carried out successfully.	Formulate an exhaustive description of the phenomenon in as unequivocal a statement of identification as possible	Transform participant's concrete language into language or concepts of science	Reflect on descriptive data, put reflections together, eliminate redundancy, and formulate the "Individual Psychological Structure" (IPS) of the experience, consistent statement of the case
7	Fill out the phenomena and features: ✓ Cycle through reflection, bracketing, intuiting ✓ Cycle between the first and second formations ✓ Integrate bracketed material into the analysis		As a final validating step, return to each participant to ask about the findings thus far	Integrate and synthesize all of the transformed meaning units into consistent statement regarding participants' experience referred to as the 'structure of the experience'.  The description can be expressed on specific (idiographic) or general (nomothetic) level	Transform or move from the "Individual Psychological Structure" of the experience to the "General Psychological Structure" (GPS) aspects of the lived experience being investigated.  This stage moves from the specific (individual) aspects of the phenomenon to the essential (general) aspects of the phenomenon
8	Determine uses for phenomena and its features		If new data are revealed during validation, incorporate them into the exhaustive description		

To arrive at the “general” aspect of lived experience, I started by elucidating the “individual instances” of the phenomenon, before delving into “features” that cut across participant’s experiences (Giorgi 2009, in Wertz 2011:151; Wertz 2011:151). As Kvale (1996:52) and Laverly (2003:23) observe, the data analysis method helped me to structure the lived experience accounts, organising them to give form and meaning to the lifeworlds, elucidating their “essences” and unearthing survivors’ and caregivers’ invisible Ebola experiences. In addition, using Wertz’s (1983/2011) framework allowed me to capture both the “unique individual” and “general aspects” of participant’s lived experiences (Wojnar & Swanson 2007:177). This enabled examination of the features of these unique lived experiences in an embodied, relational as well as in temporal and contextual manner.

This feature allowed the researcher to elucidate deeper meaning and structure of survivors’ and family caregivers’ lived experiences, resulting in a broader understanding and better conceptualisation of the “unique” and “general” aspects of their personal experiences (Koch 1999:21; Benner 2001:40; Wertz 2011:133). This attribute of Wertz’s analytical framework is consistent with the principles of “general interpretive phenomenology” according to philosopher Ricoeur who declares that such research approaches provide a “reflective method” for clarifying existence and elucidating “meanings” within people’s social cultural contexts (Ricoeur 1990, in Terra, Gonçalves, Santos & Erdmann 2009:95), thereby allowing discernment of “things” in the text of study participant’s life stories (Ricoeur 1975:93).

In keeping with the descriptive, hermeneutic and existential traditions of philosophers Husserl, Heidegger, Gadamer and Ricoeur, data analysis within Wertz’s (1983/2011) analytical framework answered the phenomenological question: How can we let that which shows itself be seen in the very way that it shows itself? As Van Manen (2011:2) points out, the researcher was primarily interested in gleaning survivors’ and close family members’ “modes” of “being-in-the-world”, including how their “life worlds” of being parents, teachers, health workers, traders, or farmers, changed as a result of their anticipation and encounter with Ebola outbreak. Wertz’s (1983/2011) method with its features consistent with general hermeneutic method was chosen because as Heidegger postulates; all “description” is always already an “interpretation” (Van Manen 2011:2), implying a method that allows interpretation of lived experience addresses the object of the study, in this case,

understandings related to the meanings survivors' and their close family members assigned to the phenomenon of constantly anticipating, experiencing and surviving an Ebola attack.

Wertz's (1983/2011) method of inquiry was also chosen because as Ricoeur argues, meanings in human experience are not given directly to us and for one to understand them, there is need to make a "hermeneutic exploration" through the person's narrative of the lived experience (Ricoeur 1995:185, in Charalambous, Papadopoulos & Beadsmoore 2008:638). Cognisant of this assertion, the meanings embedded in the narratives were examined by exploring the social cultural perspectives, notably aspects of local myths, religious practices and expressive language, within the contexts of the before, during and after of the Ebola outbreak as advocated by Ricoeur (1976:74) and explained in Charalambous et al (2008:640). This analysis aided unearthing of how survivors' and family members' interpretation of the meaning of "being", "self", and "others" changed due to their anticipation and exposure to Ebola (Charalambous et al 2008:638; Van Manen 2011:3).

In essence, Wertz's (1983/2011) framework was selected because it aided the researcher to better understand and interpret the meanings of survivors' and family members' lived experiences especially within the social-cultural and related "contexts" in which the experiences were encountered. This analytical framework also shares features with other works within the phenomenological-hermeneutical tradition, among them the methods of Diekelmann, Allen & Tanner (1989); Van Manen (1990); Crist & Tanner (2003) and Lindseth and Norberg (2004), who themselves appear to have been influenced by the existential and hermeneutic thoughts of Husserl, Heidegger, Gadamer and Ricoeur.

At the core of these frameworks influenced by transcendental, hermeneutic and existentialist thought, is the researcher arriving at both the structure and meaning of the event from the perspective of those who have experienced it first-hand, investigated from the social-cultural and related contexts within which the experience was lived. The thesis of this process was arriving at convergence of survivors' and caregivers' experiences, researcher's understandings and other sources including literature and expert opinions (Diekelmann, Allen & Tanner 1989:360; Lindseth & Norberg 2004:150; Wertz 2011:151).

The summary of the methodical steps of these frameworks are presented in Table 5.2.

Table 5.2. Summary of Interpretive Phenomenological Data Analysis Methods

SUMMARY OF INTERPRETIVE DATA ANALYSIS APPROACHES ACCORDING TO RICOEUR (1976/1978), CRIST & TANNER (2003); VAN MANEN (1990), DIEKELMANN, ALLEN & TANNER (1989) AND LINDSETH & NORBERG (2004)					
(Source: Ricoeur (1976/1978); Diekelmann, Allen & Tanner (1989); Van Manen (1990); Crist & Tanner (2003); Streubert & Carpenter 2011)					
STEP	RICOEUR (1976/1978)	CRIST & TANNER (2003)	VAN MANEN (1990)	DIEKELMANN, ALLEN & TANNER (1989)	LINDSETH & NORBERG (2004)
1	Phase 1: Initial text reading: ✓ Read each transcript several times aimed at superficial understanding of the discourse ✓ Reading done without judgement to grasp the first meanings and organise data	Phase 1. Early Focus and Lines of Inquiry: ✓ Transcripts of initial interviews are discussed ✓ Evaluate interviews and techniques used ✓ Missing or unclear data tagged for exploration ✓ New questions direct future sampling	Turn to a phenomenon or experience of serious interest and concern	Read the interview transcriptions to obtain an overall understanding of the research.	The text for analysis is a narrative interview data which was generated by encouraging the participant to narrate, as freely as possible, about his/her lived experience on specific topic.
2	Phase 2: Critical reading: Read each transcript in-depth to interpret and understand the hidden meanings	Phase 2: Central Concerns, Exemplars and Paradigm Cases: ✓ Interpretive team identifies central concerns, important themes or meanings that are unfolding for specific informants, ✓ Interpret data through writing and rewriting central concerns.	Investigate the experience as it is lived, rather than as conceptualised	Write interpretive summaries and coding for possible emerging themes.	During Naïve Reading: ✓ Read the text several times in order to grasp its meaning as a whole. ✓ Open up and allow the text to speak to you, to become touched and moved by it. ✓ Switch from a natural attitude to a phenomenological attitude.
3	Phase 3: Appropriation: Appropriation is when the apex of understanding is reached with assimilation and grasping of the revealed meaning of the experience	Phase 3. Shared Meanings: ✓ As informants' central concerns become clear, the investigator and Interpretive team members observe shared meanings. ✓ The written interpretive summary shows connections between meanings found within and across stories or constitutive patterns	Reflect on the essential themes which characterise the phenomenon	Analyse selected transcripts as a group to identify themes.	During structural (thematic) analyses: ✓ Divide text into meaning units ✓ Read through meaning units and reflect on their similarities and differences. ✓ Sort, condense and abstract meaning units to form sub-themes ✓ Assemble sub-themes into themes.
4		Phase 4. Final Interpretations: ✓ Interpretive notes and summaries provide lines of inquiry ✓ Concomitant interpretive writing and clarification of interpretations ✓ In-depth interpretation of excerpts, central concern summaries & interpretive summaries. ✓ Final interviews and observations address pending lines of inquiry	Describe the phenomenon through the art of writing and rewriting	Return to the transcriptions or the participants for clarification of disagreements in interpretation  Write a composite analysis of each transcription.	In comprehensive understanding: ✓ summarise and reflect on main categories, themes and sub-themes in relation to the: ○ research questions and the ○ context of the study  This steps helps in interpreting the whole
5		Phase 5. Dissemination of the Interpretation: ✓ Manuscripts reporting interpretations are refined with input from the interpretive team. ✓ This phase of interpretation continues to be an iterative process between narratives, field notes, and team input.	Maintain a strong and oriented relation to the phenomenon	Compare and contrast transcription (texts) to identify and describe shared practices and common meanings.	Use the emergent themes and relevant literature to illuminate various aspects of the text and through critical reflection, revise, broaden and deepen awareness (pre-understanding) about the phenomenon under inquiry.
6			Balance the research context by considering parts and whole	Elicit responses and suggestions on a final draft from interpretative team and from others familiar with the content and the methods of the study.	Use the new perspective and insights gained about the phenomenon to help others gain new insights, by writing in a way that affects people.

#### **5.4. WERTZ'S (1983/2011) EMPIRICAL PSYCHOLOGICAL REFLECTION**

Empirical psychological reflection which informed data analysis is grounded on Wertz's (1983, 1985, 2005, 2010, 2011) work and supported by related works. The inclusion of other views is consistent with the dynamic nature of qualitative research, including its emergent design and different researchers handling of aspects of the research in unique ways. Tesch (1990:96) and Klopper (2008:63) corroborate that qualitative research procedures are neither 'rigid' nor 'mechanistic' and its emergent nature allows inclusion of approaches that illumine aspects of the research process.

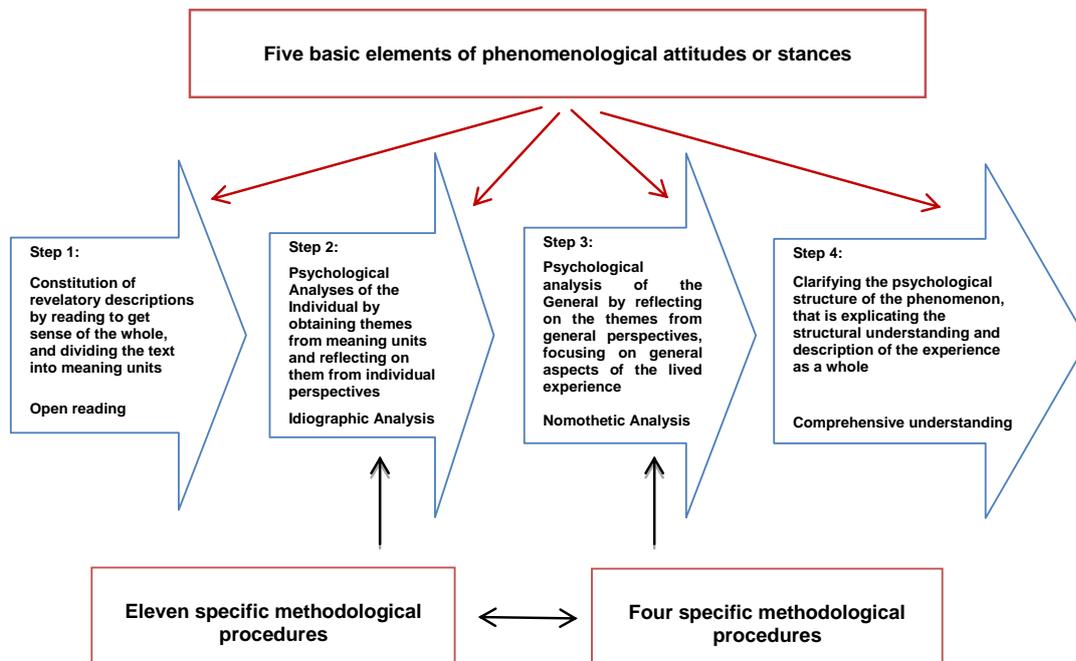
The main motivation for choosing Wertz's (1983/2011) approach is that among the many modern day proponents of the phenomenological method, Wertz has continued to clarify and amplify his method, through an array of various publications and explications (Wertz 1984, 1985, 1986, 2005, 2010, 2011). Although revised and updated regularly, these works still follow closely on that of his predecessors Husserl (1913/1962), Van Kaam (1966), Giorgio (1975/2009) and Colaizzi (1978), incorporating trends in interpretive phenomenological inquiry (refer to section 5.3).

These revisions and its applicability makes Wertz's (1983/2011) approach, a preferred research framework to arrive at both unique individual aspects of the experience and general features of the phenomenon, including meanings and structure of the experience. A key aspect of the method is that it allows articulation of these experiences from within unique and invariant contexts of those who lived it.

Wertz's (1983/2011) framework consists of three specific phases of reflection, implemented through adopting specific phenomenological attitudes or stances, including engaging in several specific methodological research procedures or research activities; while the fourth phase consists of phenomenological describing (Wertz 2011:131; Giorgi 2009, as explained in Wertz 2011:132). The specific discussions related to these four analytical steps are presented in section 5.4.1.

### 5.4.1. Phases of Empirical Psychological Reflection (EPR)

The four (4) methodical steps of Wertz's (1983/2011) Empirical Psychological Reflection framework are supported by fifteen (15) research procedures and five (5) basic phenomenological attitudes as shown diagrammatically in Figure 5.1.



**Figure 5.1. Diagrammatic presentation of Wertz's analytical approach**

Wertz (1985:161; 2010:270; 2011:131) explains that EPR occurs after the research data are well constituted, herein digitally audio-recorded during qualitative interviews and transcribed verbatim. The lived experience accounts consist of several descriptions of the “everyday life experiences” that survivors and their family caregivers experienced before, during and after and in-between Ebola outbreaks.

The EPR proceeded through the following four phases:

- Constitution of Revelatory Descriptions (Open reading).
- Psychological Analyses of the Individual (Idiographic Analysis).
- Psychological Analysis of the General (Nomothetic Analysis).
- Structural understanding and description (Comprehensive understanding).

#### 5.4.1.1. Constitution of Revelatory Descriptions

This preparatory analysis phase according to (Wertz 1985:164; 2011:131) generates organised descriptions of the lived experience expressed in the first person language of participants; one for each interview. This “data cleaning” phase characterised by “open reading” involved removing from each transcript, all the irrelevant data from the interview and ensuring all statements that reveal the experience as it occurred were left intact. This description depicted how participants experienced the threat of Ebola.

This preparatory phase that precedes in-depth data analysis is characterised by the researcher reading each interview text as a whole several times to gain an impression of the whole, followed by formulation of the researcher’s thoughts about its meaning for further analysis (Streubert & Carpenter 2011:85; Wertz’s 1985:164; 2011:131). This initial step which documents the researcher’s “impression of the text”, is consistent with data analysis within general hermeneutic phenomenological research framework. Lindholm, Uden and Rastam (1999:103), Lindseth and Norberg (2004:149) and Bäckström and Sundin (2007:246) describe this phase as “writing interpretative summaries of individual interviews and coding for emerging themes”.

In this phase, all interview transcripts were individually reviewed to gain a “good sense” of the phenomena of anticipating, experiencing and surviving an Ebola outbreak from the perspective of each survivor and family caregiver. This initial reading of transcripts which Giorgi (2009, as cited in Wertz 2011:131) and Wertz (2011:131) describe as “open reading” and interpretive scholars Lindseth and Norberg (2004:149) and Bäckström and Sundin (2007:246), as “naïve reading” focused on how survivors and caregivers perceived Ebola, what they thought symbolised people’s reaction towards them and others suspected or known to be affected by Ebola, including how it affected their everyday lives in the aftermath.

As a quality measure, my *‘initial impressions’* of the various aspects of the Ebola experience were documented and discussed with the thesis promoter who served as an external expert and a quality checker. As previously explained, discussions were held until a general agreement about their meanings was reached before proceeding.

In consonance with Wertz's (2010:271; 2011:131-136) views, I constituted each of the revelatory descriptions by engaging in the following five methodical (5) steps:

- Reading the interviews carefully and openly.
- Demarcating meaning units in the interview data.
- Judging which data constituents are revelatory for the research question.
- Regrouping the relevant constituents into appropriate patterns.
- Discarding redundant statements and re-describing the events.

#### **5.4.1.1.1. Reading the interviews carefully and openly**

Each transcript was read carefully without any special attitude to have a general understanding of each participant's lived experience. This was done by putting myself in the "*shoes*" of each survivor or family member and trying to empathically, "*live*" their experiences from inside, not just an idle spectator, asking questions such as: how might this aspect have felt?. This necessitated deep involvement with each lived experience and helping in grasping the meanings (Wertz 1985:164; Wertz 2010:271).

#### **5.4.1.1.2. Demarcating meaning units in the interview data**

The meaning units were demarcated from the interview data by focusing on and thematising sections with meanings embedded to facilitate in-depth analysis. This prevented chunks of data being left unattended, which would have occurred if apprehension of entire description occurred in a single glance (Wertz 1985:165; 2011:131). This involved re-organising entire transcripts into small "meaningful data chunks" to work with comfortably; apprehended within the context of the whole experience and consisted of "parts whose phrases required each other to stand as a distinguishable "moment" of a specific lived experience (Wertz 1985:165; 2011:131).

#### **5.4.1.1.3. Judging revelatory constituents for each research question**

This involved making crucial decisions and judging which constituents would reveal relevant information about particular aspects of participants' lived experiences in

accordance with the research questions. It involved discriminating data to inform the researcher's understanding of particular aspects of the participants' experiences. As Wertz (1985:167; 2011:136-137) posits, the revelatory nature of the sections of data were determined by my perception of what a description conveys, in regard to the different research questions; in terms of the 'before', 'during' and 'after' Ebola phase.

#### **5.4.1.1.4. Re-grouping relevant constituents into patterns**

In keeping with Wertz (1985:167; 2005:172), this step entailed re-grouping together relevant constituents (data chunks) according to their meanings and then placing them in a temporal order so that the patterns accurately expressed the sequence of the events in each story. It involved bringing together related statements so that the original temporality of the experience as lived, was re-constructed especially where order of events were not reflected, to facilitate analysis (Wertz 1985:168; 2011:138).

#### **5.4.1.1.5. Discarding redundant statements and re-describing events**

This step gives rise to the final product of this phase, "revelatory descriptions". As Wertz (1985:168; 2011:139-140) states, it involves discarding all redundant statements and re-describing the events from the first person perspective, more or less in participant's language. This final product is the "*Individual Description of the Phenomenon*", the basis for the in-depth data analysis (refer to section 5.4.1.2).

#### **5.4.1.2. Psychological Analysis of the Individual Experience**

This idiographic phase of empirical psychological analysis, Wertz (1983:204; 2011:138; Grbich 2013:Loc2278) clarify, involves carefully reading and reflecting upon the meaning units in each Individual Phenomenal Description (IPD), that is, participants' "*clean*" description of their experiences with all irrelevant statements removed, but having left all revealing details intact; to attain a deeper understanding of what is embedded in each of the meaning units regarding survivors' and family caregivers' psychological life in relation to their encounter with the Ebola outbreak.

This analytical step is consistent with the structural or thematic analysis phase of general hermeneutics method (Lindseth & Norberg 2004:150). It involves identifying patterns of meaningful connections through “interpretive reading” (Streubert & Carpenter 2011:85; Grbich 2013:61). This is what Wertz (2011:131) describes as discriminating meaning units, which lend themselves well to analytical reflection to answer the research questions and upon further psychological reflection, may result in themes which ground the study (Lindseth & Norberg 2004:150; Wertz 2011:132).

As Wertz (2011:132) declares, I systematically posed to each meaning unit the various research questions and reflected upon each of them to answer the questions. This allowed identification and documentation of unique aspects of the lived experience. In an empathic manner and using deep reflection, the unique experiences detailed in each of the IPDs were examined to grasp the psychological sense in each meaning unit in their unique contexts, in relation to other meaning units and the whole phenomenon. This resulted in conceptualisation of what each meaning unit revealed, the role it played and its contribution to survivors’ and family caregivers’ psychological processes in relation to Ebola experience (Wertz 2005:172; 2011:126).

In Wertz’s (2005:172; 2011:126) words, this phase of data analysis constituted the procedure of “intentional analysis”, described as a reflective process characterised by the researcher describing and gaining insight into the “how” and “what” of lived experience; that is how experiential processes proceed and what is experienced (Husserl 1913/1962, in Wertz 2011:126). Through intentional analysis, I deciphered “*various kinds of intentionality*”; that is, the different ways participants meaningfully experienced the phenomenon. These reflections reveal that the lived experiences are embodied, emotional, spatial, social as well as temporal (Wertz 2005:167; 2011:126).

The end result of the psychological reflection on each participant’s phenomenal description is an integrative summary of the findings. It involves pulling all reflections about each phenomenal description together, eliminating any redundancies and then concisely expressing the findings into the most revelatory aspects of each participant’s lived experience. This “*synthesised*” description, which symbolises the end product of idiographic level of analysis, is what Wertz (1985:173; 2011:142)

terms “Individual Psychological Structure” (IPS) of the phenomenon, and consists of both facts of lived experience and their psychological significance. This procedure of explicating the IPS helped me to focus thematically on the research questions within the perspective of a single “individual”, albeit with the potential to exhibit “generally essential” features of the phenomenon to other study participants (Wertz 2011:142).

To effectively apprehend the meanings in each lived experience account during this phase, I adhered to five basic “stances” or “attitudes” (refer to section 5.4.2) and eleven “active operations” (refer to section 5.4.3). These “methodological processes” enabled me to achieve the cardinal role: being the main research instrument, especially to grasp the “essential features” of each lived experience (Wertz 1985:174; 2010:272; Wertz 2011:142). Details of Individual Psychological Structures (IPSs) are highlighted in Chapter 6, to fulfil the quality control requirements of the audit trail.

#### **5.4.1.3. Psychological Analysis of the Experience in General**

This phase of psychological reflection, termed “nomothetic level” of analysis by Wertz (1983:227; 2011:150) attempts to learn and effectively portray the lived experience being investigated in general terms. It involves moving from the psychology of the individual experience to psychology of the experience in general; that is, the nuances of the experience across individuals and circumstances. This generated “general knowledge” about the phenomenon from individual examples, described as “General Psychological Structure” (GPS) of a lived experience (Wertz 1985:188; 2011:150).

To arrive at general or eidetic aspects of the lived experience, the researcher starts with the “unique” individual psychological descriptions”, which Van der Wal (2013) describes as “empirical description” and Wertz (2011:142) “individual psychological structure” and compares them for similarities and differences through the process of empirical or imaginative variation, where the experiences are varied and compared across different situations and contexts of participants. As Wertz (2011:150) explains, arriving at general elements (invariant features) of an experience, occurs through the process of “eidetic seeing”, characterised by identification of unique features that cut across different idiographic descriptions. Whilst focusing on the different individual

experiences in narratives, numerous rich and varied examples of how participants experienced the constant threat of Ebola appeared and as reflections upon the IPSs continued, general insights about these experiences surfaced (Wertz 2011:151).

The “*empirical variation*” process allowed unique empirical “*voices*” in the descriptions to be analysed to arrive at the essential meanings and structures of the participants’ lived experience, which is objective psychological knowledge (Wertz 2010:271) and is essential to understand participant’s unique lived experiences. This eidetic process started with looking at each participant’s unique description of their lived experience and then re-constructing these individual profiles of lived experiences to make sense in the “*general sense*” of the lived experience (Wertz 2011:151; Van der Wal 2013:1).

This move from “individual” to “general” aspects is critical since the individual psychological structure only reflects an “individual instance” of the phenomenon (Wertz 1985:188; 2011:150). Yet, with nomothetic analysis, the researcher transcends from individual expression of the Ebola experience to the general nature and meanings of the experience of anticipating, experiencing and living in the aftermath of life threatening conditions as a whole. This could have been projected to reflect humanity as a whole as affirmed in the data, in the literature, in the life world, in the reader’s experience, through empirical variation process (Wertz 2011:135), allowing the findings to be “*extrapolated*” to illumine other situations (Finlay 2009:9).

Articulating the GPS of lived experience requires understanding diverse individual cases (IPS) as instances of something more general and then articulating that generality of which they are particular instances (Wertz 1985:189), by articulating the “rich and varied examples of the phenomenon (Wertz 2011:151), that is the commonalities of the unique individual instances of their experiences. This transformation from “idiographic” to “nomothetic” analysis was facilitated by mulling over the question, “*What has been learned in general from each description about anticipating, experiencing, surviving Ebola and living in the aftermath of Ebola?*” This “eidetic questioning” permitted movement from “unique individual” instances to “universal features” of anticipating, experiencing and surviving life threatening situations with similar physical, psychological, social, spiritual and economic

consequences (Wertz 1985:188; 2011:126). This transition from “individual” to “general” helped me in identifying psychological processes and meanings invariantly present in the lived experience accounts of all survivors and caregivers; akin to empirical examples of anticipating, experiencing and surviving life threatening and life-limiting conditions in literature (Giorgi 2009, in Wertz 2011:151; Wertz 2011:151).

This analysis phase was bolstered by five “phenomenological attitudes” articulated in section 5.4.2 in addition to eleven “active operations” or “procedures” of empirical reflection, as described in section 5.4.3, which enabled me to apprehend the different moments and perceived meanings and structures during idiographic analysis. In addition to “phenomenological attitudes” and “active operations,” nomothetic analysis also incorporated four “active operations” described in section 5.4.4. Details of the psychological reflection employed during the nomothetic analysis follow in Chapter 6.

#### **5.4.1.4. Structural Understanding and Comprehensive Description**

Key to this step which Giorgi (2009, in Wertz 2011:132) and Wertz (2011:132) term “structural understanding and description” phase is phenomenological describing, which involves integrating and describing insights gleaned from reflections upon the meaning units. I summarised and reflecte upon themes and sub-themes in relation to the research questions and entire study (Sundin & Jansson 2003:113; Lindseth & Norberg 2004:150) and revealed various “possible ways of experiencing the world”, as a survivor or a family caregiver (Ricoeur 1976, in Bäckström & Sundin 2007:250).

Structural understanding was performed by articulating participant’s lived experiences as “a structural whole”, through “comprehensive understanding” of their unique and shared experiences (Lindseth & Norberg 2004:150; Bäckström & Sundin 2007:244). To portray my “in-depth understanding” of these experiences, I reflected deeply upon the unique individual themes, general themes and my pre-understandings about the Ebola experience. This “*fusion of horizons*” was then carefully articulated as “comprehensive understanding of the meaning and structure of participant’s lived experience of anticipating, experiencing, surviving and living in the aftermath of Ebola (Lindahl & Sandman 1998:184; Sundin & Janssen 2003:113; Wertz 2011:132-133).

This “comprehensive description” of lived experience was facilitated by deep reflection including use of empirical and imaginative variation techniques to glean further insight from different aspects of participant’s individual experiences. It also drew insight from associating the “final” themes with existing and relevant literature (Wertz 2011:160). Lindseth and Norberg (2004:150) much like Giorgi (2009, in Wertz 2011:151), agree these final descriptions arising from deep reflections, empirical variations and associations with literature, revised, widened and deepened understanding of structures and meanings of survivors’ and caregivers’ experiences.

The “comprehensive understanding” of the phenomenon was presented as “unique individual experiences”, and as “common instances within individual experiences”, and highlighted the different contexts of participants’ experiences. This step of the final phase leaned on Cauley’s (2008:425) and Van Manen’s (2011:2) recommendation that lived experience accounts should be presented in an evocative, expressive, transcendent and poetic manner, to enable the reader grasp both hard “facts” and “emotions” related to the experience. As Van der Zalm and Bergum (2000:212) posit, the “facts” of the lived experience act as building blocks of “*new knowledge*”, while the “emotions” help create “*phenomenological reverberation*”, to connect readers to the text (Causley 2008:427). In addition, this *style* was also intended to ensure the final account of survivors’ and caregivers’ lived experiences resonated with and is easily recognisable by participants (Creswell 1998: 289-290).

To boost the vividness of the experiential accounts, bits of “raw interview data”, are included into the final descriptions by incorporating participants’ verbatim expressions to enable readers follow aspects of their lived experience (Wertz 2011:161; Van Manen 2011:2). These concrete situations, including the different contexts of lived experience “*open*” windows into participants’ lifeworlds, providing readers with intuitive understanding of participant’s “world” lived experiences; by allowing access to the original experiences, i.e., “*the things themselves*”, which Husserl terms, *den Sachen selbst* (Wertz 2011:161), thus making them more understandable to others.

The “*comprehensive*” understanding of the lived experiences were documented using everyday language (Lindseth & Norberg 2004:151) so that readers could “see”,

“hear”, “touch”, “smell” or “taste” these experiences (Burroway 2003, in Caulley 2008:431). The use of everyday language is supported by Klemm (1983) who affirms that “*when we try to express the meaning of lived experience we need to use everyday language rather than abstract scientific language*” (Klemm 1983, in Lindseth & Norberg 2004:151), lest we obscure the messages in lived experience accounts.

In explicating “*comprehensive*” understanding of the lived experience, verbs instead of nouns were used to tell participant’s stories since the former are better at revealing lived experience than nouns. In addition, poetic expressions were utilised to make the narratives lively and able to carry the emotive sense of the lived experiences. As Van den Hengel (1982) proclaims, poetic language makes words mean as much as they can and creates mood, which reveals possible ways of being in the world and “shows a deeper mode of belonging to reality” (Van den Hengel 1982, as explained in Lindseth & Norberg 2004:151), while the scientific language reduces the polysemy (capacity to generate multiple meanings) of language used (Ricoeur 1991:448-462).

As Caulley (2008:424-430) advises, I attempted to ensure that the descriptions were less boring and captured “*various experience scenes*” to involve readers and to make them “*feel right there*” at the scene. It is for this reason that the final formulation of the lived experience account consisted of poetic expressions and metaphors to convey my interpreted meanings and to elicit “*phenomenological nods*”, as celebrated by philosopher Ricoeur (1976, cited in Terra et al 2009:98); Van Manen (1990:27), Lindseth and Norberg (2004:151) as well as Caulley (2008: 425-430) among others.

The specific details pertaining to the study findings are articulated in Chapter 6.

#### **5.4.2. Attitudes of Empirical Psychological Reflection**

Effective engagement in psychological reflection, Wertz (1983:204; 2011:132) insists requires researchers to adopt five basic stances or phenomenological attitudes during the idiographic and nomothetic level of analyses, among them:

- empathic immersement in the situations described
- slowing down and dwelling in each moment of the data
- magnification and amplification of the situation as experienced
- suspension of belief and employment of intense interest in experiential detail
- turning from objects to their personal/ relational meanings and significance

#### **5.4.2.1. Empathic immersement in the situations described**

This attitude entails using transcriptions as a point of access from which to “make survivor’s and family caregiver’s lived experience as the researcher’s own”, as if to “put on the shoes of each participant” as reading and immersement into descriptions of their encounters occurs. This conforms to Wertz’s (1983:204) declaration that the spirit of true phenomenology means the researcher cannot simply remain a passive spectator, but must experience the “joys” and “pains” of participants in full detail and in-depth to faithfully “know” them well. This attitude facilitated thoughtful entry into survivor’s and family caregivers’ “situations” and through careful reflection upon each phenomenal description; each of their lived experience situations were reconstructed (Wertz 1985:174; 2011:131; Grbich 2013:92). This flexible approach became vital in understanding the individuals’ and community’s’ views about the Ebola experience.

#### **5.4.2.2. Slowing down and dwelling in each moment of the data**

This phenomenological attitude cautions against glossing over details of the individual phenomenological descriptions as if they are already known (Wertz 1983:204). I remained alert and made sufficient room and time to clearly understand participants’ descriptions of their lived experience. This was done by slowing down, lingering, and dwelling with each moment of the data until such time that it made sense. This was to heed Wertz’s (1985:174) warning that if one simply glosses over incidences in participants’ descriptions, their meanings would remain largely implicit and this would defeat the central purpose of the investigation. This slow and thoughtful dwelling permitted comprehension and apprehension of the different sections of the data by “seeing” what each act or section of the narratives meant to each participant in their various contexts, what difference it made in their lives,

including how the various meaning units fitted in each survivor's and caregiver's entire lived experience account in relation to Ebola outbreaks (Wertz's 1983:205).

#### **5.4.2.3. Magnification and amplification of the situation as experienced**

This stance involves magnifying and amplifying various sections of the data to manifest their hidden meanings. This process was premised upon Wertz's (1983:205; 1985:174) affirmation that when one stops and lingers in the moment of an experience, its significance and meanings are magnified. What to the survivor or caregiver or a naïve reader seems unimportant and mundane then becomes significant and a "big deal" to the researcher. The core elements in participant's situations were grasped by magnifying and amplifying various aspects of the "raw" data, however mundane the data unit appeared at first. This "*opened*" my mental "*eyes*" and "*ears*" to the *things* hidden in each participant's lived experience account.

#### **5.4.2.4. Suspension of belief and employment of interest in the experience**

According to Wertz (1983:205) this stance is a modification of the natural attitude and the naivety with which the researcher originally "entered" the participant's situation. To ensure better understanding, Wertz (1983:205) recommends, that rather than remaining immersed in the data persistently, the researcher needs to regularly stop, take a leap backwards, abstain from continued absorption and then "wonder" afresh, what a particular way of "living" the experience means, what it is all about, including how it affects individuals and their relationships with others and other existential components including interpretation of time and space (Wertz 1985:174; 2011:132).

This "suspension of belief" compares with "bracketing" as discussed in section 2.3.6 and "reflexivity" as articulated in section 2.3.10. I reflected and critically examined the various structures and meanings of each moment in the lived experiences accounts as seen through the "*existential lenses*" of time, space and others, by alternately breaking the initial "*fusion*" with the data and stepping aside. Hence, by momentarily gaining "*freedom*" from the naïve understandings of the lived experience accounts, I was then delivered to a "*position*" where I could clearly "see" the origins, relations and the structures of each survivor's and caregiver's lived experience (Wertz 2011:132).

#### **5.4.2.5. Turning from objects to their meanings and significance**

This phenomenological stance is underpinned on Wertz's (1983:206; 2011:131) caution that during data analysis the researcher should not be concerned about "reality" or "falsity" of the objects or state of affairs in participant's descriptions; as a judge would in a court proceeding (Wertz 1985:175). This caution is based on the basic assumption of phenomenological research that reality is multiple and varies from one person to another (Guba & Lincoln 1989:105). Cognisant of this tenet, I was careful in apprehending the various situations that were meaningful to the participant, that is, I focused more pertinently on what particular aspects of the lived experience meant to survivors and caregivers through their existentially meaningful contexts.

Informed by these assumptions, I focused firmly on how the phenomenon of "living under constant threat of Ebola" appeared to survivors and family caregivers, including the meanings of various events and how these meanings arise and get transformed through the three temporal zones of the "before", "during" and "after" Ebola outbreaks. This stance delivered me to each participant's unique situation of how their encounter with Ebola affected them, thereby enabling articulation of their peculiar meanings and significance of their situations (Wertz 1983:206; 2011:131-2).

#### **5.4.3. Procedures of Empirical Psychological Reflection**

According to Wertz (1983:206; 2011:132), these 15 active methodological procedures permeate through individual and general levels of analyses; 11 of which are utilised during idiographic analysis while the remaining 4 are used during nomothetic analysis. Whilst discussed herein in a linear form, these specialised procedures according to Wertz (1985:175) constitute an inextricable unity during actual reflection. The research process was guided by Wertz's (1983:206;1985:174) assertion that in both idiographic and nomothetic analysis, these research activities (see section 5.4.3) and the attitudes (see section 5.4.2) may come into play either successively, in combinations, or in an all-in-once stroke, in every statement in each participant's individual phenomenal description. This means that these "stances" and "procedures" should be considered mutually implicative and inseparable throughout data analysis.

Consistent with Wertz (1985:175; 2011:132), the following 11 research procedures were employed during idiographic level of data analysis of participant's experiences:

- Identification of the “existential baseline” of the experience
- Reflecting on relevance of what is revealed about the phenomenon
- Explicating implicit meanings that are not thematically clear in the descriptions
- Distinguishing the various constituents that make up the entire experience
- Understanding relations among constituents and their roles to the whole
- Thematising recurrent modes of experience, meanings, and motifs
- Interrogating opacity - extending and acknowledging limits of comprehension
- Imaginatively varying constituents to identify mutual implications and invariant
- Formulating descriptive language for psychological knowledge using every day phrasing, received scientific terms, or philosophical discourse
- Verifying, modifying, and reformulating findings after returning to the data
- Using existential concepts as a heuristic (basis) to guide descriptive reflection

A detailed articulation of how each of research procedures occurred now follows:

#### **5.4.3.1. Identification of the “existential baseline” of the experience**

Wertz (1983:207) points out that implicit in the researcher's frame of reference are the norms of psychological existence, typical day-to-day life in which the phenomenon is not profoundly present or where other phenomena predominate. The “chosen” existential baseline or temporal background becomes the ground upon which the phenomenon stands out and is identified by the inquirer (Wertz 1985:175).

In this study, the experience of anticipating, experiencing and surviving an Ebola outbreak was contrasted against the ground of “*not anticipating and experiencing a serious condition*”. The existential baselines and the temporal dimensions provided the basis for intense contrast between the grounds of “*anticipating and experiencing*” and “*not anticipating and not experiencing*”. This comparison helped in delineating the precise contours of the lived experience of anticipating and experiencing an Ebola outbreak. As Wertz (1983:207) posits, the contrast between the “before” and the

“after” of the lived experience allowed the researcher to arrive at deeper understanding of these moments, by using this baseline to discern how Ebola outbreaks affected their being, say as mothers, teachers or community members.

#### **5.4.3.2. Reflecting on the relevance of each moment of lived experience**

Wertz (1983:207) states that reflection and decision-making occur constantly as the researcher analyses each lived experience. The existential baseline and the temporal dimensions provided the researcher with the basis for judging the statements in the IPDs for their relevance to each survivor’s and family caregiver’s lived experience.

I reflected on the relevance of each moment of the lived experience by asking questions such as: *“How do I understand the survivors’ and family caregiver’s lived experience of anticipating or experiencing an Ebola outbreak?”*, *“What does this statement reveal about their experiences?”*, *“How is it relevant in their situation?”* By carefully reflecting upon the various key moments in each individual phenomenal description, I then abstracted the “essential structures and meanings” in each lived experience account of every Ebola survivor and family caregiver (Wertz 1985:175).

#### **5.4.3.3. Explicating implicit meanings that are not thematically clear**

As Wertz (1983:207) explains, I was aware that the interview transcripts are not the ultimate objects of reflection, despite their necessity in helping an inquirer understand the person’s lived reality. I was further guided by the notion that psychological reflection should address the “immanent significations” (meanings) which make up Ebola survivors’ and family caregivers’ reality in their lived experience descriptions.

Wertz (1985:176) explains that once situated in the participant’s world through their description, the researcher should reflect on the “things” not explicitly mentioned in the description, but are demonstrably present, albeit implicitly in the participant’s situation. By “penetrating” the implicit horizons in the descriptions, I validated how survivors’ and caregivers’ horizons of “normalcy” were distorted by the experience of anticipating, experiencing and surviving the July 2012 Kibale Ebola outbreak.

#### **5.4.3.4. Distinguishing constituents that make up the entire experience**

Wertz (1983:208; 2011:132) recommends that once the inquirer is involved in participant's situation, they should make distinctions between different aspects of the key moments within the lived experience. This sensitivity to different aspects of a single reality enables the researcher to see hitherto hidden patterns, themes and categories related to participant's reality in terms of personal, spatial, temporal or relational dimensions. As Wertz (1985:176) declares, differentiating between different aspects of the lived experience were facilitated by "distilling" from each statement what it expressed that was different from others, using a combination of "empirical" and "imaginative" variation techniques of narrative (qualitative) data analysis.

#### **5.4.3.5. Understanding relations among constituents and their roles to the whole**

To clearly understand how various constituents relate to the entire experience, Wertz (1983:208; 2011:132) advises reflection on each constituent, focusing on what it has to do with other elements and aspects of the phenomenal description. This methodological procedure was realised by posing to major constituents questions such as: *How does this constituent relate to the whole experience? What part does it occupy? How does this affect participants in terms of temporal, spatial or relational dimensions?* This interrogation technique also facilitated the process of determining salient aspects of the phenomenon that depended upon or presupposed others. It further assisted me in decoding how different aspects of each person's lived experience related to and augmented each other (Wertz 1983:208-209; 1985:176).

#### **5.4.3.6. Thematising recurrent modes of experience, meanings and motifs**

In addition to identifying the relationships between various constituents within the experience and affirming what each of them occupies in each survivor's and caregiver's lives, I began to search for uniting and consistent elements within the diverse experiences related to the Ebola experience (Wertz 1985:176). As I "decoded" what each of the main constituents stood for, the "themes" crucial to understanding the essential aspects of participants' unique lived realities unfolded, in conformity to Wertz's (1983:209; 2011:132) declaration, moving the study forward.

#### **5.4.3.7. Interrogating opacity: acknowledging comprehension limits**

This methodological procedure involves interrogating and dwelling with data to understand their contexts and clarify vague areas that perplex the inquirer during psychological reflection (Wertz 1983:209; Wertz 2011:132). When unclear areas emerged, I reflected deeply and with consultations with the supervisor, questions such as: *“What does this mean in the context of anticipating or experiencing an illness”*; *“How did participants’ prior experience change their perspective of anticipating and/or experiencing the outbreak?”* were asked. Interrogating areas of opacity allowed me to navigate through the various opaque areas and to reveal the meanings and attain deeper understanding of lived experiences (Wertz 1985:176).

#### **5.4.3.8. Varying to identify mutual implications and invariant structures**

This analytical procedure as explained in Wertz (1983:209; 2011:133) requires the inquirer to ask whether any of the constituents, distinctions, phases, relations and the themes could be different or even absent while still presenting an individual’s unique reality. I questioned: *“Would a survivor or family member experience an outbreak differently if they had no previous information about Ebola or a similar life threatening condition?”* *“Is the experience of anticipating different if the participant was survivor or caregiver?”* Therefore, by questioning what these lived experiences would be in the different scenarios and then by imaginatively or empirically varying aspects of the descriptions, enabled me to clarify the different contours of survivors’ and caregivers’ lived experiences accounts (Wertz 1985:176; Streubert & Carpenter 2011:48).

#### **5.4.3.9. Formulating descriptive language for the psychological knowledge**

This procedure is the researcher’s attempt to express the sense made during both the idiographic and nomothetic stages of analysis (Wertz 1983:210) using descriptive language which may take the form of everyday phrasing, received scientific terms or by engaging in a philosophical dialogue (Wertz 2011:133). The descriptions are not expressed strictly in the participant’s own words, but rather using the researcher’s words as well since it is partly the researcher’s psychological reflection being expressed (Wertz 1983:210;1985:177). The transformation of the experience into

psychological language is not simply a translation of the description, but rather original speaking of the defining elements of the experience delineated from contact with survivors' and caregivers' lived experiences. Consistent with Wertz's (1985:177; 2011:133) affirmation, the words used to describe the new knowledge were chosen from everyday language, scientific vocabulary and from philosophical discourse.

#### **5.4.3.10. Verifying, modifying, and reformulating the findings**

Wertz (1985:177) says that whenever the researcher "speaks" in psychological terms, there is a distance between what is said and the participant's original description, implying the presence of an inherent danger of losing contact with participant's lived situations. This shortcoming was overcome by constantly returning to the original descriptions to verify, modify or negate new reflections about moments in participant's lived experience. This verification was facilitated by constantly comparing themes with coded individual psychological structures. This process received further scrutiny from the thesis supervisor who checked all the themes for appropriateness before the researcher "finalised" them as noted in section 4.9.1.3.

This validation exercise was guided by questions such as: "*Is everything said borne out?*", "*Is everything in participant's lived experience accurately reflected in the final description of the experience?*" This verification resulted in a tight fit between what participant's "said" and what the researcher "described" (Wertz 1985:177; 2011:133).

#### **5.4.3.11. Using existential concepts as a heuristic to guide reflection**

According to Wertz (1985:177) this last active procedure is secondary and is built upon the other specialised operations aforementioned, especially the stages that involved verification, modification and reformulation of themes. This deep level reflection may be guided by using received concepts which included existential structures related to the "self", "world" and "others" that are prevalent in participant's everyday psychological reality. Whenever a survivor and caregiver described their lived experience within a particular existential framework, I carefully pondered over how other existential concepts were involved as well (Wertz 1983:211; 1985:177).

In addition to the “self-world-others” existential concepts, I also used other concepts such as “life-world”, “being-in-the-world”, “*temporality*”, “*corporeality*” and “*spatiality*” to guide deeper level reflection and for interrogating unclear aspects of participant’s lived experiences. Incorporating life world existentials and other received concepts to guide deeper level reflection illuminated in a radically descriptive way, what was already given in the narratives, but had not yet been “discovered” in earlier reflection. These existential concepts bolstered my “descriptive reflection” and empowered me “see” and “grasp” what had been initially overlooked (Wertz 1983:211; 2011:133).

#### **5.4.4. Procedures used during Nomothetic Data Analysis**

In addition to the five (5) phenomenological stances and eleven (11) methodological procedures engaged during idiographic analysis (refer to section 5.4.3), the research process underwent four additional procedures, to move the analysis and understanding of the experiences from “individual instances” “general instances” of the phenomenon. These procedures are pertinent to the integrative nature of nomothetic analysis and enabled the researcher to arrive at general aspects of the experience (Wertz 1983: 228; 2011:133). The analytical procedures used included:

- identifying potentially general insights in individual structures.
- comparing individual examples of the experience for invariant characteristics.
- imaginative/empirical variation of individual examples to identify the invariant.
- explicit description of general psychological structures of lived experiences.

A detailed expression of how the procedures achieved general findings follows:

##### **5.4.4.1. Identifying potentially general insights in individual structures**

In this procedure, as Wertz (1983:228) recommends, I sought general patterns among the already formulated individual psychological structures. It involved articulating “elements” of the idiographic phase that had features applicable beyond the original individual context in which they were uncovered. The “general” elements were those I had considered relevant to and striking cords with other participant’s life

experiences. Distinguishing between features of the IPS that manifested a “general reality” from those that did not, started with reading and re-reading the IPSs several times, taking each statement as if they made sense in all the cases of experiencing threat of life threatening conditions comparable to Ebola (Wertz 1983:228;1985:189).

As the reflection continued, three types of statements became apparent: the first set could truly be considered “universal”; while a second set were simply too “specific” in nature; and a third set were, “equivocal”, and required further reflection. Conscious that while it is true that some elements of the lived experience immediately appeared as true-for-all cases, such a statement was not simply taken-for-granted, instead they were subjected to further consideration. This was to ensure all the elements considered “general” were well-grounded, and this identification process was aided by comparing each of the IPDs with one another as recommended by Wertz (2011:150).

#### **5.4.4.2. Comparing individual examples for general characteristics**

In this second movement, rather than uncritically assuming that any statement in the individual psychological structure would be true for all cases, the researcher had to find supporting evidence for such a decision (Wertz 1983:230). This “comparison process” involved comparing and contrasting and matching each individual’s psychological structure to all the others to establish convergences and divergences.

The “convergent” statements were taken as part of the general psychological structures of the experience, while the “divergent” statements were considered atypical and relevant only to specific individual contexts and thus excluded from ‘generalisation’ (Wertz 1985:190; 2011:150). This comparison was facilitated by placing several IPSs before me on a table and posing the most general question: *“What are the most obvious similarities among these individual experiences?”* This resulted in focused re-reading and reflection on specific aspects of the various IPSs.

In adherence to the existential grounding of this study, I also considered the temporal dimensions of “before”, “during” and “after” of Ebola as a beginning point to compare the experiences. This led to tighter questioning and eventually to decisions of what themes were fittingly “general”. In determining whether a theme was general or not, I

was guided by the principle that not all the “general” insights needed to have been made explicit during idiographic analysis. Hence new insights that emerged at this point were also considered valid as long as they were “discovered” in other IPSs as well after further immersion later during analysis process (Wertz 1985:190; 2011:150).

#### **5.4.4.3. Imaginative and empirical variation to identify general features**

Wertz (1985:190) substantiates that to achieve a “generality” beyond the actual cases to which the researcher had access through the descriptions, the procedure of imaginative and empirical variation was again employed. However, unlike when teasing out the “essentials” of an individual experience, the empirical variation at nomothetic stage is to gain insight into “generally essential” aspects of the experience.

The procedure of psychological variation aided efforts to clarify the “limits” within which the “generality” of the concepts would apply; a step facilitated by carefully considering different possible variations of the phenomenon of “experiencing the constant threat of Ebola” and seeing the “invariably essential” for an occurrence to qualify as an instance of such (Wertz 1983:232; 2011:150). The “realm of generality” chosen was limited to situations that fitted well within the broader theme “living in anticipation and/or experiencing threat to lives” with the “before”, “during” and “after” phases of the Ebola outbreak as the main temporal dimensions of the experience. In the end, the empirical and imaginative variation techniques resulted in modification of the limits of “generality” of themes to the broadest sense of experiencing an outbreak.

#### **5.4.4.4. Explicit description of general psychological structure**

Guided by Wertz (1983:234), the focus of this fourth research activity entailed languaging the “general” truths that were noticed in various IPSs. I formulated the “essentials of the generality,” that is, the necessary and sufficient conditions, constituents, and structural relations, that constitute the phenomenon in general terms; including in all instances of the phenomenon. As Wertz (1983:235) notes, I critically reflected upon various statements of the IPSs using questions such as: “*Can we have this phenomenon without this?*” When the answer in the empirical data or imaginative variation, was “no”, what the statement expressed was considered

necessary; and when the answer was “yes”, the “element” expressed therein was considered unnecessary and was dropped from the list of the “*general*” formulation.

This “add and drop” process continued through all the IPSs. After identifying the general aspects of the phenomenon, the researcher then inquisitively probed, “*If we just have this, do we have the whole phenomenon?*” If the answer was “yes,” the formulation was sufficient and if “no,” it was considered insufficient and more evidence was sought to reveal the whole phenomenon. Thereafter, this was also checked with the promoter, as external quality controller to ensure all “themes” were well grounded.

## **5.5. CONCLUSION**

In this chapter, the “descriptive” and “interpretive” aspects of data analysis processes were discussed. The analytical processes described is based mainly on the works of Wertz (1983; 1985; 2005; 2010, 2011), which shares features with the hermeneutic-phenomenological research approach of Ricoeur (1976/1978). These analyses were conducted at both idiographic (individual) and nomothetic (general) levels. In chapter 6, the salient outcomes of the analytical processes and discussions follow pertinently.

## CHAPTER 6: PRESENTATION OF DATA WITH LITERATURE SUPPORT

### 6.1. INTRODUCTION

In this chapter, the synthesised interview data are presented in the form of themes, categories and subcategories supported by meaning units (evidence) to enhance audit trail and credibility. The nomothetic analysis phase resulted in seven (7) themes, nineteen (19) categories, and thirty-six (36) subcategories as shown in Table 6.1 where each theme is shown with its categories, sub-categories and data displays.

**Table 6.1. Summary of themes and categories**

<b>SUMMARY OF THEMES AND CATEGORIES</b>	
<b>THEME 1: LIVING UNDER CONSTANT THREAT OF EBOLA</b>	<b>DATA DISPLAY 6.1.</b>
<b>1. Defining characteristics/salient features of Ebola</b> a) Fear, ostracism and stigmatisation (Data Display 6.1.1.1) b) Annihilation of sufferers actualities and possibilities (Data Display 6.1.1.2) c) Lingering nature of the traumatic experience(Data Display 6.1.1.3) d) Psychosomatic manifestations (Data Display 6.1.1.4) e) Inescapability of the Ebola experience (Data Display 6.1.1.5)	<b>Data Display 6.1.1</b>
<b>2. Response to traumatizing nature of Ebola</b> a) Seeking self-preservation and protection (Data display 6.1.2.1) b) Transcending victimhood and empowering self (Data display 6.1.2.2)	<b>Data Display 6.1.2</b>
<b>THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES</b>	<b>DATA DISPLAY 6.2</b>
<b>1. Defining moments of Ebola experience</b> a) Role of the caring other in defining moments (Data Display 6.2.1.1) b) Vacillations between hope and despair (Data Display 6.2.1.2)	<b>Data Display 6.2.1</b>
<b>2. Positive outcomes</b> a) Improved personal hygiene and protection practices (Data Display 6.2.2.1) b) Improved self-awareness and health seeking behaviour (Data Display 6.2.2.2) c) Improved clinical care practices (Data Display 6.2.2.3)	<b>Data Display 6.2.2</b>
<b>3. Negative experiences</b> a) Abandonment of culturally cherished practices (Data Display 6.2.3.1) b) Loss of related others (Data Display 6.2.3.2) c) Abandonment and rejection of sufferers (Data Display 6.2.3.3) d) Isolation and ostracism (Data Display 6.2.3.4) e) Stigmatisation, shame and embarrassment (Data Display 6.2.3.5)	<b>Data Display 6.2.3</b>
<b>THEME 3: SURVIVING EBOLA: PHYSICAL, PSYCHO-SOCIAL &amp; SPIRITUAL IMPLICATIONS</b>	<b>DATA DISPLAY 6.3</b>
<b>1. The experience of surviving Ebola (Data Display 6.3.1)</b>	<b>Data Display 6.3.1</b>
<b>2. Physical implications of surviving Ebola (Data Display 6.3.2)</b>	<b>Data Display 6.3.2</b>
<b>3. Psychological implications of surviving Ebola (Data Display 6.3.3)</b>	<b>Data Display 6.3.3</b>
<b>4. Social implications of surviving Ebola (Data Display 6.3.4)</b>	<b>Data Display 6.3.4</b>
<b>5. Spiritual implications of surviving Ebola (Data Display 6.3.5)</b>	<b>Data Display 6.3.5</b>
<b>6. Economic implications of surviving Ebola (Data Display 6.3.6)</b> a) Loss of property (Data Display 6.3.6.1) b) Loss of income (Data Display 6.3.6.2) c) Costly health checks (Data Display 6.3.6.3)	<b>Data Display 6.3.6</b>

<b>THEME 4: CARING FOR EBOLA PATIENTS: MEANINGS AND IMPLICATIONS</b>	<b>DATA DISPLAY 6.4.</b>
<b>1. Meaning of caring (Data Display 6.4.1)</b>	<b>Data Display 6.4.1</b>
<b>2. Social implications (Data Display 6.4.2)</b>	<b>Data Display 6.4.1</b>
<b>3. Psychological implications (Data Display 6.4.3)</b>	<b>Data Display 6.4.1</b>
<b>THEME 5: PUBLIC REACTION TOWARDS SURVIVORS AND CAREGIVERS</b>	<b>DATA DISPLAY 6.5</b>
<b>1. Reaction before, during and after the outbreak (Data Display 6.5.1)</b> a) Public reaction before Ebola Outbreak (Data Display 6.5.1.1) b) Public reaction during Ebola Outbreak (Data Display 6.5.1.2) c) Public reaction after Ebola Outbreak (Data Display 6.5.1.3)	<b>Data Display 6.5.1</b>
<b>2. Symbolism of public reaction (Data Display 6.5.2)</b> a) Ignorance, misconceptions and lack of knowledge ( Data Display 6.5.2.1) b) Desire for self-preservation and protection (Data Display 6.5.2.2)	<b>Data Display 6.5.2</b>
<b>THEME 6: SOCIAL-CULTURAL BELIEFS AND PRACTICES RELATED TO EBOLA</b>	<b>DATA DISPLAY 6.6</b>
<b>1. Explanatory models of causation of Ebola (Data Display 6.6.1)</b> a) Ebola as supernatural occurrence (Data Display 6.6.1.1) b) Ebola as natural occurring disease (Data Display 6.6.1.2)	<b>Data Display 6.6.1</b>
<b>2. Beliefs and practices to remedy Ebola disease (Data Display 6.6.2)</b> a) Remedying Ebola through natural means (Data Display 6.6.2.1) b) Remedying Ebola through supernatural means (Data Display 6.6.2.2) c) Remedying Ebola through both natural and supernatural means (Data Display 6.6.2.3)	<b>Data Display 6.6.2</b>
<b>THEME 7: COPING AND LIVING IN THE AFTERMATH OF EBOLA OUTBREAKS</b>	<b>DATA DISPLAY 6.7</b>
<b>1. Coping strategies used by survivors and caregivers</b> a) Battling to overcome associated challenges (Data Display 6.7.1) b) Engaging in fervent prayers and religiosity (Data Display 6.7.2) c) Seeking support from caring others (Data Display 6.7.3) d) Optimism and positive attitude (Data Display 6.7.4) e) Surrendering and accepting fate (Data Display 6.7.5) f) Avoidance, distancing and withdrawing (Data Display 6.7.6)	<b>Data Display 6.7</b>

In presenting the findings, a data display containing verbatim quotes of the interview data is displayed at the beginning of each sub-section to enhance clarity of the themes, categories and sub-categories. The meaning units are also included to provide empirical evidence to support each category or sub-category that emerged under each of the seven themes. Whenever necessary, verbatim expressions have also been included to substantiate specific findings. These findings are discussed with literature support to substantiate various themes, categories and subcategories.

## 6.2. DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA

The concept of “threat” is explained in the Merriam-Webster Online Dictionary (2013a:1) as “the possibility that something bad or harmful could happen”. Similarly, the Cambridge Online Dictionaries define “threat” as “a suggestion that something unpleasant or violent will happen, especially if a particular action or order is not followed (Cambridge Online Dictionary 2013a:1). Participants expressed both implicitly and explicitly that the threat and the experience of Ebola infection was both traumatizing and upsetting. The Cambridge Online Dictionary (2013b:1) considers “trauma” as “severe emotional shock and pain caused by an extremely upsetting experience”. Also the Merriam-Webster Online Dictionary (2013b:1) explains “trauma” as “a very difficult or unpleasant experience that causes someone to have mental or emotional problems usually for a long time”. These unpleasant experiences equate to anticipating, witnessing, getting infected and surviving Ebola as survivor or caregiver.

Participants described living under constant threat of Ebola in terms of the defining or salient features of the experience and how they responded to these experiences. The two categories that emerged under this theme are summarised in data display 6.1.

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**DATA DISPLAY 6.1.**  
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA**  
**SUMMARY**

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1. Defining characteristics/salient features of Ebola (Data Display 6.1.1)
  2. Response to traumatising nature of Ebola (Data Display 6.1.2)
- 

The defining features of the Ebola experience were related to annihilation of survivors’ and caregivers’ actualities and possibilities; lingering nature of the traumatic experience; psychosomatic manifestations and inescapability of the experience. As survivors and caregivers underwent this experience, they responded by seeking opportunities for self-preservation by keeping away from situations that could aggravate their wellbeing. In addition, survivors and caregivers also engaged in combative actions to protect themselves and others from the traumatic experience.

### 6.2.1. Defining characteristics of living under constant threat of Ebola

Ebola was experienced as a traumatic event that was sure to cause “certain death” and this elicited fear and anxiety in all survivors and caregivers. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) of the American Psychiatric Association (2000:463) considers a situation as traumatic, where there is “direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one’s physical integrity or witnessing an event that involves death, injury or a threat to the physical integrity of another person; or learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate”; and that the affected person’s response to the event must involve intense fear, helplessness or horror as one participant affirms:

I also associate the Ebola experience with certain death. The epidemic killed many people. All ages of people died, babies, children and even the elderly all died. So thinking about the experience, it is evident Ebola is a serious disease that kills most of the people who get it. This is what makes people fear (Data: 294).

The features that made Ebola traumatizing to participants relate to it causing fear, ostracism and stigma, annihilate sufferers’ actualities and possibilities; lingering negative experience; psychosomatic manifestations and the fact that nearly everyone could get infected (inescapability), the summary of which is in data display 6.1.1.

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**DATA DISPLAY 6.1.1**  
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA**  
**CATEGORY 1: DEFINING CHARACTERISTICS OF LIVING UNDER THREAT OF EBOLA**  
**SUMMARY**

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1. Fear, ostracism and stigmatisation (Data Display 6.1.1.1)
  2. Annihilation of sufferers actualities and possibilities (Data Display 6.1.1.2)
  3. Lingering nature of the traumatic experience(Data Display 6.1.1.3)
  4. Psychosomatic manifestations (Data Display 6.1.1.4)
    - ✓ Emotional Reaction (Data Display 6.1.1.4.1)
    - ✓ Corporeal Reaction (Data Display 6.1.1.4.2)
  5. Inescapability of the Ebola experience (Data Display 6.1.1.5)
- 

#### 6.2.1.1. Fear, Ostracism and Stigmatisation

The threat of Ebola was characterised by widespread fear and panic, right from the time Ebola was confirmed. The concept of “fear” is defined by the Oxford Online Dictionary (2013a:1) as “an unpleasant emotion caused by the threat of danger, pain,

or harm”, while panic, a closely related state is “sudden uncontrollable fear or anxiety, often causing wildly unthinking behaviour” (Oxford Online Dictionary 2013b:1). In the present study, “fear” refers to the unpleasant emotion experienced while “panic”, means the unreasonable behaviour people exhibited because of the threat of Ebola. The findings show that the fear of infection resulted in widespread panic and hysteria:

As the outbreak was announced, fear and panic gripped nearly everybody. People feared each other so much so that everybody started avoiding one another...avoiding getting close to one another for fear of getting infected. People became suspicious about each other. And for us who had the illness at home, the fear towards... [us]...was so overwhelming that people would openly isolate and shun us (Data: 252).

The findings also reveal that survivors and caregivers, much like the public became suspicious of each other. As this continued, patients, survivors, caregivers and family members experienced ostracism and outright rejection as illustrated in data display 6.1.1.1 which contains statements related to fear, ostracism, and stigmatisation:

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**DATA DISPLAY 6.1.1.1**  
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA**  
**CATEGORY 1: DEFINING CHARACTERISTICS OF LIVING UNDER THREAT OF EBOLA**  
**SUBCATEGORY 1: FEAR, OSTRACISM, AND STIGMATISATION**

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- ...people reacted...with anxiety as they did because it is a killer disease which spreads rapidly over a short time. People shunned the affected persons because if you touch the body fluids of a person with Ebola, it very easily spreads to you...people reacted frantically due to danger of the disease (Data: 47).
  - ...neighbours and relatives shunned and avoided us [because of] nothing more than fear of infection...So people believed that if anybody came to my house, they would most likely contract Ebola....(Data: 104).
  - ...they feared death, because they knew any person who got infected would ultimately die. And what scared people most was xx's death. Whilst they knew people died of Ebola, they wondered how a health worker could die with all the care given to her. This made them to fear Ebola even more (Data: 171).
  - As the outbreak was announced, fear and panic gripped nearly everybody. People feared each other so much so that everybody started avoiding one another...avoiding getting close to one another for fear of getting infected. People became suspicious about each other. And for us who had the illness at home, the fear towards... [us]...was so overwhelming that people would openly isolate and shun us (Data: 252).
  - When the epidemic was declared as Ebola, neighbours and other people who knew we had Ebola in our home were very reluctant to associate with us for a period of about six months. Whenever people just saw me or other family members, they feared us because of the misconception that whoever, came to our family, left with an infection. The shunning was so common...even up to now few people have...come to visit us. Most people still anxious about visiting us thinking may be our home is still unsafe (Data: 262).
- 

William (2007:427) defines ostracism as the act of “ignoring and excluding individuals or groups by individuals or groups”, and the related act of social rejection, as “an explicit declaration that an individual or group is not wanted by others”. Regardless of the duration of ostracism, it is experienced as harmful because it thwarts four essential human needs of belonging, self-esteem, control, and meaningful existence

and elicits psychological pain and negative affect (Williams 2009, in Wesselman, Nairne & Williams 2012:310; Nezelek, Wesselman, Wheeler & Williams 2012:92-93). As ostracism continued, more fear piled as patients, caregivers and close family members were stigmatised. Stigma is defined by Goffman (1963), as an “attribute or characteristic that is profoundly discrediting to the individual possessing the attribute or characteristic” (Goffman 1963, in Florom-Smith & De Santis 2012:154). Similarly, Herek (2002) considers stigma as “a lasting, negatively valued circumstance, status, or characteristic that discredits and disadvantages individuals” (Herek 2002:595). Participants reported incidences of being discredited and disadvantaged for being infected with Ebola, caring for and being associated with persons infected by Ebola.

These fear generated antisocial behaviours are similar to those experienced by survivors and their close associates during the 2000/2001 Ebola outbreak in Gulu, northern Uganda. Kabanankye (2001:12) and Hewlett and Amola (2003:1246) explain that the frightening disease picture exacerbated by media reports resulted in unprecedented levels of fear and panic leading to intense stigmatisation in the community. The situation was so tense that many survivors and their family members were not allowed to return home from hospital, their clothes and property burned and some marriages dissipated needlessly. Survivors’ children were told not to touch them and wives were ordered to go back to their parents’ homes by husbands who were too afraid to take them back (Kabanankye 2001:12; Hewlett & Amola 2003:1246; Hewlett & Hewlett 2005:295). Similar incidences of ostracism and stigmatisation of survivors and their close associates relates to SARS (Siu 2008:729), avian flu, and H5N1 outbreaks (Barrett & Brown 2008:34), in leprosy (Wong & Subramaniam 2002:86) and HIV/AIDS cases (Florom-Smith & De Santis 2012:155).

When left unchecked, such stigma and ostracism can motivate widespread concealment, delay early detection efforts and treatment and promote further spread of infection (McGrath 1993:64). The stigmatised person or group too gets negatively affected because they may take undesirable health decisions which may too worsen their health and wellbeing (Barrett & Brown 2008:34; Wesselman et al 2013:108).

### 6.2.1.2. Annihilation of sufferers' actualities and possibilities

Being infected with Ebola poses a serious threat to the life of the sufferer even in the presence of health workers. Often, sufferers become defenceless and are exposed to death. The vulnerability of the sufferer even in the face of health care is apparent largely because of the dread experienced by the health workers themselves. The illness interferes with their physical wellbeing, manifests in physical symptoms and the feeling of vulnerability leads to a sense of despair and helplessness. The scenarios that played out in data display 6.1.1.2 are supportive of this category.

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#### DATA DISPLAY 6.1.1.2

##### THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA CATEGORY 1: DEFINING CHARACTERISTICS OF LIVING UNDER THREAT OF EBOLA SUBCATEGORY 2: ANNIHILATION OF SUFFERERS' ACTUALITIES AND POSSIBILITIES

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- I got a spontaneous abortion. The foetus came out, but the placenta was retained. I was all alone. I tried to deliver the placenta myself, but it failed to come out. As I tried to pull the placenta, it broke. There was no care giver in the ward. I bled so much and I collapsed and became unconscious (Data:5).
  - They told us that whoever gets infected with Ebola has minimal chances of survival. This news frightened me and worried me a lot. I was afraid the whole family would die, because most people were sick. I knew we would die one by one until we are all dead in the whole family (Data: 80).
  - The fear and dread for Ebola was so much....because...it kills many within a short time, including wiping out entire families... the level of panic and anxiety became so overpowering that some people who experienced Ebola, said they would have preferred to have HIV/AIDS instead of Ebola(Data: 135).
  - As I waited for the signs, my mind was filled with worries about the future of my children. I was not even sure that my husband would live because he had also been involved in caring for xx before she died. So I was worried that he would also perish (Data: 158).
  - The Ebola experience made me think that if ever the disease were to break out again, I would rather kill myself early enough before I get infected to avoid the intense suffering, pain, vomiting, diarrhoea and above all the very painful palpitations...that feel like a burning sensation in the upper chest (Data:293).
- 

The feeling of helpless and desperation is greater where health workers are unwilling to help because, they too are afraid of the illness as this participant affirmed:

“They would not touch me. I became desperate. I asked my husband to plead with the health workers to come and treat me (Data: 6)”.

Survivors received news of their diagnosis with intense feelings of terror, fear and anxiety, far beyond the danger usually associated with HIV infection. Caregivers experienced the anticipation of the onset of symptoms and their death as a time of worry and despair about the future. This despair appears to have been exacerbated

by witnessing the excruciating pain and suffering of their patients. The annihilation and crisis experienced by participants is similar to the one described by Breggin (1997:2-5) who terms them as “crises and emergencies” that need the attention of psychotherapists and counsellors. These include threats of suicide and homicide, potentially violent behaviour, trauma from rape or battery, newly discovered cancer or HIV, separation and divorce, death of a loved one, sexual or physical abuse in a family, illness in a loved one, bankruptcy, unemployment and homelessness or losing a child killed in an accident. A characteristic feature of all these emotional crises is the element of trauma experienced by the sufferer (DSM-IV 2000: 463). Whilst most caregivers never sero-converted to Ebola, they were inevitably traumatised because those who help the severely traumatised, in this case persons affected by Ebola often themselves become traumatised much like the “victims” (Briere & Scott 2006:10-12).

### **6.2.1.3. Lingering nature of the traumatic experience**

Participants reported that they experienced the trauma of Ebola for prolonged periods, lingering on, even after declaring the end of the epidemic. The meaning units supportive of the traumatic experience are illustrated in data display 6.1.1.3.

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**DATA DISPLAY 6.1.1.3**  
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA**  
**CATEGORY 1: DEFINING CHARACTERISTICS OF LIVING UNDER THREAT OF EBOLA**  
**SUBCATEGORY 3: LINGERING NATURE OF THE TRAUMATIC EXPERIENCE**

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- When recently another Ebola outbreak happened in Congo and in Luwero, I felt pity for the affected people. I would pray to God that they also survive like I did here in Kibale... When I saw them on TV, I recalled my personal struggle in the isolation ward. I felt their suffering (Data: 20).
  - When I heard there was an Ebola outbreak in Congo, Luwero... my first reaction was that of fear... I stopped shaking people's hands as I greeted them. I even stopped sharing clothing with other people...I was worried that if this time I got infected; I would not survive and would die (Data: 72).
  - when I reflect about this whole experience, I feel a lot of agony and pain in my heart. But with nothing much to do about it, I regain my strength and try to forget about it. I sometimes feel angry, because the way we used to live before Ebola is not how it is today. I feel very lonely these days (Data: 107).
  - As the relatives continued to fall sick and die, one after another, I became fearful that the next person to fall sick and die would be me. This fear continued to haunt me until after about a year, when I became confident that this illness would not return (Data: 244).
- 

This persistence of the traumatic experience was witnessed again when other Ebola outbreaks occurred in neighbouring districts and countries. This evidences that presence of Ebola or thought of Ebola triggers feeling of threat and anxiety leading to psychosomatic manifestations and symptoms such as fear, panic as well as sadness.

#### 6.2.1.4. Psychosomatic manifestations

Encyclopaedia Britannica (2013:1-2) defines a psychosomatic manifestation as a condition in which an individual's psychological stresses adversely affect their physiological (somatic) functioning, usually due to the aroused emotional state. This high level arousal often induces bodily symptoms such as hypertension, respiratory ailments, gastrointestinal disturbances, migraine and tension headaches, pelvic pain, impotence, frigidity, dermatitis and ulcers (Encyclopaedia Britannica, EB 2013:2).

The sub-categories supporting psychosomatic manifestations experienced by survivors and family caregivers are presented under emotional (psychological) reaction and corporeal (somatic) reaction as illustrated in data display 6.1.1.4.

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**DATA DISPLAY 6.1.1.4**  
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA**  
**CATEGORY 1: DEFINING CHARACTERISTICS OF LIVING UNDER THREAT OF EBOLA**  
**SUBCATEGORY 4: PSYCHOSOMATIC MANIFESTATIONS OF EBOLA INFECTION**  
**SUMMARY**

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1. Emotional Reaction (Data Display 6.1.1.4.1)
  2. Corporeal Reaction (Data Display 6.1.1.4.2)
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Similar experience of psychosomatic manifestations was documented by Employee Assistance Program (2013:1-2), a US based rehabilitation program, which found that when people experience tragic events, their reactions may be emotional, physical, mental or behavioural. The reactions reported include anxiety or nervousness, irritability, depression, anger, mood swings, physical symptoms like chronic aches and pains or difficulty sleeping, including nightmares. Whilst most of the "aftershocks" appear almost immediately, some appear a few hours, days or even months later.

##### 6.2.1.4.1. Emotional reaction

Participants reported experiencing a plethora of strong emotional reactions among them sadness, anger, and anxiety as they anticipated or recovered from Ebola infection, as highlighted in data display 6.1.1.4.1. These reactions often occurred as survivors and caregivers were reminded of the traumatic event or heard that another outbreak of Ebola had occurred in a neighbouring district or a neighbouring country.

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**DATA DISPLAY 6.1.1.4.1**
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA  
 CATEGORY 1: DEFINING CHARACTERISTICS OF LIVING UNDER THREAT OF EBOLA  
 SUBCATEGORY 4: PSYCHOSOMATIC MANIFESTATIONS OF EBOLA INFECTION  
 SUB-SUBCATEGORY 1: EMOTIONAL REACTION TO EBOLA**


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- ...when they confirmed that she had Ebola. I immediately thought I would also get infected. I became so frightened and immensely shocked. I got so worried and I started trembling and would shiver (Data: 121).
  - When it was declared that the mysterious illness was Ebola...I knew I could not escape being infected since I nursed her. I was nervous and in a state of shock. I thought a lot and when I went to bed, I couldn't sleep (Data: 153).
  - What worried me even more is the fact that Ebola kills within a few days. I was also particularly bothered by the fact that normally when Ebola enters a family; it leaves the whole family at a risk of death. This realisation was overpowering (Data: 211).
- 

Mikkelsen and Einarsen (2002:88) affirm that individuals may experience emotional reactions when they re-live previous traumatic experiences in dreams, thoughts or when they experience psychological distress and/or physiological reactivity when exposed to cues that symbolise or resemble the tragic event. Hamama-Raz, Solomon, Schachter and Azizi (2007:287) add that survivors of cancer experience emotional symptoms of high sense of vulnerability, fear of recurrence and death (Siegel 1990:21-24; Halstead & Fernsler 1994:94-96) and anxiety, depression and feelings of loss of control (Amir & Ramati 2002:21-26). In further support of these findings, a study conducted among active duty military officers in the USA, discovered that the study participants experienced peri-traumatic (on going) feelings or emotions including being afraid, humiliated, detached, angry, horrified and sad while post traumatic symptoms included fear, humiliation, sadness, anger and numbness (Stein, Mills, Arditte, Mendoza, Borah, Resick, Liz & Wright 2012:793-94).

#### **6.2.1.4.2. Corporeal reaction**

The term corporeal refers to the physical body. In the context of the study, corporeal reactions refer to physical symptoms participants experienced. Participants reported bodily manifestations as headache, palpitations, heart ache, and body pains among others, as illustrated in the verbatim quotes highlighted in data display 6.1.1.4.2.

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**DATA DISPLAY 6.1.1.4.2**
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA  
 CATEGORY 1: DEFINING CHARACTERISTICS OF LIVING UNDER THREAT OF EBOLA  
 SUBCATEGORY 4: PSYCHOSOMATIC MANIFESTATIONS OF EBOLA INFECTION  
 SUB-SUBCATEGORY 2: CORPOREAL REACTION TO EBOLA**


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- In the hospital when they tested my blood and found that I had Ebola...I knew it was now finished... I felt grave pain. I had persistent pain in my heart and my mind (Data: 64).
  - These days when I reflect about this whole experience, I feel a lot of agony and pain in my heart. I feel very lonely these days. There are barely any people in my compound.... (Data: 107).
  - As I waited for the signs and symptoms of Ebola to develop, I could not sleep. I was very worried about leaving my children as orphans. I knew that once I got Ebola, it meant I would die...This feeling of helplessness continued for some time. I would think all the time. I worried so much; I even got fever and headache. I was fearful that the signs of Ebola would appear (Data: 123).
- 

Similar observations are documented by Hansen (2008:1-4) who describes that persons who experience severe traumatic situations may present with somatic manifestations of stomach problems, weight loss, palpitation, chest pain, headache, sweating, infections and hyperventilation. Smith, Segal and Segal (2013:1-3) substantiate that when such situations are not addressed and they persist for long, serious health problems may arise because of their potential to disrupt every human system, making the affected person more vulnerable to anxiety and depression.

#### **6.2.1.5. Inescapability of the traumatic experience**

Participants experienced the traumatic experience of Ebola either as they anticipated, experienced or witnessed the epidemic, regardless of whether they were survivors or caregivers or members of the community. The severity of the infection alongside the scary clinical presentation created an impression that “no one was safe”, implying that the inevitable was “becoming infected and dying”. The verbatim quotes illustrated on data display 6.1.1.5 support this category, which signify inescapability of Ebola.

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**DATA DISPLAY 6.1.1.5**
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA  
 CATEGORY 1: DEFINING CHARACTERISTICS OF LIVING UNDER THREAT OF EBOLA  
 SUBCATEGORY 5: INESCAPABILITY OF THE TRAUMATIC EXPERIENCE**


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- When my blood test results came, I was worried and thought that I would not heal as was portrayed initially on newspapers and as the public was insinuating about Ebola... I was worried. And so I waited to die...I would sometimes refuse them to attend to me. When they asked me, aren't you going to bathe? I sometimes refused. I had resolved to be left alone, unattended to, so that I would keep in one position until I died (Data: 34).
  - ...we began to receive caregivers who would come for treatment because they had begun to falsely experience signs and symptoms of Ebola. When we examined them, most times we found they were not ill in actual sense. A few of these people were brought ...by relatives while others simply walked in on their own believing they could have Ebola (Data: 117).
  - I was so worried because AA, who had already succumbed to Ebola after looking after xx, had spent a number of days in my house. We had been looking after xx's baby together, before she developed signs of fever and was admitted. I had been involved in the care of all these people,...staying in same room... worse still, even sharing a bed with them (Data:184).
- 

As highlighted in the verbatim quotes survivors strongly believed that they would not survive the onslaught of Ebola, especially in light of the media coverage of the epidemic as well as considering the clinical picture of the illness. Caregivers too believed they would become infected and die from Ebola related complications, apparently bolstered by the scary stories in the media, the panicky responses and behaviour of health workers, and their repeated exposure to the patients (Data:184). This feeling of inevitability is congruent with MacNeil and Rollin's (2012:1-2) affirmation that Ebola epidemics are characterised by media hype and largely sensationalist accounts (Semmler 1998:149) making them to be widely recognised and feared. It is this perception about Ebola which led Schwartz (1995:A2) to describe the Ebola as "an epidemic of heightened apprehension and misinformation".

### **6.2.2. Response to the traumatizing nature of Ebola**

Whilst survivors anticipated their death and caregivers expected to contract Ebola, all participants responded to the illness in ways that may be categorised as struggling to secure or protect their survival or wellbeing, which is akin to the concept of resilience. Johnson, Polusny, Erbes, King, King, Litz, Schnurr, Friedman, Pietrzak, and Southwick (2009, as cited in Ballenger-Browning & Johnson 2009:2) define resilience as a "psychological process developed in response to intense life stressors that facilitates healthy functioning". Similarly, Bonanno (2004:20) suggests that resilience should be conceptualised as "the ability to maintain relatively healthy and stable

levels of physical and psychological functioning in the wake of traumatic experiences”. The notion of resilience should be understood as survivors’, caregivers’ and community’s ability to maintain fairly stable lives despite the various challenges and threats through specific “interventional steps” as highlighted in data display 6.1.2.

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**DATA DISPLAY 6.1.2**  
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA**  
**CATEGORY 2: RESPONSE TO TRAUMATISING NATURE OF EBOLA**  
**SUMMARY**

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1. Seeking self-preservation and protection (Data Display 6.1.2.1).
  2. Transcending victimhood and empowering self for the future (Data Display 6.1.2.2).
- 

### 6.2.2.1. Seeking self-preservation and protection

The study found that both survivors and caregivers responded resiliently by engaging in a number of actions and processes to “protect” and “immunise” themselves against the traumatising effects of Ebola infection. This involved exercising better caution and personal protection strategies as affirmed in verbatim quotes in data display 6.1.2.1:

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**DATA DISPLAY 6.1.2.1**  
**THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA**  
**CATEGORY 2: RESPONSE TO TRAUMATIZING NATURE OF EBOLA**  
**SUB-CATEGORY 1: SEEKING SELF-PRESERVATION AND PROTECTION**

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- When I heard there was an Ebola outbreak...I decided...I would keep cleanliness as a priority and then become more careful. So I started cleaning my home with Jik (Chlorine solution). I focused on being more hygienic and avoided situations that could bring back the disease. I stopped shaking people’s hands...I even stopped sharing clothing with other people (Data: 72).
  - I was very careful when caring for patients especially the very sick ones during the 21 days...so that I did not contract Ebola. As I waited to see if would develop any signs of Ebola, I continued to do work with the patients. We would go out for health education and counselling sessions to help calm the community. This helped to keep me calm and focused (Data: 127).
  - While my personal life was full of worries, my professional life was not affected as much. I was still able to perform my work related activities... In the hospital, the fear was much less. What also strengthened me was the fact that I had adequate protection as I cared for the patients. With adequate precautions, I would not come into direct contact with the patients (Data: 159).
- 

Participants reported engaging in activities to reduce the painful “anticipation” experience and avoided further exposure to Ebola. Such self-preservation and protection actions which enhance affected individuals’ adaptive outcomes in the face of adversity. Similar findings are documented by Campbell-Sills, Cohan and Stein (2006:585) following a study on the relationship of resilience to personality traits, coping styles and psychiatric symptoms among students as well as by Ballenger-Browning and Johnson (2009:2-4) on investigations conducted on human resilience.

### 6.2.2.2. Transcending victimhood and empowering self

Whilst the experience of Ebola destabilised survivors and caregivers due to the fear and anxiety related to the possibility of infection and death, as well as negative social consequences, participants simultaneously engaged in activities that helped them transcend their state of being “victims” of the Ebola experience to that of being empowered members of society to levels close to the pre-math of the Ebola outbreak. The concept of “survivor” should be understood to mean experiencing a negative event and ably overcoming it with minimal consequences. In contrast, the notion of “victim” should denote situations where a person who experiences a negative event fails to overcome it and continues to live a psychologically distressed life filled with depression and anxiety among others (Reich 2006:793; Hofer 2006:259). The verbatim quotes in data display 6.1.2.2 relate to participant’s experiences highlighted.

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#### DATA DISPLAY 6.1.2.2

##### THEME 1: DESCRIPTIVE OVERVIEW OF LIVING UNDER CONSTANT THREAT OF EBOLA CATEGORY 2: RESPONSE TO TRAUMATIZING NATURE OF EBOLA SUB-CATEGORY 2: TRANSCENDING VICTIMHOOD AND EMPOWERMENT OF SELF

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- By the time I regained my consciousness, I was not thinking about anything. I did not even fear death. Neither was I worried that I had been diagnosed with Ebola and that I may die. I was firm. I did not even worry about my relatives back home. I was not even worried about dying from Ebola, although I knew Ebola was a serious illness. I had a positive attitude (Data: 9).
  - I even became more confident when I read in the newspapers that survival is enhanced if Ebola is managed in time by promptly treating signs and symptoms such as diarrhoea or vomiting...I was using antibiotics...I had medication to prevent me from vomiting ..[and] for minimising fever. These measures were reassuring and made me more confident that I would survive (Data: 39).
  - And when recently an outbreak of Ebola was declared... I felt scared. I became worried that the disease could return to Kibale. So I began to pray for the people, and asked God to hear our prayers so that the disease can be wiped out before it spreads to Kibale (Data: 227).
- 

These efforts of self-empowerment to overcome the victimhood of Ebola is consistent with reports by Sanjuán, Molero, Fuster, and Nouvilas (2013:710) declaring that during traumatic events, affected persons often engaged in processes to rid themselves of threats so that they live a near normal life. Rothbaum, Weisz and Snyder (1982) as cited in Sanjuán et al (2013:710) much like Heckhausen and Schulz (1995) agree that when sufferers adopt strategies to find solutions such as planning a course of action or changing their negative perceptions about being “victimised”, such adaptive behaviours result in better health outcomes and wellbeing.

### 6.3. NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL ASPECTS

In this section, the findings specific to the theme, “nature of the Ebola experience” as lived by survivors and caregivers are delineated. Survivors and caregivers reported this experience as both positive and negative. The 3 main categories that emerged from this theme that relates to the nature of Ebola are illustrated in data display 6.2.

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**DATA DISPLAY 6.2**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**SUMMARY**

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1. Defining moments of Ebola experience (Data Display 6.2.1).
  2. Positive outcomes of Ebola experience (Data Display 6.2.2).
  3. Negative experiences of Ebola experience (Data Display 6.2.3).
- 

#### 6.3.1. Defining moments of the Ebola experience

Ebola infection was experienced by participants dependent on how the event affected their lives, including circumstances that led them to consider it as positive or negative experience. Regardless of whether they classified their experience as positive or negative, Ebola was experienced as “grave” and “life threatening”. It not only affected participant’s physical wellbeing but it threatened their personhood. This observation underscored the vitality of supportive others in the threatening journey. The findings also reveal that the graveness of the experience meant survivors and caregivers oscillated between “good” and “bad” feelings during and after the outbreak as depicting in the moments of lived experience highlighted in data display 6.2.1.

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**DATA DISPLAY 6.2.1.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**CATEGORY 1: DEFINING MOMENTS OF EBOLA EXPERIENCE**  
**SUMMARY**

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1. Role of the caring other in defining moments (Data Display 6.2.1.1).
  2. Vacillations between hope and despair (Data Display 6.2.1.2).
- 

##### 6.3.1.1. Role of the caring other in defining moments

The findings reveal that the presence and actions of the supportive or caring other was very critical in participant’s experience of the threat of Ebola as well as when they contracted the infection. This phenomenon is similarly described by Usher and Grigg (2011:33) who explain that in responding to traumatic events, others may help

the affected persons to meet their basic needs including providing reliable information to help them. Grigg and Hughes (2010:33) as explained in Usher and Grigg (2011:33) emphasise that during challenging times, protecting survivors and propping them up through appropriate mechanisms is critical, as exhibited in data display 6.2.1.1.

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**DATA DISPLAY 6.2.1.1.**

**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**

**CATEGORY 1: DEFINING MOMENTS OF EBOLA EXPERIENCE**

**SUBCATEGORY 1: ROLE OF THE CARING OTHER IN DEFINING MOMENTS**

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- The encouragement and the visits by various people after being discharged from hospital made me feel good, especially when they showed me love...Their support made me feel good and strong (Data:15).
  - Then one day, as I lay down on the floor, I suddenly heard a group of people...They told me, YY we have come to remove your placenta. When they removed the placenta, the bleeding reduced. Then they gave me a tablet to insert vaginally to stop the bleeding...the bleeding minimised... (Data: 7).
  - My relatives played a great role in caring for me during the illness, especially in filling the gaps where health workers were absent or unwilling. When my hopes seemed to fade away, my sister assured me that I should not worry; she would take care of me. My husband was really supportive (Data: 32).
- 

### **6.3.1.2. Vacillations between hope and despair**

The findings also reveal that survivors and caregivers experienced simultaneous episodes of hoping for desirable outcomes while at the same time anticipating the worst to come. For survivors, their hope was hinged on surviving despite knowing that others had died, while for caregivers, their hoped that despite the exposure to the virus, they would not sero-convert and get infected and eventually die from Ebola. The feeling of despair and hopelessness emanated from various reasons including the scary nature of Ebola worsened by the media exaggeration, poor social health education efforts and heightened public awareness, exacerbated by unusually cowardly behaviour of local leaders and health workers. In data display 6.2.1.2, statements revelatory of these vacillations between hope and despair are highlighted.

For survivors, hoping to survive was vitally important. However, whilst they hoped to survive, they still harboured the fear and the feeling that “things could turn against their wishes and they perish” as had happened to others, as this participant affirmed:

...when the health workers came...to inform me that the last test results were negative, I was shocked...I asked myself is it Ebola that I have survived? I could not believe them because the other patient we had been admitted [with] to the isolation ward suddenly deteriorated... within a few minutes she deteriorated [and died]...Her rapid and sudden deterioration and death frightened and shook me to the core. I began to imagine that I too could deteriorate and die like her (Data: 12).

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**DATA DISPLAY 6.2.1.2.**
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES****CATEGORY 1: DEFINING MOMENTS OF EBOLA****SUBCATEGORY 2: VACILLATIONS BETWEEN HOPE AND DESPAIR**


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- ...the question of surviving became increasingly important to me. Although I wanted to survive, nevertheless, I was not confident about my survival. I wondered whether I would really survive. I sometimes, reassured myself that antibiotics and intravenous fluids I received might...help me recover... (Data: 37).
  - ...when they tested my blood and found that I had Ebola, I felt very bad. I thought that my days on earth were now numbered. I knew Ebola would kill me. I feared a lot. My fears were heightened when [another] patient collapsed. This frightened me and escalated the intense fear inside me. When I was moved to another side of the ward, I felt my life had changed. I began to wait for the day I would die. I knew I was now finished and I had nothing to do. I felt grave pain. I had persistent pain in my heart and mind (Data: 64).
  - When it was announced that the illness that had been killing people was Ebola, an overwhelming sense of despair and fear filled the entire community. Those who were particularly affected were people who were directly involved in caring for sick relatives or friends with Ebola. The fear and anxiety was so prevalent that some people even wanted to run away [from Kibale] (Data: 116).
- 

Similar experience of hoping for survival while anticipating death was documented by Locsin & Matua (2002:176) following a study on contacts of the 2000/2001 Ebola outbreak in Mbarara, Uganda. In this study, the contacts simultaneously anticipated their death, while they hoped to live through and survive the onslaught of the epidemic. Culver, a Denver Post, Staff Writer (1999, Oct 23: A-1) declares that the experience of a life threatening and traumatic event may trigger feelings of helplessness and hopelessness, when sufferers feel overwhelmed by their circumstances. This feeling of despair appears to be connected to sufferers feeling unsafe, being unable to control their situation and feeling terrorised by the event (Denver Post 1999: A-1). These arguments confirm that feelings of despair are common in the face of life threatening illness such as Ebola among others conditions.

**6.3.2. Positive Outcomes**

Whilst the experience was largely negative for most survivors and caregivers, participants however, did affirm that nevertheless they learnt some positive lessons from their exposure to the outbreak. The positive growth led to improvements in personal hygiene and protection practices at home and at the work place and increased their self-awareness and health seeking behaviour patterns. In addition to these growth areas, survivors and caregivers who were health workers reported the experience made them adopt better patient care practices during and in the aftermath of Ebola. The evidence supportive of positive outcomes is in display 6.2.2.

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**DATA DISPLAY 6.2.2.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**CATEGORY 2: POSITIVE OUTCOMES**  
**SUMMARY**

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1. Improved personal hygiene and protection practices (Data Display 6.2.2.1).
  2. Improved self-awareness and health seeking behaviour (Data Display 6.2.2.2).
  3. Improved clinical care practices (Data Display 6.2.2.3).
- 

These findings appear consistent with results of other studies that indicate that the suffering and struggle to recover in the aftermath of a traumatic experience often yields remarkable transformation and positive growth as described in Walsh (2007:208). A report detailing posttraumatic growth, revealed that positive individual changes were found in five areas of participants' lives: emergence of new opportunities and possibilities; deeper relationships and greater compassion for others; feeling strengthened to meet future life challenges; reordered priorities and fuller appreciation of life and deepening spirituality (Calhoun & Tedeschi 1999, 2006, in Walsh 2007: 208). These findings further support the positive outcomes of Ebola.

#### **6.3.2.1. Improved personal hygiene and protection practices**

Whilst the news of a new Ebola attack is experienced as a frightening encounter, one of the positive aspects of this news is that it prompts survivors and caregivers and their communities to engage in acts of self-preservation, meant to deter possible re-infection. In terms of improvements in personal hygiene and personal protection practices, participants intimated that they began to invest in efforts to enhance cleanliness at their homes and the work place. This act of cleanliness was perceived to keep the infection out of their homes and work places. In addition, participants also reported halting practices that they thought could expose them to infection such as handshakes and sharing of personal effects like clothing among others. Further evidence supportive of the subcategory related to participant's improved personal hygiene and personal protection are highlighted verbatim in data display 6.2.2.1.

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**DATA DISPLAY 6.2.2.1.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**CATEGORY 2: POSITIVE OUTCOMES**  
**SUBCATEGORY 1: IMPROVED PERSONAL HYGIENE AND PROTECTION PRACTICES**

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- When I heard there was an Ebola outbreak...my first reaction was that of fear. Later on, I calmed down. I decided that...I would keep cleanliness as a priority and then become more careful. So I started cleaning my home with Jik (Chlorine solution). I became more conscious of dirt because I knew it was dirt and chaff that would facilitate the entry of the disease to my area. I also focused on being more hygienic and avoided situations that could bring back the disease. I stopped shaking people's hands. I even stopped sharing clothing with other people...I became more vigilant (Data: 72).
  - The experience of being involved with Ebola as a family care giver has helped change my health behaviour. These days I am more conscious about any disease. I do not take things for granted, be it a fever, diarrhoea, vomiting. Any situation I am a bit more conscious in my health practices now. Even in my clinical practice, this time when I am doing physical examinations, I put on examination gloves and regularly wash my hands with soap and water, which I never used to do before the outbreak. Generally, I have become more conscious with observing universal precautions (Data: 168).
  - These days I am careful when dealing with the sick, no matter who they are. Today, even if you are my friend, I consider anybody sick as sick, meaning that even if it is my daughter, I can't be as close to them as I used to be... now any illness means being extremely careful when caring, even if you have malaria now I have to protect myself. When I am in the ward, I put on gloves. I always wash with soap and Jik; even at home I have Jik. When I get home from the hospital I wash. This experience has taught you to be more careful with personal care and personal protection (Data: 202).
- 

These practices were consistent with the reports by Biryabarema (2012, Jul 31:1) detailing Ugandan President Yoweri Museveni's advice to the nationals to avoid shaking hands, casual sex and do-it-yourself burials so as to reduce chances of contracting the deadly Ebola virus. This advice was to augment the efforts of the national epidemic team and authorities to alter people's behaviour to stop virus spread. Such improved personal hygiene and protection practices led to more vigilance about protection of survivor's, caregivers' and family members, and these practices were aimed at ensuring the safety of participants and that of their families.

### **6.3.2.2. Improved self-awareness and health seeking behaviour**

In addition to improvements in personal infection prevention behaviour, participants also noted improvement in their self-awareness and health seeking behaviour. This improvement was borne out of the desire to stay healthy as this participant declares:

...when it was announced that this could be a serious disease, people became vigilant and became eager to report any incidences in their community (Data: 152).

Similar statements that support this subcategory are summarised in display 6.2.2.2.

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**DATA DISPLAY 6.2.2.2.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL ASPECTS**  
**CATEGORY 2: POSITIVE OUTCOMES**  
**SUBCATEGORY 2: IMPROVED AWARENESS/HEALTH SEEKING BEHAVIOUR**

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- Things changed a lot...during the epidemic...and after. In the hospital, I walked through disinfectant solution when I was being discharged...when I reached home there was Jik everywhere. People could no longer move freely in the community...in the bank, tellers used gloves to handle cash (Data: 22).
  - We began to receive care givers who would come for treatment because they had begun to falsely experience signs and symptoms of Ebola....most were not ill... A few...were brought to the health unit by relatives while others simply walked in on their own believing they could have Ebola (Data: 117).
  - My practice as a nurse has changed a lot as a result of the Ebola epidemic. I developed a greater self-awareness... and my consciousness about infection became heightened....This sense of consciousness was particularly pronounced as we were being monitored... (Data: 138).
- 

Kooken (2008:73-74) also found that cancer patients exhibited increased vigilance when dealing with fear of death, especially when they saw death approaching. Participants became vigilant when they wanted to have some control in their situation, desired to stay alive and when they felt responsible for significant others.

This implies that fear summons vigilance from within the sufferer as a protective shield to enable them deal with the fear, pain, injuries and detrimental decisions, and make sense of what is happening to them. In similar way, this fear of life threatening situations propels sufferers to pay close attention to their health (Kooken 2008: 74).

### **6.3.2.3. Improved clinical care practices**

In addition to showing improvements in personal hygiene and personal protection practices as well as showing increased self-awareness and better health seeking behaviour, the findings suggest that some participants especially those working within the health sector also witnessed an improvement in their personal clinical practices.

The findings show that the improvements in the clinical practice of the health workers who had become exposed to Ebola related to loving their work, taking better patient history and examinations, better considerations for consultations and observance of precautions as supported by verbatim quotes on data display 6.2.2.3.

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**DATA DISPLAY 6.2.2.3.**
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES****CATEGORY 2: POSITIVE OUTCOMES****SUBCATEGORY 3: IMPROVED CLINICAL CARE PRACTICES**


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- As a clinician the Ebola experience taught me that one needs to assess and understand the patients... before any interventions. I learnt that as a caregiver when you do not understand something about the patient, you need to ask...you need to be careful, take detailed history and ...ensure you have personal protection always whenever you are with the patient. It also means when in doubt, consult a more knowledgeable person...before proceeding further with caring... (Data: 50).
  - My practice as a midwife has now changed significantly when I compare what I do now to what I used to do before the outbreak. These days I am so alert. And when I am with patients, I observe them very critically from head to toe. I now have quick plans and I consult immediately if there is something I don't understand. I...now I restrain myself from touching patients and attendants.... (Data: 51).
  - The experience of being involved with Ebola as a family care giver has helped change my health behaviour. These days I am more conscious about any disease. I do not take things for granted, be it a fever, diarrhoea, vomiting. Any situation I am a bit more conscious in my health practices now. Even in my clinical practice, this time when I am doing physical examinations, I put on examination gloves and regularly wash my hands with soap and water, which I never used to do before the outbreak (Data: 168).
- 

Another key dimension that arose from the study is the better appreciation by survivors and caregivers, the proper way patients ought to be cared for while in health units. Upon reflecting on own challenges, participants reiterated the need for proper care for those afflicted by life threatening conditions and other situations.

When I see patients, especially those who need quick attention, I feel compelled to help them. Their suffering makes me to vividly remember my own experience, when I was alone in the isolation ward, with no person to help me, and being left alone...without a carer (Data: 16).

Calhoun and Tedeschi (2006, in Walsh 2007:208) document similar instances where survivors expressed increased desire to help others and developed deeper relationships with needy people after their own ordeals. The researchers corroborate that it is individual's suffering and the struggle to recover in the aftermath of a traumatic experience that precipitates their transformation and positive growth leading to deeper relationships and greater compassion towards self and others.

**6.3.3. Negative experiences**

Whilst the Ebola experience resulted in positive outcomes for some participants, however, the experience was generally negative for most survivors and caregivers. The negative experiences relate to abandonment of culturally cherished norms and practices; the loss of related others; abandonment and rejection of sufferers; stigmatisation and shaming and embarrassment as well as isolation and ostracism. The subcategories detailing the negative outcomes experienced are in display 6.2.3.

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**DATA DISPLAY 6.2.3.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**CATEGORY 3: NEGATIVE EXPERIENCES**  
**SUMMARY**

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1. Abandonment of culturally cherished practices (Data Display 6.2.3.1).
  2. Loss of related others (Data Display 6.2.3.2).
  3. Abandonment and rejection of sufferers (Data Display 6.2.3.3).
  4. Isolation and ostracism (Data Display 6.2.3.4).
  5. Stigmatisation, shame and embarrassment (Data Display 6.2.3.5).
- 

These findings are consistent with results of other studies and indicate that the suffering experienced during the course and in the aftermath of a traumatic experience yields several negative feelings and experiences. This claim is validated by similar study conducted among active military service personnel in the USA by Stein et al (2012:793-794) where they found that officers exposed to traumatic war events tended to experience a myriad of negative feelings including being afraid, humiliated, detached, angry, horrified and sad. Whilst these feelings were individualised, overall it led to generalisation of these experiences as being negative.

### **6.3.3.1. Abandonment of culturally cherished practices**

The threat and reality of Ebola outbreaks ignited widespread fear and heightened concern for wellbeing. This was characterised by avoidance of situations construed to compromise such wellbeing including abandoning established cultural practices.

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**DATA DISPLAY 6.2.3.1.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**CATEGORY 3: NEGATIVE EXPERIENCES**  
**SUBCATEGORY 1: ABANDONMENT OF CULTURALLY CHERISHED PRACTICES**

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- When one dies... relatives were not allowed to take part in the burial ceremony. Instead one would be entombed by the epidemic response burial team members... including saying no prayers during the burial... the burial was done in a hurry, and the burial practices worried the population (Data: 136).
  - I was worried about dying and most crucially about the fact that my fellow Christians would not pray for me, especially during the burial, because the burials were carried out by burial teams (Data:188).
  - I pitied myself, I said I am going to die; people are not going to bury me in a good way.... (Data: 190).
- 

As exemplified by the verbatim quotes set out in data display 6.2.3.1, the socio-cultural practices whose abandonment bothered participants and was dearly missed relate to cultural and religious befitting burial practices. Whilst abandonment of culturally sanctioned burial practices were believed to minimise the spread of Ebola,

the practice was perceived largely as negative by survivors and caregivers similar to the views obtained during 2000/2001 Gulu outbreak (Hewlett & Amola 2003:1247).

### **6.3.3.2. Loss of related others**

Another negative experience is the dramatic loss of lives, especially of close relatives in a short span of time, described as overwhelming and depressing by participants. Caregivers reported memories of the deceased continued to affect them negatively leading to feelings of prolonged sadness and agony as voiced in data display 6.2.3.2.

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**DATA DISPLAY 6.2.3.2.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**CATEGORY 3: NEGATIVE EXPERIENCES**  
**SUBCATEGORY 2: LOSS OF RELATED OTHERS**

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- The experience of losing many relatives in such a short span of time was incredibly overwhelming and depressing, coupled with the manner in which the fact that people were fearing us (Data:86).
  - As my children and relatives died...neighbours wondered what the problem could be. The multiple and sudden deaths in my family were being discussed...people kept wondering why... (Data: 106).
  - The memories of the relatives we lost continue to hurt me and my family members even up to now...we feel very sad,... even up to now a day does not pass by without one weeping (Data: 260).
- 

The loss of a loved one is often accompanied by a severe emotional burden sometimes resulting in major psychiatric complications of depression (Clayton 1990:34; Gilbar & Ben-Zur 2002:422) and anxiety related symptoms such as tension, headaches, palpitations and chest pain (Jacobs, Hansen, Kasl & Ostfeld 1990:269; Balk, Zaengle & Corr 2011:149). Current evidence suggests that bereavement impacts individuals physically, cognitively, emotionally, interpersonally, behaviourally and spiritually, meaning that the loss of a close relative, may lead to emotional reaction of fear, anger, guilt, confusion, sadness and loneliness (Balk 2009, in Balk, Zaengle & Corr 2011:149). This reaction is not only limited to relatives of the ceased.

In another study involving caregivers, Dumont, Dumont and Mongeau (2008:1052) found that caregivers experienced negative repercussions when their patients died, with some failing to adjust effectively to their bereavement experience. The researchers noted that whenever such caregivers failed to adjust to their experience of bereavement and loss, they were observed to experience substantially detrimental consequences including failing health and wellbeing, probably due to prolonged sadness and grief as reported and observed during July 2012 Kibale Ebola outbreak.

### 6.3.3.3. Abandonment and rejection of sufferers

Another negative experience associated with Ebola was that the heightened desire by the public to stay healthy resulted in survivors and caregivers being neglected and rejected by communities, sometimes by own family members, and even by members of the health care team. At the height of the epidemic, being neglected or abandoned was not uncommon even in health facilities such as hospitals as herein reiterated:

When my diagnosis was confirmed, I felt neglected because whenever I could hand over my file to be seen by a doctor, no one was there to receive it...I did not have any one to help me. I was neglected. I even reached an extent of sleeping down on the floor in the hospital corridor. I became desperate. I thought of escaping from the hospital, but I could not manage to do so, I was then so weak (Data: 31).

Data display 6.2.3.3 highlights experiences related to abandonment and rejection.

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**DATA DISPLAY 6.2.3.3.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**CATEGORY 3: NEGATIVE EXPERIENCES**  
**SUBCATEGORY 3: ABANDONMENT/REJECTION OF SUFFERERS**

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- When I requested the attending nurse to bring me more blankets..., she never returned. I waited for the blanket in vain. Well, God did his work and I slept eventually. And when I woke up I found the chills and rigor was no more. I was grateful to God for preserving me through the night (Data: 11).
  - What pains me most when I reflect upon my struggles with Ebola is to fight this disease alone until I survived. I felt I was not given anything. I went to expensive hospitals where I bought all drugs. I spent a lot of money .... I sold what I could. Lots of money was spent but I was left out... (Data: 55).
  - In the community because people knew that I took care of xx, they would run away from me. Even shop owners and market vendors did not want to give us food and other items because they feared us...people would say don't give her anything. We could not buy anything... (Data: 134).
- 

The rampant rejection experienced by survivors and caregivers appears to have been related to the perception that they harboured the deadly virus despite being declared Ebola free. Locsin and Matua (2002:174) found similar outcomes when contact persons following the 2000/2001 Ebola outbreak in Mbarara, Uganda, were openly rejected by their communities due to the prevailing fear and anxiety about Ebola. As a result, contact persons, suspects and immediate family suffered abandonment and rejection during and following the outbreak. Hewlett and Amola (2003:1246) document similar findings during the 2000/2001 outbreak in Gulu, northern Uganda where they found that spouses abandoned their loved ones, survivors were barred from returning home from hospital and children were ordered not to touch surviving parents and relatives. Outside, survivors and close family members were stopped from walking in the neighbourhood and rejected in watering wells as well as markets.

### 6.3.3.4. Isolation and ostracism

Throughout the epidemic and thereafter, persons who were directly connected to the outbreak were frequently isolated by the public including their close associates. For survivors and caregivers, the isolation meant they could no longer freely interact with others as they were able to do before the Ebola outbreak. This ostracism appears to have been linked to the fear associated with the outbreak. Important highlights of the isolation suffered by survivors and caregivers are illustrated on data display 6.2.3.4.

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**DATA DISPLAY 6.2.3.4.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**CATEGORY 3: NEGATIVE EXPERIENCES**  
**SUBCATEGORY 4: ISOLATION AND OSTRACISM**

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- I used to feel very bad when I realised that the people I called my friends, with whom I grew up and went to school suddenly would turn away and flee from me... (Data: 67).
  - When I came back home from the hospital, most people were not willing to stay with us as a result of the outbreak...Most people actively avoided me and my family members...(Data: 83).
  - When people knew that I had nursed all these people who had Ebola, they could run away from me. I could not even buy airtime. I could not walk freely. People would call each other and whisper, you come and see xx, the one who was treating Ebola, and she has Ebola also (Data: 193).
- 

Ostracism is the intentional ignoring and excluding of individuals or groups by individuals or groups who belong to a more dominant group (William 2007:236; Wesselmann, Wirth, Pryor, Reeder, & Williams 2013:108). According to William (2007: 236), initial reactions to even the most minimal forms of ostracism are painful, distressing and undesirable. When ostracised, individuals simultaneously experience social pain, distress, and their fundamental human needs of belonging, self-esteem, control, and meaningful existence are threatened (Williams 2007: 236; Williams 2009, in Wesselmann et al 2013:108). These negative physiological, affective, cognitive, and behavioural responses means ostracism leads to “social death” because they often sever social linkages crucial for individual’s survival through challenging times (Williams 2009, in Wesselmann et al 2013:108; Williams & Nida 2011:71). Similarly, Salvy, Bowker, Nitecki, Kluczynski, Germeroth and Roemmich (2011:39) point out that the experience of ostracism may negatively impact a person’s abilities to self-regulate and this may lead to negative health behaviours in the long run affecting the individual’s physiological, affective, cognitive, and behavioural wellbeing. The study findings appear consistent with conclusion of these related research investigations.

### 6.3.3.5. Stigmatisation, shame and embarrassment

The study findings revealed that survivors and caregivers were subjected to acts of prejudice, quarantined and ultimately refused to mix with other members of the society. This exposed them and their families to stigmatisation, shame and embarrassment. Stigma refers to socially devalued characteristic that exposes a person to acts of prejudice and discrimination (Earnshaw & Chaudoir 2009, in Chaudoir, Norton, Earnshaw, Moneyham, Mugavero & Hiers 2012: 2383). Consequently, participants were discriminated against, ridiculed by shopkeepers, public transport operators, acquaintances, neighbours and by family members, even after the epidemic ended. Data display 6.2.3.5 highlights accounts of stigmatisation, shame and embarrassment suffered by survivors, caregivers and family members.

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**DATA DISPLAY 6.2.3.5.**  
**THEME 2: NATURE OF EBOLA EXPERIENCE: UNIQUE AND GENERAL EXPERIENCES**  
**CATEGORY 3: NEGATIVE EXPERIENCES**  
**SUBCATEGORY 5: STIGMATISATION, SHAME AND EMBARRASSMENT**

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- When I am traveling...for long distance travels, I go to the bushes to find a place to urinate...When you stop the driver, some laugh at you, they blame me for stopping the vehicle over a short distance. Some question you and embarrass you... (Data: 54).
  - I think...[survivors]... should be accepted as normal people who should not to be segregated...even up to today, there are people in the community who are still labelled as having Ebola. Part of the labelling...is the fact that people don't know much about the illness... (Data: 169).
  - ...my immediate neighbours would complain! ...they would say, even [my] hens have Ebola. They could chase them away...The public concluded that, everything, everybody from me was infected. Even my family members would be chased including my house girl... (Data: 194).
- 

Stigmatisation occurs when a larger group expresses negative attitude about socially unacceptable features of a smaller group (Scambler 1998:1054; Zickmund, Masuda, Ippolito & LaBrecque 2003:835). This prejudicial association of the sufferer with the unwanted characteristic, means the group is often blamed and embarrassed (Duffy 2005:13-14), making them feel trapped and shamed, leading to loss of self-esteem and reduction of their quality of life (Miller & Major 2000, in Zickmund et al 2003:835; Zickmund et al 2003:835). When nothing is done to resolve the situation, some sufferers develop a number of negative outcomes including feelings of depression, sadness and worry, which may affect their relationship with family members, health teams and workmates. This may further weaken their resolve to deal with associated challenges as reported by some survivors and caregivers (Zickmund et al 2003: 835).

## 6.4. SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS

Surviving Ebola was found to have profound effect on the wellbeing of survivors and family care givers. These effects are fivefold: physical, psychological, social, spiritual and economic in nature and are consistent with the views of LeMay and Wilson (2008:473) who point out that experiencing very serious illness such as Ebola often results in affected persons experiencing widespread consequences which may affect their physical, emotional, social as well as spiritual wellbeing. For some positive outcomes result, leading to increased self-awareness and an opportunity for psychological growth and deepening relationships with significant others (Carpenter, Brockopp & Andrykowski 1999:1402; Petrie, Buick, Weinman & Booth 1999:538; Taylor 2000:721; LeMay & Wilson 2008:473). However, for a few others, the experience usually results in a prolonged struggle with their lives leading to feelings of hopelessness, despair and general sense of demoralisation due to the turmoil and confusion the complexities and reality of the illness brings into their lives (Petrie et al 1999: 537; Kissane, Clarke & Street 2001:12; LeMay & Wilson 2008: 473). In data display 6.3 categories specific to the surviving an Ebola outbreak are explicated.

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### DATA DISPLAY 6.3

#### THEME 3: SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS SUMMARY

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1. The experience of surviving Ebola (Data Display 6.3.1).
  2. Physical implications of being surviving Ebola (Data Display 6.3.2).
  3. Psychological implications of surviving Ebola (Data Display 6.3.3).
  4. Social implications of surviving Ebola (Data Display 6.3.4).
  5. Spiritual implications of surviving Ebola (Data Display 6.3.5).
  6. Economic implications of surviving Ebola (Data Display 6.3.6).
- 

### 6.4.1. The experience of surviving Ebola

Surviving Ebola is met with extreme excitement and thankfulness, as “the impossible becoming a reality”. The excitement appears to derive from having “conquered certain death” from the dreaded illness and is experienced with expressions of “thankfulness” to God, Almighty and health team members who played a significant role in their care, leading to their recovery from the illness as this survivor narrates:

When I knew that other people who had Ebola did not make it and yet I was able to survive; I was very thankful to God. I thanked God that I survived. ...I also thank health workers who regularly came home to counsel us and to explain to us how to be careful, so that we could recover well (Data: 82).

The findings show that for some, surviving Ebola was “unexpected” and “as a sort of miracle”, resulting in a feeling of lost hope being re-born, signalling the beginning of a gradual and steady return of hope and confidence, as alluded to by this participant:

So when Mary’s husband also called to tell us that her results were negative, I said God is good. I became happy and I gained courage. My worries began to reduce at hearing that Mary had survived. I was no longer as worried as I was before the negative results. This news gave me confidence (Data: 131).

Still for another group of participants, the initial news of surviving Ebola was received with disbelief, unsure whether they had really survived the illness especially in the face of continuing physical symptoms of the illness. So for individuals, declaring them as “survivors” was received with reservation and caution (Data: 65). In yet another dimension, caring for Ebola patients and then being declared Ebola free was an immensely pleasant experience. This experience was widely interpreted by the study participants as a sign of God listening to their ardent invocations and prayers:

So when we were declared Ebola free, I thought that the time had not yet come for me to perish like my other relatives. I felt very lucky, because, despite looking after several family members including those who had already died, and even making burial arrangements, and looking after their orphaned children, I did not develop any sign of the disease. I was confident God had listened to my prayers of preserving my life and that of the remaining members of my family (Data: 238).

These verbatim descriptions reveal survival experience was largely unexpected and resulted in a myriad of positive feelings including excitement, hope and thankfulness, although a few others expressed scepticism and reservation about their survival from Ebola as exemplified in some of the verbatim quotes presented in data display 6.3.1.

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**DATA DISPLAY 6.3.1.**

**THEME 3: SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS**  
**CATEGORY 1: THE EXPERIENCE OF SURVIVING EBOLA**

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- As the days passed on and I was not dying, I began to feel good. I became increasingly confident about my survival as I realised that I had spent several days, although sick, while I waited to die, I hadn’t died as yet...I noticed I was regaining my health. I was no longer going to die (Data: 38).
  - When they said I tested Ebola negative, I couldn’t believe. Filled with doubt deep down in my heart, I thought, they could not have found me negative, especially when a few days earlier my blood had tested positive. I thought to myself may be the test was not done right. Even then there was no specific medicine they had given me to say that I had been cured by that medication... (Data: 65).
  - When they confirmed that I was among those few people who had been infected, but had now fully recovered, I was thankful to God for saving my life. I was told my blood type was a strong one, which was not weakened by Ebola like for other people. When I heard this, I thanked God (Data: 81).
-

These positive experiences associated with surviving Ebola compare well against findings of Petrie and others (1999:538) and LeMay and Wilson (2008:473) who found that the vast majority of individuals and their families adjusted and coped effectively with the challenges associated with the illness. The scepticism about survival voiced by some survivors is consistent with findings of a study conducted by Matua and Locsin (2005:148) in Gulu district which found that survivors had “disbelief in their survival” after being officially declared as negative. However, while the Gulu participants saw survival as a temporary mitigation of signs and symptoms, and “awaited for the return of Ebola”, conversely, Kibale participants considered their survival as unexpected and “impossible” given the deaths and the fact that no specific medicine had been given to the patients. In other words, some could not believe they survived Ebola. This is consistent with what De Roo, Ado, Rose, Guimard, Fonck and Colebunders (1998:883) found out characterised by similar incidence of “denial” of survival by patients during a survey among survivors of 1995 Kikwit Ebola epidemic.

#### **6.4.2. Physical implications of surviving Ebola**

As a life-threatening disease associated with multiple organ and multisystem involvement (Okware, Omaswa, Zaramba, Opio, Lutwama, Kamugisha, Rwaguma, Kagwa & Lamunu 2002:1068; Wamala, Lukwago, Malimbo, Nguku, Yoti, Musenero & Okware 2010:1087) survivors of Ebola frequently present with symptoms many of which are related to the effect of the virus on organ and body systems. As reported in previous studies, survivors found the physical consequences of Ebola distressful.

It was clear from the findings that the physical consequences of the illness such as body weakness, memory loss and bladder weakness imposed on survivors by the sequel of the disease process are experienced as highly stressful and often elicit profound emotional reactions from the affected especially when survivors feel they are being stigmatised and blamed for “weaknesses”, for which they should not be held “culpable”. Data display 6.3.2 displays verbatim expressions related to the category: physical implications of surviving Ebola quoting participant’s experiences.

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**DATA DISPLAY 6.3.2.**
**THEME 3: SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS**  
**CATEGORY 2: PHYSICAL IMPLICATIONS OF SURVIVING EBOLA**


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- After some time, the health workers told me that my results were okay and that I was going to be discharged...I was very weak... when I lay in bed, I could not even lift myself from the bed (Data: 10).
  - The illness has left me with many weaknesses; my health is not yet all that good. I have been advised to see a physician for nearly everything on me, from my bladder to memory loss... (Data: 53).
  - As I [recovered]...I needed to see a physician in relation to forgetfulness, urinary frequency and uterine growths. I had also wanted to see a gynaecologist because I did not have menstrual periods (Data: 59).
- 

In addition to the above complications, survivors in other outbreaks have also complained of ophthalmic complications among them eye pain, photophobia, hyper lacrimation, and progressive visual loss, acute anterior uveitis (Kibadi, Mupapa, Kuvula, Massamba, Ndaberey, Muyembe-Tamfum, De Roo & Colebunders 1999:13). In addition, Kaguna (2001:5) and Wanyaye (2001:7) have also documented that for survivors, the return of normal body functioning during recovery period is a very slow and striking experience, with frequent complaints of slow gain of appetite, marked weakness and weight loss. Also, late complications related to musculo-skeletal, nervous and uro-genital systems are common (Kaguna 2001:7; Wanyaye 2001:8-9).

#### **6.4.3. Psychological implications of surviving Ebola**

Surviving Ebola is undoubtedly associated with several psychological consequences. According to Horowitz (1978) as explained in Van der Kolk, McFarlane and Weisaeth (2007:5-6), after experiencing a traumatic event, most people get preoccupied for a while with memories of the traumatic event as a way of modifying the painful memories to increase their tolerance to them. And as time goes on, it is expected that these painful memories should disappear and the person adapts and integrates and finally emerges stronger to face other challenges (Van der Kolk et al 2007:6-8).

However, when such persons begin to organise their lives around the traumatic event and they fail to transcend the negative experience, it could mean they are tending toward posttraumatic stress disorder, a more grievous psychological problem (Van der Kolk et al 2007: 6). The psychological symptoms survivors presented were mostly fear, depression, hopelessness, pain, altered body image and numbness among others. In data display 6.3.3, statements illustrating these symptoms are presented.

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**DATA DISPLAY 6.3.3.****THEME 3: SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS**  
**CATEGORY 3: PSYCHOLOGICAL IMPLICATIONS OF SURVIVING EBOLA**

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- Whenever I am reminded about Ebola, I find I cannot control crying because recalling my situation stresses me. And when I reflect about my experience, sometimes I think a lot because the illness didn't leave me the way I was before. The illness has left me with many weaknesses... (Data: 53).
  - These days when I think about Ebola, what come into my mind are the thoughts...that I would return home dead. I did not have any hope that I would survive the illness...To this day, when I think about Ebola, it is like thinking about death. I begin to experience pain in my whole body... (Data: 69).
  - When I discovered that I was recovering from...Ebola which usually kills its victims, I did not know whether to feel happy or sad. I had lost words. I kept looking on and waiting to see what would happen to me next. I did not know what to expect (Data: 99).
- 

Consistent with these negative feelings experienced by Kibale survivors, De Roo et al (1998:884) reporting on survivor's psychological effects of being infected during the 1995 Kikwit outbreak, document widespread fear, discrimination, shame, blame and stigmatisation. The intense fear was related to pain and suffering, dying a horrible death, separation from relatives and abandonment by close relatives. The most discouraging experience reported was witnessing the death of friends and colleagues in the isolation unit and being resented by medical staff (De Roo et al 1998:885-886).

Despite these challenges, De Roo et al (1998:885) reports that all survivors felt their belief in God and their spirituality had been strengthened resolutely by the experience. De Roo et al (1998:885) compare these psychological reactions to those that were also experienced in Europe in the middle ages during the bubonic plague.

These reactions compare well with experiences of other life threatening conditions notably HIV/AIDS infection (Gilmore & Somerville 1994:1339), Hepatitis C patients (Zickmund et al 2003:835); patients, survivors and contacts of SARS infection (Leung & Guan 2004:3; Siu 2008:729) and by cancer survivors (Adler & Page 2008:33). Such psychological reactions arise out of people's attempt to escape, control, deny or displace their fear associated with such terrifying disease (De Roo et al 1998:885).

#### 6.4.4. Social implications of surviving Ebola

In addition to the physical and psychological implications, survivors and caregivers also reported incidences that negatively affected their relationship with other members of the society. A significant social outcome of surviving Ebola is that it affected how others related to survivors and caregivers, as this participant declares:

When I came back from hospital after having survived Ebola, the people never used to come to my home. Even up to today, many of them have continued to avoid [me] since the outbreak occurred almost a year ago. Only a few of them who supported me during the illness and funerals... (Data: 102).

This verbatim quote appears to paint a picture of social isolation and rejection suffered during the outbreak and long after the epidemic ended. The verbatim quotes in data display 6.3.4 depict social challenges associated with surviving the outbreak.

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#### DATA DISPLAY 6.3.4.

#### THEME 3: SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS CATEGORY 4: SOCIAL IMPLICATIONS OF SURVIVING EBOLA

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- When the neighbours knew that the people I had been looking after were dying of Ebola, they feared to interact with me and other members of the family. We were isolated and quarantined so much...the remaining children in the family could not go to school. I could not even go to town... (Data: 236).
  - As the outbreak was announced, fear and panic gripped nearly everybody. Everyone began avoiding getting close to one another for fear of getting infected. And for us who had the illness at home, the fear towards me and my family was so overwhelming that people would openly isolate us (Data:252).
  - The neighbours and...the community treated us very badly. Overwhelmed by fear and anxiety, the people would simply look at us and couldn't sympathise with us. They couldn't come home to visit us and would run away and avoid us when we went to town... (Data: 282).
- 

Mason (2008:1267) describes similar experience of ostracism, social isolation, open rejection and discrimination of affected infected persons and their families during the 2007 Ebola Bundibugyo outbreak. He adds that as the epidemic ravaged on, people believed to be infected were forcibly quarantined by the community even to the point of using threat of violence, including stoning to stop the members of labelled families from leaving their homes, for fear they would be spreading Ebola (Mason 2008:1267).

In the same way, Person, Sy, Holton, Govert and Liang (2004:358) while explaining the genesis of the widespread fear and stigma during the SARS outbreak, cites (Das 2001) as noting that the fear and hysteria arose due to underlying anxiety about the deadly disease about which little was known. Person et al (2004:358) note that the social unrest including stigmatisation of potential SARS patients emerged early in the

outbreak, as global media reported dramatic stories from Asia in print media, television, and the internet. Person et al (2004:358) conclude that mitigating fear and discrimination directed at persons infected with, and affected by, infectious disease can be important in controlling transmission, because ostracised and stigmatised persons may delay seeking care or choose to hide in the community undetected which may have grievous epidemiological consequences as reported during 1995 Kikwit outbreak (De Roo et al 1998:884); 2000/2001 Gulu outbreak (Hewlett & Amola 2003:1245) as well as the 2007 Bundibugyo Ebola epidemic (Mason 2008:1267).

#### **6.4.5. Spiritual implications of surviving Ebola**

In addition to the physical, social, economic and psychological consequences of experiencing and living through the aftermath of Ebola, participants also reported spiritual dimension to their experience. Nearly all survivors experienced transcending the Ebola experience as a manifestation of “still having to complete one’s mission on earth”, stemming from the belief of “being left by God to fulfil a mission” or as a sort of “reward” by God for diligent service to humanity before dying eventually. In this study and in literature, the role of spirituality and religiosity is cardinal in helping the affected to appreciate and cope with traumatic events, as illustrated in data display 6.3.5.

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##### **DATA DISPLAY 6.3.5.**

##### **THEME 3: SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS CATEGORY 5: SPIRITUAL IMPLICATIONS OF SURVIVING EBOLA**

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- As a survivor, one of the key lessons I learnt from this outbreak is to keep loving God. When you love God or when you keep praying sometimes God can answer your prayers... (Data: 21).
  - When I was declared Ebola free, I felt so good... I started praising God and began to reflect upon why I survived. I thought, maybe, it meant God wants me to do more work for him...as I reflected, I told myself, maybe God wanted me to survive this Ebola,...to... fulfil God’s work...(Data: 40).
  - As I recovered at home...I was contemplating whether I should continue with my job in Kibale or not. I began to think, maybe, why God left me in this world is to fulfil his plans and this meant that I make sure that I do my work well...I became convinced that probably that’s why I remained alive...(Data: 43).
- 

The role of spirituality and religion in interpreting survivorship and related experiences is well documented in literature. In a recent review involving breast cancer survivors, Schreiber and Brockopp (2012:91) emphasise that survivors who believed in “a highly engaged God reported a higher psychological well-being and decreased stress, anxiety, depression, and concern about recurrence”. Ai, Peterson, Tice and Koenig (2005:54), in an earlier study, also found that spiritually inclined actions such as

praying, fasting and fervent belief in God were vital in patient's journey during crises. The researchers conclude that prayer and related faith based actions present a spiritual means of achieving self-empowerment, which is a critical component for positive outcomes and wellbeing during traumatic and life threatening events. Indeed, Ai et al (2005:54) affirm that prayers may also help the affected find meaningful solutions to their problems and to achieve a sufficient "distance" from their distress.

#### **6.4.6. Economic implications of surviving Ebola**

The economic implications of Ebola outbreak arise out of various reasons including difficulties experienced in getting work or sustaining work due to poor health or widespread social rejection due to fear that sufferers could still be harbouring Ebola. These economic implications are not new, even during the 2000/2001 Ebola outbreak in Gulu, survivors and their families faced similar challenges. A particular feature of the 2012 Kibale outbreak like the Gulu epidemic is the challenges of reintegrating survivors and caregivers into their primary communities, after they became outcasts; expelled from homes, their clothes and property burnt and the possibility of finding work vanished (Sandbladh 2001: 267). As stressed in data display 6.3.6, the sub-categories that illuminate participant's economic experiences relate to loss of property and income sources and increased health spending due to treatment costs.

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**DATA DISPLAY 6.3.6.**  
**THEME 3: SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS**  
**CATEGORY 6: ECONOMIC IMPLICATIONS OF SURVIVING EBOLA**  
**SUMMARY**

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1. Loss of property (Data Display 6.3.6.1).
  2. Loss of income (Data Display 6.3.6.2).
  3. Costly health checks (Data Display 6.3.6.3).
- 

One of the factors that exacerbated the economic challenges of survivors and caregivers related to an increased orphan burden following demise of close relatives. Survivors and caregivers had to meet financial obligations of deceased relatives', children among them school fees, medical bills and household needs, all of which became "too heavy to bear", as this participant affirms in her lamentation:

The epidemic has...numerous challenges for me...one of the most pressing problems I now face is that of orphans left by my sisters, brothers, uncles and aunts...the responsibility of guiding them and providing for their needs is overwhelming...(Data: 261).

This experience of financial difficulty experienced after Ebola outbreaks is comparable to the financial crises related to the HIV/AIDS orphan crises in communities in East, Central and Southern Africa that continue to drastically outstretch the established caring mechanisms for orphans. Much like the HIV/AIDS orphan situation, as reported by Nyambedha, Wandibba and Aagaard-Hansen (2003:301-302) as well as Andrews, Skinner and Zuma (2006:271) some survivors and caregivers reported that a major economic consequence of the outbreak is dealing with overwhelming demands of orphans. This situation is compounded by the fact that in most cases the capacity of affected families to meet the needs of these orphans in terms of education, health, clothing and nutrition is severely outstretched.

#### **6.4.6.1. Loss of property**

The findings reveal that survivors and caregivers lost property due to the epidemic response efforts as well as due to the memory loss, a direct sequel of the disease. The loss from surveillance action was inflicted when volunteers working with surveillance teams upon reaching the home of Ebola patients or contacts or suspects gathered and burnt personal belongings such as beddings, clothing and household items for fear they would harbour the virus. In terms of the loss associated with memory loss, a participant maintained that her forgetfulness has led to her losing many light items following Ebola. In data display 6.3.6.1, highlights of participants' verbatim quotes pointing out to experiences related loss of property are illustrated.

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##### **DATA DISPLAY 6.3.6.1.**

##### **THEME 3: SURVIVING EBOLA: PHYSICAL, PSYCHOLOGICAL & SOCIAL IMPLICATIONS CATEGORY 6: ECONOMIC IMPLICATIONS OF SURVIVING EBOLA SUB-CATEGORY 1: LOSS OF PROPERTY**

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- I have become very forgetful, especially when it comes to objects...This forgetfulness and memory loss has made me lose lots of property. I have lost a lot of bags, money, phones, pens... (Data: 53).
  - The Ebola experience made me lose a lot of personal belongings...some properties were destroyed because of being sprayed upon, while others were completely burnt... (Data: 56).
  - ...most of the personal belonging the people who died of Ebola had used before their death were all burnt....our house was sprayed over and over again as we continued to stay at home... (Data: 257).
- 

The study revealed that while some compensation took place after the epidemic, most survivors and caregivers agree that the value of personal belongings damaged or lost far exceeded the government compensation. Participants complained this anomaly created a severe financial burden on them, for which they were ill prepared.

Incidences of burning property of actual and suspected patients were also reported during the 2000/2001 Ebola outbreak (Lamunu et al 2002:13; Hewlett & Amola 2003:1246) where local communities burned all the properties of the suspected and convalescent Ebola cases fearing they were still contaminated. Such indiscriminate destruction of property in the homes of suspected or confirmed cases threatened epidemic response efforts negatively as it led to a temporary hiding of suspects in the community (Lamunu et al 2002:13) as communities became weary of the economic loss if they reported suspected cases. Besides the loss created unprecedented financial stress to survivors, caregivers and families (Hewlett & Hewlett 2005:289-90).

To avert such negative consequences, Lamunu et al (2002:13) as well as Vanessa and Matthias (2012:71) recommend that adequate compensation should be provided and communities should be educated about the dangers of the hyper-vigilance which risks leaving affected persons in abject poverty, given that most outbreaks tend to occur in impoverished communities (Hewlett & Hewlett 2005:293; Shears 2007:217).

#### **6.4.6.2. Loss of income**

Another economic consequence of surviving Ebola is suffering loss of income as a result of survivors' and care givers reduced ability to work due to their illness and the stigma and rejection they face. As the epidemic raged on, the stigmatisation associated with discrimination was rife and this had economic ramifications since survivors, caregivers and sometimes their families could no longer participate in any economic activity because of the fear inspired stigmatisation in the community. In data display 6.3.6.2, examples of experiences related to loss of income are clarified.

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#### **DATA DISPLAY 6.3.6.2.**

#### **THEME 3: SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS**

#### **CATEGORY 6: ECONOMIC IMPLICATIONS OF SURVIVING EBOLA**

#### **SUB-CATEGORY 2: LOSS OF INCOME**

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- The false news of my death was particularly a great blow for me...These announcements made me lose my customers of the saloon,...most of them thought that I had died [as announced]...(Data:87).
  - Before the Ebola outbreak, I had a sizeable number of customers in my saloon...after closing my salon for four months when I had to remain at home... I lost most of my regular customers (Data: 93).
  - The loss of my customers has affected my zeal for the business...when I go to work, I often spend the whole day in the saloon without any return, yet I have to pay rent... (Data: 94).
-

The loss of income experienced by survivors and caregivers is comparable to the situation of cancer survivors described by Adler and Page (2008:33-34) particularly when prospective employers become aware of an employee's history of cancer resulting in them being discriminated against by potential employers. This scenario is comparable to losing customers due to the discrimination associated with stigma experienced by both survivors and caregivers who were involved in retail businesses.

The loss of income reported by these participants is comparable to the income losses incurred by south Asians living in China town in Toronto, Canada during the 2003/2004 SARS outbreak in Hong Kong and Canada. Leung and Guan (2004:4) report that members of Chinese and Southeast Asian communities were frequently stigmatised and alienated, discriminated against and even harassed. This had a negative economic impact because their businesses were hard hit as their shops were shunned. Another negative economic aspect of the SARS epidemic that compares well with the income loss suffered during the Kibale 2012 Ebola outbreak is the job loss suffered by south Asians because of the presumed contact they had with their SARS positive relatives, leading to unfair dismissals (Leung & Guan 2004:4). While employment issues were not explored in great detail, what emerged is that the widespread discrimination negatively affected survivors and caregivers businesses.

#### **6.4.6.3. Costly health checks**

Another economic consequence associated with the outbreak relates to costly health check-ups and treatments survivors underwent as they recuperated from the sequel of Ebola. As reported in previous outbreaks (Kibadi et al 1999:13-14; Kaguna 2001:5-6; Feldmann & Geisbert 2011:3-4) survivors of the 2012 Kibale outbreak too complained of several dysfunctions in almost all body systems. This therefore meant they had to seek healthcare, often paying expensively for treatments. The verbatim quotes in data display 6.3.6.3 support claims of costly health checks and treatments.

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**DATA DISPLAY 6.3.6.3.**
**THEME 3: SURVIVING EBOLA: IMPLICATIONS FOR SURVIVORS AND CAREGIVERS**  
**CATEGORY 6: ECONOMIC IMPLICATIONS OF SURVIVING EBOLA**  
**SUB-CATEGORY 3: COSTLY HEALTH CHECKS**


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- I am worried about my financial security. Although I am willing to continue [with treatment], the sickness has drained all our financial resources...I am still paying loans that I took... (Data: 58).
  - As I was recovering ...I needed to see a physician in relation to issues related to forgetfulness, urinary frequency and uterine growths. I told my husband to take another loan....I even told [him] to sell our land so that we could get money, so that I could recover quickly...and have good food (Data:59).
- 

These verbatim expressions signal the presence of financial stress some participants' experienced, especially survivors who had to undergo these expensive treatments and investigations. Similar experience of financial crises has been reported among survivors of other life-threatening illnesses, notably cancer (Adler & Page 2008:34); SARS (Leung & Guan 2004:4; Siu 2008:730) outbreaks and the HIV/AIDS pandemic (Duffy 2005:14; Florom-Smith & De Santis 2012:161). In most cases, the financial crises arise because survivors have reduced opportunity to work because of widespread discrimination (Leung & Guan 2004:3; Duffy 2005:14; Adler & Page 2008:34); reduced physical and mental capacity to perform their job (Feldmann & Geisbert 2011:4; Florom-Smith & De Santis 2012:161) or have increased financial burden due to costly treatments or increased expenditures due to the need to support close relatives (Nyambedha et al 2003: 301; Adler & Page 2008:34; Taiwo 2012:280).

## **6.5. CARING FOR EBOLA PATIENTS: MEANINGS AND IMPLICATIONS**

Realising that the patient you have been caring for is infected with Ebola is a deeply fear-inducing and stressful event, especially knowing that Ebola is a life-threatening disease. Most participants reported experiencing a range of feelings: broadly categorised as social or psychological consequences. The social implications were stigma, isolation, discrimination and ostracism, while psychological features included fear, despair, stress and anxiety, sleeplessness, paralysis, helplessness and anorexia. As the epidemic spread, the fear in the community led to their unfair discrimination and ostracism which eventually resulted in caregivers being unfairly targeted, leading to incidences of feeling downtrodden and depressed. In a way, inadvertently care givers were forced to "carry" the social and psychological burden associated with the outbreak as illustrated in the verbatim quotes of data display 6.4:

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**DATA DISPLAY 6.4**  
**THEME 4: CARING FOR EBOLA PATIENTS: MEANINGS AND IMPLICATIONS**  
**SUMMARY**

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1. Meaning of caring (Data Display 6.4.1).
  2. Social implications (Data Display 6.4.2).
  3. Psychological implications (Data Display 6.4.3).
- 

Similar experience of depression and sadness has been reported among caregivers of stroke patients in the United Kingdom by Wade, Legh-Smith and Hewer (1986:420) in a study that focused on the effects of living with and looking after stroke survivors. The researchers concluded that the emotional reaction of the carers may have been precipitated by the life threatening event of stroke which prompted anxiety symptoms.

### **6.5.1. Meaning of caring**

Caring for Ebola patients was experienced as a stressful, burdensome and depressing event, in part due to the risks involved, but also by witnessing the suffering and the untimely death of a close relative or friend. Knowing that ones' patients had Ebola was very frightening and unsettling, because it signalled that they too could get infected and die or at least carry the "social burden" of being associated with Ebola. This reality shock precipitated feelings of sadness, fear and depression:

When xx was admitted to hospital, we were informed that her blood was taken for testing... [and] when the results came back...[confirming] that she had Ebola. I immediately thought I would also get infected. I became so frightened and immensely shocked. I got so worried...I started trembling and would shiver. Immediately I developed fever; headache and I lost the appetite...at night I couldn't sleep (Data: 121).

It is clear from the narrative that caregivers dreaded Ebola infection and lived in constant anticipation of this greatly traumatising infection. Hansen (2008:2) and Stein et al (2012:794), claim that the psychosomatic symptoms experienced were due to the overwhelming fear of impending death and resulted in the caregivers experiencing somatic manifestations characterised by feelings or emotions of fear, humiliation, detachment, anger, horror, sadness and numbness among others. This culminated in survivors exercising great care during patient care as explained in data display 6.4.1.

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**DATA DISPLAY 6.4.1.**
**THEME 4: CARING FOR EBOLA PATIENTS: MEANINGS AND IMPLICATIONS**  
**CATEGORY 1: MEANING OF CARING**


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- I was very careful when caring for patients especially the very sick ones during the 21 days. They had told us that if we are not infected within these three weeks, we would not get infected. So I was very careful so that I did not contract Ebola (Data: 127).
  - ...I learnt...from caring for xx that when you are caring for a loved one, be it a husband, child or sister, it is good to take standard precautions. Because you never know what disease it could be and so since the risk of being infected is high, one needs to take personal precautions (Data: 170).
  - These days I am careful when dealing with the sick, no matter who they are...I consider anybody sick as sick, meaning that even if it is my daughter, I can't be as close to them as I used to be. So now any illness means being extremely careful when caring, I have to protect myself (Data: 202).
- 

Similar experience of caregiver burden and stress has been reported widely in literature. These include expressions of depression (Han & Haley 1999:1480; Henriksson, Årestedt, Benzein, Ternstedt & Andershed 2013:258); anxiety (Kitze, von Cramon & Wilz 2002:402; Henriksson et al 2013:258) and social isolation (Hansen 2008:3-4; Stein et al 2012:793) among others. When these symptoms are not addressed, many caregivers may deteriorate further, with some slipping into a life of vicarious traumatisation and eventual burnout (Hudson 2004:60; Kliman 2010:23; Hudson, Thomas, Trauer, Remedios & Clarke 2011:523; Henriksson et al 2013: 258).

### **6.5.2. Social implications of caring for Ebola patients**

Caregivers reported negative experiences associated with caring for close relatives and friends diagnosed with Ebola, characterised by social isolation, rejection and discrimination, resulting in widespread stigmatisation as affirmed in this declaration:

After xx died, most people began to fear me when they knew I was involved in her care. There was also an ongoing rumour that that all those who cared for xx were sick and were dying...when I knew people were afraid of me, I became more cautious when outside of home or hospital. I would not go to town...I wouldn't go to my private clinic...because people were still afraid of me...I wouldn't even go to church (Data: 160).

These experiences are similar to those experienced by survivors discussed in section 6.4.4, and are illustrative of the social implications of caring for Ebola patients as experienced by care givers, examples of which are reiterated in data display 6.4.2.

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**DATA DISPLAY 6.4.2.**
**THEME 4: CARING FOR EBOLA PATIENTS: MEANINGS AND IMPLICATIONS**  
**CATEGORY 2: SOCIAL IMPLICATIONS**


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- When people knew that I had nursed all these people who had Ebola, they could run away [saying], she has Ebola also...the whole community was running away from me, from hospital, town and even the community where I am staying. When I saw people running away, I would feel terribly bad! (Data: 193).
  - The neighbours who rejected me and my family would never come home. They kept gossiping about my family, discouraging people from coming home, claiming there is a patient with Ebola [there] (Data: 215).
  - [Before] Ebola, we had a very good relationship with neighbours. We related well with each other. They would visit us at home regularly as we would visit them. We would even cook and take meals together...But when my mother feels ill, this pattern of life changed abruptly (Data: 284).
- 

As in previous outbreaks, caregivers expressed that the community “blindly” discriminated against them and “concluded” they had Ebola. Such experiences of ostracism and discrimination and stigmatisation have been reported during previous Ebola outbreaks (De Roo et al 1998:884; Hewlett & Amola 2003:1245; Mason 2008:1267) and SARS outbreaks (Person et al 2004:358; Leung & Guan 2004:4-5).

### 6.5.3. Psychological implications of caring for Ebola patients

The psychological consequences experienced by caregivers are similar to those experienced by the survivors as detailed in section 6.4.3. These emotional reactions include despair, anxiety, sleeplessness, paralysis, helplessness, loss of appetite and stress among others as expressed in verbatim quotes exhibited in data display 6.4.3.

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**DATA DISPLAY 6.4.3.**
**THEME 4: CARING FOR EBOLA PATIENTS: MEANINGS AND IMPLICATIONS**  
**CATEGORY 3: PSYCHOLOGICAL IMPLICATIONS**


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- When it was announced in the local radio stations and in the newspapers that ...that the illness that had been mysteriously killing people was Ebola, an overwhelming sense of despair and fear filled the entire community...some people even wanted to run away from Kibale (Data: 116).
  - As I waited for the signs and symptoms of Ebola to develop, I could not sleep. I was very worried about leaving my children as orphans. I knew that once I got Ebola, it meant I would die. So I just sat there, almost too paralysed to do anything, as I waited for the outcome. I felt defeated. I had nothing to do. This feeling of helplessness continued for some time. I would think all the time. (Data: 123).
  - In the initial days, I could not eat and drink at all...I was not feeling hungry because of much stress. Each time I went to the hospital...the patients...were dying very badly; the diarrhoea was profuse and uncontrollable. I would ask myself...am I going to die like that? I was worried about dying (Data: 188).
- 

In addition to the despair, anxiety, sleeplessness, paralysis and helplessness experienced because of the anticipated infection, another reason for caregivers' psychological stress was helplessly witnessing the death of their loved ones. Caregivers reported that the memories of deceased relatives have continued to linger in their minds, which they find hurtful. De Roo et al (1998:884) report similar

experiences of psychological stress arising from witnessing death of relatives following a study on the feelings and experiences of survivors of the 1995 Kikwit outbreak. In agreement, a study correlating cancer patient's quality of life with predictors of bereaved caregivers' found that bereaved caregivers were at increased risk for developing psychiatric illness because of the stress associated with the patient's death (Wright, Keating, Balboni, Matulonis, Block & Prigerson 2010: 4457).

## 6.6. PUBLIC REACTION TOWARDS SURVIVORS AND CARE GIVERS

In this section the reaction of the public to the outbreak of Ebola is explored at the backdrop of how the community existed before the outbreak. The reaction of the public is described in light of the before, during and the after declaration of the epidemic, followed by synthesis of symbolism of public reaction to explain the reaction and behaviour of the public during and following the July 2012 outbreak. The specific categories denoting public reaction to Ebola are shown in data display 6.5.

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**DATA DISPLAY 6.5**  
**THEME 5: PUBLIC REACTION TOWARDS SURVIVORS AND CARE GIVERS**  
**SUMMARY**

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1. Reaction before, during and after the outbreak (Data Display 6.5.1).
  2. Symbolism of public reaction (Data Display 6.5.2).
- 

### 6.6.1. Reaction before, during and after the outbreak

The findings indicate that prior to Ebola outbreak the surrounding communities in Kibale were socially vibrant where individuals and families carried on their routine in their homes, shops, places of work and interacted uninhibited as herein explained:

I remember, before Ebola, we had a very good relationship with neighbours. We related well with each other. They would visit us at home regularly as we would visit them. The fact that my late mother was a well-known herbalist meant she always had many visitors and patients who came home to take medicine for their sick children. They would come home and would entertain them... (Data: 284).

This verbatim quote illustrates the existence of a stable community where social interactions were "normal" prior to confirmation of the outbreak of Ebola. This normalcy persisted even in the early days of the outbreak, especially when the community had not yet fully conceptualised the mysterious death was Ebola.

However, the reaction of the public changed abruptly when the “unnamed disease” was eventually declared as Ebola by the Ministry of Health and WHO in July 2012. This announcement resulted in drastic changes in the way people, including medical workers interacted with each other and especially how they viewed Ebola patients, their close relatives and caregivers. As explained in section 6.2.1.1, there was paralysing fear resulting in ostracism and stigmatisation in the entire spectrum of community life: home, institutions and community as shown in data display 6.5.1, highlighting public reaction before, during and after the outbreak was announced.

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#### DATA DISPLAY 6.5.1

##### THEME 5: PUBLIC REACTION TOWARDS SURVIVORS AND CARE GIVERS CATEGORY 1: PUBLIC REACTION BEFORE, DURING AND AFTER THE OUTBREAK

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###### Public reaction before Ebola Outbreak (Data Display 6.5.1.1).

- [Initially] people who died were buried decently because nobody had yet understood the cause of death. But when the disease was diagnosed as being Ebola, very few people...attended the burial (Data: 112).
- I used to relate well with the community...home before the Ebola outbreak. But when some neighbours got to know that I had been looking after patients with Ebola...they started avoiding me (Data: 219).
- I remember, before Ebola, we had a very good relationship with neighbours. We related well with them...They liked us and we like them. They would visit us...regularly and we would visit them (Data: 284).

###### Public reaction during Ebola Outbreak (Data Display 6.5.1.2).

- When my diagnosis was confirmed, I felt neglected because whenever I could hand over my file to be seen by a doctor, no one was there to receive it. I began to despair.... I was neglected... (Data: 31).
- Another incidence where I was stigmatised is when a fellow family care giver and I had gone to town to buy some provisions for another patient. When we gave the shop attendant money...she never wanted to touch the money...she held the notes at the edge, and... she then put the money aside...(Data:165)
- When...neighbours...knew we had Ebola in our home were very reluctant to associate with us for a period of about six months...even up to now few people have been able to come to visit us (Data:262).

###### Public reaction after Ebola outbreak (Data Display 6.5.1.3).

- When I went back home from hospital the people feared me a lot. Even my neighbours were afraid of me. Very few people came by to visit me and even then when they did, they kept at a distance. They thought I was still sick... Their fears got even worse whenever health workers came by to check on me (Data: 66).
  - When I compare my life after Ebola with my previous life, there is a significant difference. Before the Ebola outbreak, I had a sizeable number of customers in my saloon... after closing my salon for four months when I had to remain at home following the outbreak; I lost most of my regular customers... (Data: 93).
  - When I compare the way people used to relate to me before Ebola to what is happening now, I see a significant difference. Before Ebola, people always used to come home. After they knew some people in the family had died of Ebola, they no longer come, fearing they would get infected and die... (Data: 103).
- 

These findings confirm that before Ebola outbreak was announced, the community was well integrated, with people carrying on their businesses uninterrupted. It is evidence that the announcements precipitated fear, panic and ostracism and this

eventually resulted in widespread stigmatisation of individuals and families who were either infected or believed to be infected. The fear and panic appear to have been exacerbated by media reports that amplified the magnitude and ferocity of Ebola.

In literature, a similar incidence of media exaggeration of the virility of an epidemic has been mentioned by Duncan and Schaller (2009:111) who explain that perceived vulnerability to a disease is not only influenced by the “actual” vulnerability but may also be influenced by anything that makes disease appear perceptually striking. They maintain that media coverage of disease outbreaks can have a substantial impact on the extent to which people worry about disease transmission and the extent to which they have an impact on disease-relevant prejudices and stigma. News media may create an exaggerated perception of threat posed by infectious diseases as seen during the 2003 Asian SARS epidemic (Siu 2008:729; Duncan & Schaller 2009:111).

Therefore when the danger associated with a disease is significant, a “wild” reaction occurs, leading to widespread fear and panic. As articulated in sections 6.3.3.3 and 6.3.3.4, the resulting fear induced abandonment, social isolation and ostracism gave rise to unprecedented levels of stigmatisation as illustrated in section 6.3.3.5. This meant survivors and caregivers no longer interacted freely with others. In the absence of supportive others, actions of uncaring public, especially the constant shame and embarrassment increases risk for developing more grievous psychiatric complications by survivors (Van der Kolk et al 2007:6-7;Wright et al 2010:4457).

In fact, during the 2000/2001 Ebola epidemic in Gulu, such “negative pressure” of social stigma and the stress of rejection because of one’s association with Ebola led a man to kill himself. Hewlett and Amola (2003:1246) report that due to overwhelming stigma, a distraught widower no longer able to take taunts by his community, including being labelled “Ebola”, like his deceased wife, decided to end his life too. Such examples signify that when not properly countered, severe ostracism and associated stigma can have serious negative consequences during such epidemics.

## 6.6.2. Symbolism of public reaction

A synthesis of the reasons why the public reacted to announcement of Ebola with immense social unrest characterised by acts of widespread rejection, social isolation and stigma gave rise to two main reasons as shown in data display 6.5.2. The first was due to ignorance, misconceptions and lack of knowledge about Ebola, and this resulted in the second: innate individual and community desire for self-preservation.

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**DATA DISPLAY 6.5.2.**  
**THEME 5: PUBLIC REACTION TOWARDS SURVIVORS AND CARE GIVERS**  
**CATEGORY 2: SYMBOLISM OF PUBLIC REACTION**

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**Ignorance, misconceptions and lack of knowledge (Data display 6.5.2.1).**

- ...the behaviour members of the community exhibited, was [due to] a combination of actors... because Ebola was a new disease, most people lacked knowledge about it, including how it spreads (Data: 171).
- I came to realise that people often ran away because they did not know the mode of transmission of Ebola. Some thought it was airborne...they feared, that is why they were stoning my animals (Data: 197).

**Desire for self-preservation and protection (Data display 6.5.2.2).**

- ...when the team that was attending to me realised that I had Ebola...immediately they moved out of my room, they... started discussing among themselves...they started gathering gloves... (Data: 30).
  - ...my practice has now changed...I used to be very social with patients and their attendants. But now I restrain myself from touching [them], especially if I don't know much about them... (Data: 51).
  - ...I was informed that xx's disease was Ebola; I was so shocked that I wanted to run away from the child. I even contemplated abandoning the child...I left all my personal belongings in the hospital... (Data: 182).
- 

### 6.6.2.1. Ignorance, misconceptions and lack of knowledge

The “wild reaction” of the community appears to have been fuelled by their ignorance about Ebola especially the mode of transmission. Participants reported that the antisocial reaction could in part be explained by the fact that Ebola was a new disease and most people lacked knowledge about it, including its mode of transmission (Data display 6.5.2.1). Since little was known about the illness, it was easy for it to appear strange, which fuelled misconceptions about a “strange” illness:

...part of the labelling [was ] due to strange nature of the disease, and the fact that people don't know much about it...some thought it was like HIV, they would stigmatise and isolate survivors (Data:169).

Barrett and Brown (2008:35) document that ignorance and poor understanding can contribute significantly towards fuelling fear, ostracism and stigma about a disease,

contending that ignorance easily leads to misinformation about the disease, which may result in panic and stigma. In panic and ostracism, health seeking behaviour may be negatively affected and this may reduce chances of early detection and treatment, furthering the spread of disease (Florum-Smith & DeSantis 2012:155-56).

In addition, the panic and stigma increasing the social marginalisation of the affected persons, in turn leading to reduced opportunities for work resulting in poverty and neglect, thereby further increasing their susceptibility to poorer health (Florum-Smith & DeSantis 2012:155). If such trends remain for long, another danger is that the stigmatised may begin to distrust health authorities and resist cooperation during public health emergencies, thereby thwarting epidemic control efforts (Florum-Smith & DeSantis 2012:155). The misconceptions, rumours and falsehoods in the community also amplified perceptions of risk and result in mass panic and “migratory” movements, further complicating the health of affected populations (Hewlett & Hewlett 2005: 295; Barrett & Brown 2008: 35; Florum-Smith & DeSantis 2012:155).

An incidence of “ignorance induced fear and panic” occurred in the western Indian city of Surat where the 1994 *Yersinia pestis* (pneumonic plague) epidemic resulted in over half a million people fleeing the city, including 78% of health care providers (Roja 1997:2; Shah 1997, in Barrett & Brown 2008:35). There was mass panic due to ignorance and poor understanding of the disease transmission process, leading to intense fear, panic and turning away of “epidemic refugees” from neighbouring communities. The hysteria was so overwhelming that even trains passed through without stopping and ships refused its cargo (Roja 1997:3; Barrett & Brown 2008:35).

The ignorance induced fear and stigma reached global proportions when international flights to India were cancelled and outgoing passengers quarantined, including the world famous Mother Teresa (Roja 1997:2-4; Barrett & Brown 2008:35). The misinformation led several Persian Gulf states to ban Indian imports, resulting in major economic losses. This was a case of “stigma epidemic” spreading much farther and faster than the pathogen itself; and this inhibited epidemic response, creating new social and public health complexities (Roja 1997:3-4; Barrett & Brown 2008:35).

### 6.6.2.2. Desire for self-preservation and protection

As illustrated in data display 6.5.2.2, an important rationale that emerged is that the public reacted with great fear and rejected affected persons due to innate desire to preserve and protect oneself and vulnerable others from the danger of Ebola, an occurrence, comparable to Hans Selye's (1907-1983), "fight or flight" response to stressors (Selye 1936, in McEwen 2005:316). A participant recalls that when her illness was confirmed to be Ebola, suddenly terror filled the room, and the health workers were frightened, signifying that they appraised her illness as dangerous:

...when the team that was attending to me realised that I had Ebola...immediately they moved out of my room, they...started discussing among themselves...they started gathering gloves...Some even proposed [discharge], saying that they would not manage to treat me at the national hospital (Data: 30).

The team members' immediate reaction was of rejection, wanting to get rid of imminent danger. A caregiver reacted similarly, nearly abandoning the sick baby of a colleague, when she suddenly realised that its mother had died of Ebola. Appraising her continued stay with the baby as being danger, a "flight reaction" emerged:

I was informed that xx's disease was Ebola; I was so shocked that I wanted to run away from the child. I even contemplated abandoning the child...I left my personal belongings in the hospital... (Data: 182).

It is evident from these narratives that when the stressor (disease) is perceived to be too great to overcome, a flight reaction takes over as observed during the Ebola outbreak. This partly explains why those perceived to be sources of "stressors" were frequently rejected and isolated. This observation receives further credence through Wesselmann, Wirth, Pryor, Reeder and Williams' (2013:109) declaration that human beings appear to use "ostracism" as a form of social control tool to influence group members perceived as burdensome: in this case "harmful", because of their exposure to Ebola. Kurzban and Leary (2001) and Dijker much like Koomen (2007, in Wesselmann et al 2013:109) both agree, affirming that ostracism may serve as a social tool to enhance group survival by culling harmful or burdensome members.

Wesselmann, Nairne and Williams (2012:311) further adds that groups of humans and non-human social animals use ostracism as a form of social control on problematic group members, and when needed, use it to ultimately remove such

“undesirable members”. In the present study, it meant that the population ostracised the affected persons in their attempt to keep safe. In other words, it served to quench the community’s evolutionary desire for personal preservation against killer diseases.

## **6.7. SOCIAL-CULTURAL BELIEFS AND PRACTICES RELATED TO EBOLA**

The emergence of Ebola resulted in several explanatory models to help the community come to terms with what Ebola was in order to deal with the crises. In this section, the different perspectives (models) are presented, including practices that were used to mitigate the epidemic. Beliefs should be understood as tenets held by the community in the Kibale area (Merriam-Webster Online Dictionary 2013c:1) and practices as peoples’ actions based on established beliefs and related customs (Merriam-Webster Online Dictionary 2013d:1). The socio-cultural beliefs and practices related to Ebola therefore imply the various beliefs and practices held by communities following Ebola, including the cultural models the community adopted to explain the origin and how to deal with the strange illness. The type of explanatory model an individual or community holds is critical because it influences how they and related others interpret health messages, seek health care and behave in the face of illness including course of treatment they choose to follow (Tirodkar, Baker, Makoul, Khurana, Paracha & Kandula 2011:386; Johnson, Sathyaseelan, Charles, Jeyaseelan & Jacob 2012:2). The specific categories related to the theme of socio-cultural beliefs and practices related to Ebola are illustrated in data display 6.6:

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**DATA DISPLAY 6.6**  
**THEME 6: SOCIAL-CULTURAL BELIEFS AND PRACTICES RELATED TO EBOLA**  
**SUMMARY**

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1. Explanatory models of causation of Ebola (Data Display 6.6.1).
  2. Beliefs and practices to remedy Ebola disease (Data Display 6.6.2).
- 

### **6.7.1. Explanatory models of causation of Ebola**

A cultural explanatory model of an illness (CEMI) is an “individual’s socially transmitted knowledge and explanation for a particular illness and includes his or her own ideas about signs, symptoms, cause, treatments, prevention, and prognosis about the illness” (Kleinman 1980, in Hewlett & Hewlett 2005:291). Fryberg and Markus (2007:1381) add that cultural models consist of culturally derived ideas and

practices that are embodied, enacted, or instituted in everyday life, providing information about what is desirable, what is right or what is wrong within the community. In essence, explanatory models give form and direction to individual experiences, by shaping and influencing their perceptions, cognition, emotion and motivation of members within the defined group and in turn influence their choices.

In further support, Kiropoulos and Bauer (2011:23) substantiate that CEMIs are generally coherent with an individual's cultural beliefs and socially patterned modes of understanding and significantly influence people's illness experience and their response to the illness, including symptom presentation, help-seeking practices and adoption of treatment options. The significance of CEMIs is underpinned on the fact that they help to explain how individuals or groups perceive an illness including the significance of symptoms including meaning, cause, and mode of onset, likely course, severity and appropriate form of treatment (Kleinman 1980, in Charles, Manoranjitham & Jacob 2007:329; Kiropoulos & Bauer 2011:23). CEMIs may thus be useful frameworks which others may use to guide detailed examination of how people conceptualise their illness experience, including how they respond to the illness experience as well as their motivations for the various choices of where to seek help. In data display 6.6.1, the beliefs related to the causation of Ebola are articulated.

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**DATA DISPLAY 6.6.1.**  
**THEME 6: SOCIAL-CULTURAL BELIEFS AND PRACTICES RELATED TO EBOLA**  
**CATEGORY 1: EXPLANATORY MODELS OF CAUSATION**

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1. Ebola as supernatural occurrence (Data Display 6.6.1.1).
  2. Ebola as natural occurring disease (Data display 6.6.1.2).
- 

The occurrence of Ebola was attributed to either "supernatural" or "natural" causes. This is consistent with the perceptions of Italian, Greek and Turkish immigrants regarding the causes of mental illness (Minas, Klimidis & Tuncer 2007, in Kiropoulos & Bauer 2011:23; Kiropoulos & Bauer 2011:23) as well as the socio-cultural beliefs of the sub-saharan African communities including those prevalent in Kibale district, the study area (section 3.4) which categorise illnesses according to naturalistic and personalistic causes. Similar to sub-saharan community beliefs, for these immigrants, supernatural causes were magico-religious and metaphysical factors and natural causes included psychosis, depression, family, relationship and parenting problems.

### 6.7.1.1. Ebola as supernatural occurrence

Participants subscribed to the “supernatural” theory blamed satanic or evil spirits; punishment by deities and “bad” others; familial disagreements; and witchcraft, charm or sorcery for the outbreak as illustrated with specific example in data display 6.6.1.1.

#### 6.7.1.1.1. Ebola: result of satanic attack or evil spirits

The theory that equated Ebola to “satanic or evil spirit attack” was particularly prevalent in the early days of the epidemic, where it resulted in mysterious deaths. The community explained the cause of the illness as being the work of satanic or evil spirits, from unknown places or who had been sent by “bad” people as explained:

We thought they had been attacked by “bulogo” or “amahembe” a satanic entity. It was widely believed the affected families were targeted by someone with satanic powers who wanted to finish them off (Data: 70).

This observation is akin to a study on stigma and explanatory models among people with schizophrenia and their relatives in Vellore, South India (Charles, Manoranjitham, Jacob 2007:329) which found that many locals considered the cause of schizophrenia as the work of evil spirits, karma and black magic. This view also compares well with the spiritual explanation of dementia held by many Muslim populations especially in the Middle East (Hussain 2001:6), where they attribute the changes in older persons’ behaviour and functioning as a product of spiritual forces.

In elucidating this explanatory model further, Downs, Clare and Mackenzie (2006:238) quote Hussain (2001) as describing that in many Muslim communities it is believed that illness can occur when a person is possessed by “*jinn*”, an ubiquitous semi-human spirit (Hussain 2001:6; Downs et al 2006:238), an argument that compares well with the beliefs held Ebola by communities in the sub-saharan Africa.

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**DATA DISPLAY 6.6.1.1**
**THEME 6: SOCIAL-CULTURAL BELIEFS AND PRACTICES RELATED TO EBOLA**
**CATEGORY 1: EXPLANATORY MODELS OF CAUSATION**
**SUB-CATEGORY 1: EBOLA AS SUPERNATURAL OCCURRENCE**


---

**Ebola: result of satanic or evil spirit attack (Data Display 6.6.1.1.1).**

- We thought they had been attacked by “bulogo” or “amahembe” a satanic entity. It was widely believed the affected families were targeted by someone with satanic powers who wanted to finish them off (Data: 70).
- After the fever treatment failed using the usual medications, we thought that the illness could have a spiritual aspect to it, may be the work of Satan... (Data: 243).
- Initially, our thoughts settled on the work of evil powers...because of the circumstances under which the young baby died. The baby was put to sleep before they left for the garden (Data: 265).

**Ebola: result of punishment by deities and “evil” others (Data Display 6.6.1.1.2).**

- The community widely believed that the family had been involved in something wrong or evil. So people here initially thought “Ebola” had been sent to the wrongdoers (Data: 17).
- So when the mysterious illness struck, we were convinced the in-laws had sent evil spirits to cause our family trouble as they had promised (Data: 74).

**Ebola: result of inter and intra familial disagreements or feuds (Data Display 6.6.1.1.3).**

- The community believed the first family to be affected might have had problems with other people, and so these people might have been the one causing them problems (Data: 24).
- ...we thought these were satanic attacks, being the work of evil spirits sent by enemies of our family or evil doers ...[especially] my brother’s parents-in-law because of...an on-going feud between us (Data:76).
- ...but as the unexplained ailments and deaths continued, we began to suspect witchcraft as being the motif behind the deaths. It became clear to us that we were being targeted by enemies (Data: 288).

**Ebola: result of witchcraft, charm, sorcery and magic (Data Display 6.6.1.1.4)**

- A number of them believed the disease was not Ebola but rather magic (Data: 139).
  - At the beginning, people associated the illness with witchcraft... [and believed that] if some touched those patients...who had been attacked by some witchcraft... they would get the disease (Data:172).
  - Some thought she was bewitched, while others said she had been poisoned (Data: 222).
- 

**6.7.1.1.2. Ebola: result of punishment by deities and evil others**

As highlighted in data display 6.6.1.1.2, participants also pointed out that Ebola arose as a result of punishment being unleashed on families who were involved in wrong doing. When a person or family failed to meet certain social or cultural obligations, it was thought that they could suffer affliction as a punitive consequence mediated by deities or evil humans working through spiritual actors as this participant affirmed:

The community widely believed that the family had been involved in something wrong or evil.

So people here initially thought “Ebola” had been sent to the wrongdoers (Data: 17).

The belief that life-threatening illness can be a form of punishment by deities played out in Gulu, Uganda, during the 2000/2001 Ebola outbreak, where the mysterious disease, hitherto unknown to the locals, resulted in them “categorising” it as the work

of “*Jok*”, which is a term reserved for potent spirits or gods among the Acholi of northern Uganda (Hewlett & Amola 2003:1243; Hewlett & Hewlett 2005:292). Although, *Jok* are benevolent, but they can also cause harm if they get offended by acts of misbehaviour which may upset the deities including not listening to them and not showing them respect as expected (Hewlett & Amola 2003:1243; Hewlett & Hewlett 2005:292), implying that “angry” *jok* may unleash illness on affected people.

Similar arguments for the central role of deities or metaphysical powers in disease causation is documented by Kiropoulos and Bauer (2011:23) when they quote Minas et al’s (2007) study which found that much like their Greek and Italian counterparts, many Turkish immigrants to Australia too, held the belief that magico-religious and metaphysical factors, occupied a central place in explaining the origin of mental illness (Kiropoulos & Bauer 2011:23-24). A similar view of the role of deities using disease to punish transgressors has been found among some Chinese communities who believe that a man who has a sexual encounter with a prostitute may end up with leprosy as a punishment for their moral lapse (Skinsnes 1964, as cited in Wong & Subramanian 2002:88). These views regarding disease causation are comparable to the role of “deities” ascribed to by survivors and family caregivers in Kibale district.

#### **6.7.1.1.3. Ebola: result of familial disagreements or feuds**

As presented in data display 6.6.1.1.3, participants also explained that another “cause” of the mysterious disease which was later confirmed to be Ebola was the outcome of intra and inter family disagreements and feuds. A peculiar aspect of this model was that the aggrieved family was believed to have sent satanic attacks to avenge themselves on the affected family. This model explained the use of spiritual actors such as ‘*amahembe*’ (satanic entity) to cause disease to offending families. Similar experiences where families or others have been accused of sending out malevolently interfering “waves” causing disease are so entrenched in many communities across the non-western world. According to Mills (2013:23), the existence of indigenous terminology to describe such malevolent interference “waves” implies their deep rooted nature in these societies. For instance the Zande in South Sudan term it “*mangu*”, the Sotho in Northern Lesotho, call it “*loya*”, the Ladakhi, who live in the rural valleys of Ladakh in the Western Himalayan ranges of

India, refer to it as “*gnodpa*”. The centrality of these negative, “energies”, is that “jealous” or “bad” people, either as wizards or witches can use them to “send” mysterious disease to afflict others, either innocently or in retaliation for their wrong doing (Wong & Subramaniam 2002: 88; Charles et al 2007: 329; Mills 2013: 23).

#### **6.7.1.1.4. Ebola: result of bewitchment, charm or sorcery**

Most participants described that early in the epidemic; most people believed that Ebola was a form of witchcraft, especially when the fever and vomiting, the early signs and symptoms of the infection could not respond to the established fever treatment, both known herbal and western remedies. As highlighted in data display 6.6.1.1.4, the locals in Kibale district, where the study was conducted, firmly believed that the mysterious deaths were due to charm, sorcery or even magic. In their systematic review on the socio-cultural issues related to leprosy control and management, Wong and Subramaniam (2002:88-89) found that leprosy, an infectious disease that is also highly feared by communities worldwide labelled it a disease caused by witchcraft, charm, black magic, or curse. These views were found to be closely knit cultural belief systems among communities in Africa and South Asia.

In yet another study, in Vellore, South India, Charles et al (2007:329) found that the communities there considered the cause of schizophrenia as “karma”, “witchcraft” or “black magic”, which views are comparable to that of communities in Kibale over Ebola. In Masindi, Uganda, Borchert, Mutyaba, Van Kerkhove, Lutwama, Luwaga, Bisoborwa, Turyagaruka, Pirard, Ndayimirije, Roddy and Van Der Stuyft (2011:13) recently reported that during the 2000/2001 Ebola outbreak, due to uneasy neighbourliness, an immigrant family firmly believed that they had been charmed when they got an Ebola infection. This family rejected the notion of infection transmission; instead the “poisoning” theory gained plausibility because the locals who lived among the index family remained unaffected. Since the notion of poisoning is widespread in sub-Saharan Africa, Borchert et al (2011:13) argues that such allegations of poisoning often become highly believable in the face of a mysterious illness, especially when disagreement exists among within affected communities. This is affirmation reinforces one of the claims reported during the July 2012 Ebola outbreak in Kibale district where the index family blamed their in-laws for the deaths.

### 6.7.1.2. Ebola as a natural occurring disease

The findings show that in initial stages, most people believed that the mysterious illness was caused by “supernatural” forces; however, as the disease spread further, participants reported that many members of their community began to embrace the “natural” explanatory model, especially after confirmation of the outbreak. However, despite confirming Ebola virus, as the cause of the disease that spreads through contact from one person to another, some continued to hold Ebola as a product of supernatural forces. Whilst this opinion persisted, most people became convinced that Ebola was a naturally occurring disease as summarised in data display 6.6.1.2.

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**DATA DISPLAY 6.6.1.2**  
**THEME 6: SOCIAL-CULTURAL BELIEFS AND PRACTICES RELATED TO EBOLA**  
**CATEGORY 1: EXPLANATORY MODELS OF CAUSATION**  
**SUB-CATEGORY 2: EBOLA AS NATURAL DISEASE**

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**Ebola: a disease resulting from natural causes (Data Display 6.6.1.2.1).**

- Some thought it was severe malaria or diarrhoea... [and] others thought it was the usual nose bleeding that some people normally have (Data: 23).
- But for me Ebola is a real disease although many thought it was magic, although they couldn't explain the source of the magic (Data: 139).
- ...the medical personnel thought of conditions like cholera, because of copious diarrhoea. These rumours were particularly rife in the early days, before the confirmation of the outbreak... (Data: 185).
- When I was busy looking after my aunt and her child, people advanced numerous reasons for her death...others claimed her death was related to postnatal complications (Data: 222).

**Ebola: disease resulting from eating or having contact with wild animals (Data Display 6.6.1.2.2).**

- Some people said that Ebola came as a result of the affected persons eating monkeys. Others said they ate an infected pig (Data: 139).
  - Some from monkeys, while others said it was from the bats (Data: 185).
  - When I trace the origin of the illness, just before the outbreak occurred, the monkey population in the area had increased as well as rats and bats (Data: 288).
- 

In the initial stages of the outbreak, the community did not know what was causing these sudden and mysterious deaths of up to eight people in the same village. Those belonging to the “natural” causation model maintained Ebola was a normal disease, perhaps resistant or complicated fever (data display 6.6.1.2.1); while others believed it was a regular disease originating from infected wild animals contracted by humans by eating forbidden food or having contact with wild animals (data display 6.6.1.2.2).

#### **6.7.1.2.1. Ebola: disease that results from natural causes**

Whilst others thought Ebola was of “magical” origin, some people believed that the presenting signs and symptoms suggested that the illness was of “normal” disease picture that required treatment from established health outpost such as clinics and health centres and hospitals. The belief that Ebola patients had contracted a naturally occurring illness was buttressed by symptoms classical with severe malaria, cholera, epistaxis and delivery associated bleeding as summarised in data display 6.6.1.2.1.

Similar classification of Ebola as a “natural occurring illness” was also noted among the Acholi people during the 2000/2001 Ebola outbreak in Gulu, Uganda (Hewlett & Amola 2003:1243) as well as among the Mbeti, Mboko, Kota Mongome, Bakola tribes in the villages of Kéllé and Mbomo, in the Republic of Congo (RoC) (Hewlett & Hewlett 2005:292). In both areas, early in the epidemic began, villagers viewed it as regular illness and responded to the symptoms with known biomedical (tetracycline, pain killers, anti-malarials) and indigenous medicines (fever and diarrhoea herbs).

#### **6.7.1.2.2. Ebola: disease that results from eating wild animals**

As summarised in data display 6.6.1.2.2, some participants who considered Ebola as a natural disease believed it was a new illness that resulted from eating or having contact with or eating infected wild animals such as monkeys, rats, bats, pigs, and other rodents, which are a common source of meat in most local communities in Kibale area. For such people, Ebola was not “magical”, rather a normal disease like other established infectious diseases and advocated that those who got infected had to seek health care from established herbalists or take usual fever medications.

This observation is similar to what Hewlett and Amola (2003:1243) reported among the Acholi people during the 2000/2001 Ebola outbreak as well as the tribes in the villages of Kéllé and Mbomo in Congo during 2002/2003 Ebola outbreak (Hewlett & Hewlett 2005:292), where locals sought biomedical and herbal cures for treatment.

## 6.7.2. Practices to remedy Ebola epidemic

The practices participants reportedly used to deal with the onslaught of Ebola depended on whether they considered it as a product of “natural” or “supernatural” occurrence. Individuals who believed Ebola was a normal disease sought treatment from regular clinics and nearby health facilities hospitals to treat initial symptoms of the illness. However, those who believed Ebola had supernatural causes sought supernatural means to remedy the infection. A third group of community members, unsure of how to categorise Ebola, opted for both natural and supernatural remedies. In data display 6.6.2, various aspects of these explanatory models are demonstrated:

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### DATA DISPLAY 6.6.2.

#### THEME 6: SOCIAL-CULTURAL BELIEFS AND PRACTICES RELATED TO EBOLA CATEGORY 2: PRACTICES TO REMEDY EBOLA DISEASE

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##### Remedying Ebola through natural means (Data display 6.6.2.1).

- I started experiencing headache, fever, vomiting and diarrhoea. Immediately ..., I went for treatment...to the clinic; they tested my blood.... So I returned home and took a dose of antimalarial medication (Data: 26).
- When I fell sick I went for treatment immediately to a nearby clinic (Data: 75).
- As usual, we thought the fever was malaria, but then she tested negative for malarial parasites. Despite these negative blood smear results, she took some Coartem, an antimalarial medication (Data: 143).

##### Remedying Ebola through supernatural means (Data display 6.6.2.2).

- Initially starting off as an ordinary fever, the fever progressively became worse. I could not improve despite taking fever medication. So I decided to call a priest so that I could receive the sacraments for the sick before I went to hospital. So when they gave me the sacraments, I was firm (Data: 01).
- As prescribed by culture, when *Amahembe* is suspected, some people go to small gods, deities for consultations, while others go for regular prayers for healing. As for me, I went for treatment and regular prayers...several people prayed for me, when I was still at home, before...hospital (Data:18).
- The period following Ebola was very challenging for me ...I prayed to God that I may survive. In case I did not survive, I implored God to let me die alone, and save those who had cared for me... (Data 52).
- So when we concluded that the illness was caused by evil spirits which the in-laws could have sent, the whole family who were mostly sick were taken for prayers at 'Bisaaka's place at 'Kapiyemi (Data: 77).
- After the fever treatment failed using the usual medications, we thought that the illness ...may be the work of Satan or it could be related to witchcraft from others...so we decided to take the family members to the prayer palace so that they could receive healing from the spiritualist there (Data: 243).

##### Remedying Ebola through both natural and supernatural means (Data display 6.6.2.3).

- When I fell sick I went for treatment immediately to a nearby clinic. Then the following week...everybody at home started feeling ill...children and adults alike. We became convinced ... that evil spirits were causing these unusual ailments and deaths which had by now killed two members of the family... (Data: 75).
  - We even treated ourselves with the usual fever tablets and intravenous antimalarial medications at home....when the fever management failed...we decided to go for prayers and then later to hospital. So we decided to proceed to hospital to seek for further treatment (Data: 110).
  - Initially we thought this strange disease was Malaria, so we treated everything related to the fever using the locally known remedies and even using regular malaria treatment at a nearby clinic (Data: 241).
-

### 6.7.2.1. Remediating Ebola through natural means

As illustrated in data display 6.6.2.1, some participants reported that early in the epidemic, they sought treatment from regular clinics and hospitals when they began to experience symptoms of ill-health notably headache, diarrhoea and fever. This choice of biomedically operated clinics and hospitals as first line of treatment was underpinned on their belief that Ebola was a normal illness and that established treatment regimen were the most appropriate method to deal with the illness as articulated in section 6.7.1.2.1. In Kibale, much like in Gulu and Mbomo communities, when locals classified Ebola as a “natural” occurring illness, they treated the ensuing symptoms using locally established biomedical and indigenous treatment for fever, diarrhoea and vomiting. This observation agrees with the reactions of the Acholi peoples during the 2000/2001 Ebola outbreak in Gulu, Uganda (Hewlett & Amola 2003:1243) and Kéllé and Mbomo tribal communities, in the Republic of the Congo (RoC) (Hewlett & Hewlett 2005:292). Similar use of medical facilities for treatment of life threatening and a highly stigmatising condition has been documented by Charles and colleagues (2007:329) when they studied explanatory models of schizophrenia in a community in Vellore, India. The researchers documented that where individuals and families explained schizophrenia as a regular disease, they sought and utilised health care services from established medical facilities such as clinics and hospitals.

### 6.7.2.2. Remediating Ebola through supernatural means

While some participants sought natural means to rid themselves of the signs and symptoms of what became Ebola, others decided to seek supernatural remedies, from established places of worship such as churches, mosques, and healing palaces operated by locally revered prophets and prophetesses and spiritualists and healers.

When “*Amahembe*”, (*witchcraft, charm*) is suspected, some people go to small gods, deities for consultations, while others go for regular [church/mosque type] prayers for healing....(Data:18).

As illustrated in data display 6.6.2.2, for most participants, seeking supernatural treatment was especially relevant when they perceived the cause of the mysterious illness as being supernatural factors such as charms from enemies, curses from neighbours or black magic being sent from bad people, in some cases from in-laws.

Similar use of supernatural means: prayer, charm removal and the like as a trusted remedy has been documented among Vietnamese. Phan and Silvoe (1999) as cited in Niemi, Falkenberg, Nguyen, Nguyen, Patel and Faxelid (2010:30) found that families sought healthcare for mental illness from traditional Vietnamese and Chinese medicine sources, a practice analogous to witchcraft, spiritual blessing and sorcery.

Even the local tribes of Kéllé and Mbomo, in the Republic of Congo sought similar supernatural means during 2002/2003 Ebola outbreak when deaths continued, despite the natural remedies. Hewlett and Hewlett (2005:292) note that when the natural remedies failed to stop the deaths, the locals began to attribute the deaths to sorcery, locally termed “*ekundu*”. With this classification, they sought spiritual means which involved getting a traditional healer to identify and destroy the source of the “negative energy” placed by a sorcerer, after which affected persons’ would improve.

#### **6.7.2.3. Remedying Ebola through both natural and supernatural means**

As articulated in data display 6.6.2.3, some participants reported having sought assistance against the Ebola outbreak simultaneously from both natural and supernatural means. Upon becoming ill, some families, although convinced the strange illness could be due to “supernatural” factors associated with evil spirit and witchcraft, they also sought help from established biomedical sources to deal with the symptoms of the illness. In effect, they consulted both supernatural remedies like spiritual healers, prophets, prophetesses, witchdoctors, as well as drug shops, clinics and hospitals where they received biomedical remedies like antimalarials and antibiotics. In explaining rationale for the “double sided action”, a participant noted:

We even treated ourselves with the usual fever tablets and intravenous antimalarial medications at home....when the fever management failed...we decided to go for prayers and then later to hospital. So we decided to proceed to hospital to seek for further treatment (Data: 110).

Similar instances where communities seek treatment from both natural and supernatural sources has been documented among the Acholi of Gulu, Uganda as well as the tribes of Kéllé and Mbomo, in the RoC during 2000/2001 and 2002/2003 Ebola outbreaks respectively. Hewlett and Hewlett (2005:292) explain that such a model of using several cultural models to guide treatment is not uncommon in both

countries, especially where health workers like members of their local community subscribe to both spiritual remedies (healing, rituals, cleansing remedies) as well as biomedical approaches (tetracycline, antimalarial use) to treat illness. It was clear from the findings that there was fluid movement between the “natural” explanatory model and the “supernatural” explanatory model of disease causation and this consequently influenced how individuals understood and treated an Ebola outbreak.

The use of multiple explanatory modes for understanding illness experiences and guiding treatment have also been documented among people with schizophrenia and their relatives in Vellore, South India (Charles, et al 2007:329; Johnson, et al 2012:2); South Asian immigrants in Chicago, USA (Tirodkar et al 2011:386); as well as among indigenous tribes in central, western and northern Uganda (Okello & Neema 2007:15). This “eclectic” explanatory model of health, which values both spiritual model of causation as well as the bio-psycho-social model of causation seems to be a widely practised paradigm in many societies in Africa, Asia, Middle East (Charles et al 2007:329; Okello & Neema 2007:15; Tirodkar et al 2011:386), as well as in some of the western populations (McCabe & Priebe 2004:29-3; Johnson et al 2011:2-4).

## **6.8. COPING WITH AND LIVING IN THE AFTERMATH OF EBOLA**

As explained in section 6.3, the physical, psychological, social, spiritual and economic consequences of living with or under constant threat of life threatening illness like Ebola creates a burden that affected persons; as survivors, caregivers and families have to withstand and live through buttressed by what is termed, “coping”. The capacity to stand “strong” leads such persons to sail through a traumatic event with minimum consequences. Lazarus and Folkman (1984:141) much like Bowman, Deimling, Smerglia, Sage and Kahana (2003:227) contend that, before individuals adopt their particular coping strategy, they usually first judge the situation in terms of how it can be controlled, especially the degree of challenge or its felt negativity.

When an event is appraised to have damaging consequences, then the individual unleashes the coping process (Lazarus & Folkman 1984, cited in Manne 2007:192) consisting of one or more strategies depending on whether or not the stressor is

appraised as controllable. Where the stressor is considered “manageable” then the individual adopts a “problem-focused” coping strategy, intended to resolve the problem among others which consists of information seeking, looking for instrumental support, and problem-solving efforts. In contrast, when appraised as uncontrollable, individuals may choose an emotion-focused coping strategy, involving altering their emotional response to the presence of the stressor, through acceptance, positive reappraisal, distancing, avoidance and seeking emotional support without attempting to change the situation itself (Lazarus & Folkman 1984, in Manne 2007:192). The specific coping strategies survivor and caregivers used to deal with the negative consequences of the Ebola outbreak are highlighted in data display 6.7.

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**DATA DISPLAY 6.7**  
**THEME 7: COPING WITH AND LIVING THE AFTERMATH OF EBOLA OUTBREAKS**  
**SUMMARY**

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1. Battling to overcome associated challenges (Data Display 6.7.1).
  2. Engaging in fervent prayers and religiosity (Data Display 6.7.2).
  3. Seeking support from caring others (Data Display 6.7.3).
  4. Optimism and positive attitude (Data Display 6.7.4).
  5. Surrendering and accepting fate (Data Display 6.7.5).
  6. Avoidance, distancing and withdrawing (Data Display 6.7.6).
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### 6.8.1. Battling to overcome associated challenges

As exemplified in data display 6.7.1 by the verbatim quotes, engaging in “battles” to overcome the Ebola relate challenges was raised by participants as being an important strategy that enabled them deal with the negative consequences of Ebola.

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**DATA DISPLAY 6.7.1**  
**THEME 7: COPING WITH AND LIVING THE AFTERMATH OF EBOLA OUTBREAKS**  
**CATEGORY 1: BATTLING TO OVERCOME ASSOCIATED CHALLENGES**

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- I could not improve despite taking fever medication...I decided to call a priest so that I could receive the sacraments for the sick...when they gave me the sacrament, I was firm... (Data: 1).
  - When I could not bear feeling lonely any more, I decided to pull down the empty houses. The empty houses were a constant reminder of my loss...So I decided to demolish the empty houses... (Data: 109).
  - As we feared and panicked about...death, we kept together as a family...We continued to take necessary precautions, like washing our hands...and using antinfective materials like Jik... (Data: 256).
- 

Because the advent of Ebola was associated with negativity, many survivors and caregivers found strength in “facing” the sickness and the associated consequences “head on”, by engaging in activities that were perceived to lessen the physical and

the psychological pain associated with the infection, such as destroying artefacts that would remind them of their tragedy (Data 109). This “battle” to overcome the stress of Ebola and redeem self, which some participants engaged in is consistent with what Hoffman, Lent, and Raque-Bogdan (2013:247) describe as “coping appraisal”, a process which begins by the affected evaluating the nature of the stressor, to determine whether they have the “essential” capabilities and resources to deal with it. The appraisal involves seeking information about treatment options, likelihood of their success, availability of supporting resources like finances as well as social support to assess whether they can meet the threat (Hoffman et al 2013:247). It is after this appraisal that affected persons decide to engage in either “problem-focused or emotion-focused coping” strategy (Manne 2007:193; Hoffman et al 2013:248-250).

### **6.8.2. Engaging in fervent prayers and increased religiosity**

As exemplified by quotes in data display 6.7.2, participants reported that engaging in fervent prayer and religious activities facilitated their journey of coping with fear, anxiety, social isolation and the widespread stigma they had to face from others.

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**DATA DISPLAY 6.7.2**  
**THEME 7: COPING WITH AND LIVING THE AFTERMATH OF EBOLA OUTBREAKS**  
**CATEGORY 2: FERVENT PRAYERS AND INCREASED RELIGIOSITY**

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- I resorted to prayers to make me strong and move on... I used to pray to God that the people who had touched me should not die... I also prayed to God that I may survive. In case I did not survive, I implored God to let me die alone, and save those who had cared for me (Data: 52).
  - I was also able to live through...the challenges by embarking on singing religious songs and being active in serving God in our local church. This new way of life really improved my life by taking away all the pain and agony that I had before. It became my new way of living after... (Data: 226).
  - What gave me strength during these difficult moments when I lost many of my relatives...know that God is present. I would pray to God asking him to preserve us now that other family members had already perished. I would ask God to keep members of my family alive (Data: 237).
- 

The use of prayer to overcome challenges associated with life-altering conditions has been found to help patients, survivors and their families overcome the associated stress. In a study involving patients scheduled to undergo operations due to advanced stages of cardiac disease, Ai, Ladd, Peterson, Cook, Shearer and Koenig (2010:799) found prayer was a unique coping resource for these patients undergoing health crises. Quoting James (1958), Ai et al (2010:799) claim that the positive effect of prayer during coping in crises may be due to the psychological effect it has on the

practitioner. As affirmed by James (1901-1958:352) and explicated by Ai and others (2010:799), prayer involves inward communion or conversation with a divine power and is the soul and essence of religion. Therefore, prayer helps the practitioner find comfort from the sacred interconnectedness in one's faith or a sense of meaning in the midst of distress (Ai, Tice & Kelsey 2009, in Ai et al 2010:799). Such connectedness improves health-related well-being including adjustment to illness experience (Levin 2004:70) and tends to be associated with a more positive attitude (Ai, Peterson, Tice & Koenig 2005:24) and reduced depression (Ai et al 2010: 803).

### 6.8.3. Seeking support from caring others

As emphasised in data display 6.7.3, seeking support from caring others, whether relatives or friends, particularly support that is perceived to be instrumental to facilitate wellbeing including to “win the battle against ostracism and social rejection”, was found to be an important coping strategy by all survivors and family caregivers.

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**DATA DISPLAY 6.7.3**  
**THEME 7: COPING WITH AND LIVING THE AFTERMATH OF EBOLA OUTBREAKS**  
**CATEGORY 3: SEEKING SUPPORT FROM CARING OTHERS**

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- My relatives played a great role in caring for me during the illness, especially in filling the gaps where the health workers were absent or unwilling. When my hopes seemed to fade away, my sister assured me that I should not worry, she would take care of me. My husband was really supportive (Data: 32).
  - Also when I started seeing people coming back to me and not fear me anymore, I became relieved... Even what strengthened me further were the moments when I would go to church and people were no longer afraid of me anymore; I started forgetting about the disease and living a normal life (Data:71).
  - What has helped me to live a normal life despite all these difficulties was the love from my parents. My parents kept comforting me and supporting me every day. They kept encouraging me... (Data: 224).
  - What helped me to live through the period of quarantine and isolation was the counselling and support, I received from the health workers...they would counsel us and encourage us to be strong (Data: 268).
- 

These findings are consistent those of a study conducted among Iranian cancer patients where it was discovered that one of the resources used by patients to cope with the challenges of cancer is their social relationships with family members, spouses, friends, and even health care professionals (Rahnama, Khoshknab, Maddah & Ahmadi 2012:5). Similar findings elucidating vitality of physical and emotional support are documented by Seçkin (2013:97) in a study on cancer patients receiving web based social support. The findings revealed that the e-support increased their perceived control over cancer and led to higher levels of satisfaction.

Trimble, Hannigan and Gaffney (2012:118) also found that professional support services especially use of support groups helped family members of suicide victims to cope with their bereavement experience. The social support helped them to express their feelings, to feel accepted and to share own stories. It also provided them an avenue to hear stories of others, which enabled them to contextualise, normalise and understand, own feelings which is key to effective coping (Trimble et al 2012:118).

#### **6.8.4. Being optimistic and having positive attitude**

Participants explained, as stressed in data display 6.7.4, that being optimistic and positive, even in the face of several challenges associated with Ebola infection was an effective strategy, because it enabled survivors and caregivers to transcend the suffering experience and reclaim their well-being with minimum of consequences. Herein, positive attitude is expressed in terms of firmness, strength and hopefulness.

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**DATA DISPLAY 6.7.4**  
**THEME 7: COPING WITH AND LIVING THE AFTERMATH OF EBOLA OUTBREAKS**  
**CATEGORY 4: BEING OPTIMISTIC AND HAVING POSITIVE ATTITUDE**

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- By the time I regained my consciousness...I did not even fear death. Neither was I worried that I had been diagnosed with Ebola and that I may die. I was firm. I was not afraid...(Data: 9).
  - When we were being shunned ...I had to stand strong even in difficult circumstances (Data: 105).
  - When I realised that the neighbours and relatives were not comfortable with us and had stopped associating with us...we decided to remain strong. I had to develop a strong heart (Data: 113).
  - I decided to have a strong heart. I told myself, that I would stay regardless of the circumstances...these sons and daughters who died were my biological children. I had to be a strong woman (Data: 114).
- 

Adopting a positive attitude and being optimistic in the face of life-threatening illness have been demonstrated to have beneficial results by Coyne and Tennen (2010:2). In a recent systematic review, Coyne and Tennen (2010:2) discovered that having a positive attitude in the face of challenge helps the affected person adapt better (Fredrickson 2001:219) and helps the sufferer's previously unrealised resilience to emerge following adversity (Bonanno 2004:20; Zautra, Johnson & Davis 2005:212). Similarly, Ai, Peterson, Tice and Koenig (2005:48) found that having positive attitude during medical emergencies and life threatening situations builds sufferers' level of optimism and this tends to increase their interest and willingness to survive and overcome the negative consequences of the illness. This sense of optimism is often described as "hardiness" and enables better adaptation to life-threatening situations (Dewar & Lee 2000:914). This was noted to increase participants' resilience to Ebola.

### 6.8.5. Surrendering and accepting their fate

Surrendering and accepting their situation of entrapment was noted to have a unique positive effect on survivors and caregivers, particularly in helping them cope with their distress. Coming to terms with the inescapability of the deleterious consequences of Ebola helped survivors and caregivers to devise strategies that facilitated their coping efforts and to live meaningfully in the aftermath despite the ostracism and social stigma. In data display 6.7.5, quotes illuminate how participants accepted their fate.

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**DATA DISPLAY 6.7.5**  
**THEME 7: COPING WITH AND LIVING THE AFTERMATH OF EBOLA OUTBREAKS**  
**CATEGORY 5: SURRENDERING AND ACCEPTING THEIR FATE**

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- One of the best things I got to know after the death of my relatives was that dying is normal. So, I knew that I would die anytime. As time went on, I got used to the situation (Data: 85).
  - I could think about my brothers and sisters who died including the babies we lost...this is when I realised everybody is going to die, so we just accepted our situation (Data: 86).
  - Although people behaved unfamiliarly to me and my family members, it did not affect me so much because I knew what they were going through (Data:161).
  - I realised that I had been exposed; I said to myself, I now have nothing to do. I told myself, since there was now nothing much I could do...I need to be strong and face what comes my way (Data: 208).
  - Whilst people continued to run away from us, we decided not to mind so much about it, instead, we would just stayed home and waited to see what would happen to us next,... (Data: 286).
- 

Alberts, Schneider and Martijn (2012:864) point out that acceptance of sufferers' situation during crises helps individuals to cope better because it changes their relationships and attitude towards the usually negative feelings that accompany such crises. In fact Bishop (2002) as noted in Alberts et al (2012:864) explains that acceptance helps individual to adopt a non-judgemental attitude toward their emotions, and with time this "flexibility" enables them to adapt to uncomfortable emotions triggered by the traumatic situation, which helps to increase their resilience.

Likewise, Kranz, Bollinger and Nilges (2010:1022) in a study involving patients with chronic pain, found that acceptance plays an important role in coping with pain. The researchers claim that patients who reported greater acceptance of pain also reported less pain-related suffering: reduced anxiety and depression levels and tended to do better in activities of daily living. Acceptance resulted in affective well-being as patients were more likely to disengage from aspirations to get rid of their pain, instead to learn to live with it and reorient their goals beyond pain reduction.

### 6.8.6. Avoidance, distancing and withdrawing

As illuminated in data display 6.7.6, participants reported that they were able to cope with the aftermath of Ebola by avoiding, distancing themselves from or withdrawing from situations they perceived as stressful or that reminded them of their suffering. These efforts which may be categorised as “avoidance coping” mechanisms included keeping busy, refusing to focus on experience and withdrawing from other people.

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**DATA DISPLAY 6.7.6**  
**THEME 7: COPING WITH AND LIVING THE AFTERMATH OF EBOLA OUTBREAKS**  
**CATEGORY 6: AVOIDANCE, DISTANCING AND WITHDRAWING**

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- Another source of strength ... was spending time in the hospital and keeping busy...I would go home when it was already dark, already tired, and ready to sleep. So keeping busy helped us (Data: 176).
  - These days...I no longer worry about people in the neighbourhood any more, refusing to associate with us. I try not to think too much about Ebola...the past because Ebola is a very serious thing (Data: 248).
  - What helped us when most people did not want to associate with us especially when they avoided us was to keep indoors most times.... I decided to just kept home and relax (Data: 84).
  - Another thing that helped me to withstand the pressure of seeing people running away from me was to minimise my movements outside of the home...I withdrew and stayed alone at my home (Data: 204).
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Similar use of “avoidance” or “distraction” techniques in coping has been documented by Read, Kinali, Muntoni, Weaver and Garralda (2011:24) in a study involving siblings of young people with Duchenne muscular dystrophy where they found that siblings often chose to avoid realities of the illness by removing themselves from difficult situations. The use of “distraction” and “suppression” to cope with stressful situations has also been highlighted following a study conducted among refugee youths from South Sudan who were resettled in the USA. The study revealed that suppression of traumatic memories and associated feelings was used in addition to distraction in minimising opportunities for negative thoughts and feelings (Goodman 2004:1184).

While these avoidance coping strategies may have positive results in the short run, by helping the sufferer manage to “ward off” the intrusive symptoms associated with the stressful situation, in the long run it is negative because it interferes with more concrete efforts to enhance resilience and health outcomes (Filipas & Ullman 2006:654). In a study involving caregivers of patients with Huntington’s disease, one of the negative effects of avoidance coping revealed was that it falsely portrayed caregivers as not needing help which was contrary to the whole truth. This led to

significant reduction in the “quality” and “quantity” of family support to caregivers and this negatively affected their wellbeing in the long run (Lowit & van Teijlingen 2005:7).

## **6.9. CONCLUSION**

In this chapter, data presentation with themes, categories, subcategories and sub-subcategories were presented with literature support. The following themes emerged:

- Living under constant threat of Ebola
- Nature of Ebola experience: unique and general meanings
- Surviving Ebola: physical, psycho-social, spiritual, economic implications
- Caring for Ebola patients: social and psychological implications
- Public reaction toward persons affected by Ebola
- Social-cultural beliefs and practices related to Ebola
- Coping with and living in the aftermath of Ebola outbreaks

These seven themes led to a deeper understanding of the “phenomenon of living in constant anticipation of an Ebola outbreak. In chapter 8, the central construct of “adaptation” that emerged from the themes and supporting categories, subcategories and sub-subcategories are discussed in relation to nursing and non-nursing theories.

## **CHAPTER 7: RELATING EMERGENT CONSTRUCTS TO EXISTING THEORIES**

### **7.1. INTRODUCTION**

In this chapter, as recommended in Wertz (2011:160); “adaptation” is discussed as the single most encompassing and general “structure” of the experience of “living in constant anticipation of Ebola”; a structure most accommodative of the themes and categories relating to participants’ lived experiences. The concept of “adaptation” arose from interpretation of the themes and categories derived in Chapter 6 in line with the recommendations of Wertz (2011:160). The exposition of a single encompassing construct is also congruent with tenets of interpretive phenomenology (Ricoeur 1990, as explained in Terra et al 2009: 95; Bäckström & Sundin 2007: 244).

The Merriam-Webster Online Dictionary (2014:1) defines “adaptation” as a modification of an organism or its parts that make it more fit for existence under the conditions of its environment”. Linley (2003:601) adds that “adaptations” represent a homeostatic return to a baseline of pre-trauma functioning” and likens it to a “springboard” that propels the survivor to a higher level of functioning than that which they held previously. However, this understanding of adaptation should not be taken to imply that nothing has been lost as a result of the traumatic experience, but rather that the persons involved have the capacity to bounce back and live “near normal life” after the traumatic event (Linley 2003:601). In other words, adaptation should be perceived to involve adjustments or transformations a person or a group makes in response to actual or potential undesirable changes and their consequences on their life ways. I propose “adaptation” should be understood as on-going transformations survivors and caregivers underwent that enabled them to cope and live with their changed realities following an Ebola outbreak (among them rejection, ostracism and stigma) and being critically aware of the threat of pending future Ebola outbreaks.

When survivors and caregivers adapt effectively to the stressors related to their association with Ebola, it is expected that their resilience to such outbreaks in future should increase. In the context of this study, resilience should be understood to

denote “bouncing back” or “rebounding” following adversity. It should be understood in relation to the concepts of resistance, adaptation, coping, hope, growth and recovery. In other words, after adapting effectively to Ebola either innately or through family and community support efforts, it is anticipated that the people in the Ebola prone areas will then develop the ability to resist, cope, recover, and succeed better in the face of adverse experiences such as an Ebola outbreak and the accompanying mass social reaction to it. The knowledge gained through deeper understandings of peoples’ adaptive modes can be used to enable individuals to become resilient by taking on an active role in confronting such an adverse event and over time even learn to adapt to, and live with, the reality of such an unpleasant occurrence; eventually integrating the reality of the event into their lives (Reich 2006:793; De Santis 2008:282; Davydov et al 2010:481). Understanding adaptation is critical to recommend appropriate interventions that may address the unmet needs of individuals who may encounter similar life threatening conditions. I arrived at “adaptation”, after working through several layers of individual, typical and general aspects of the experiences of participants’ (data) during both the idiographic and nomothetic phases of data analysis. While considering adaptation as accommodative concept, I concentrated on what the different texts were saying and what they conveyed (Ricoeur 1976, cited in Bäckström & Sundin 2007:244). This proved essential to arrive at a general description (knowledge) of participant’s lived experiences, which is foundational to phenomenological research (Wertz 2011:150).

Adaptation the unifying concept threads through various data units, sub-categories, categories and the main themes as articulated in chapter six. Upon careful introspection and synthesis, adaptation emerged as key praxis in support of all the data displays and the main themes arrived at in chapter 6 (data displays 6.1 to 6.7). In this chapter, I discuss the research findings in terms of the Roy’s Adaptation Model (RAM) (Roy 1984; Roy & Andrews 1999; Roy & Zhan 2001), an established theoretical framework in nursing. This discussion and integration are consistent with the “theory generating and development” aims of qualitative research, which according to Strong (2013:506) and Creswell (2014:65) begins with the researcher gathering data, categorising the data into themes and eventually coming up with generalisations that are compared with existing knowledge in literature through a

reflective and interpretive approach. This largely inductive approach (of moving from small parts to broad generalisations) results in general explanations which the researcher can use to challenge existing theory and inspire new theory development (Strong 2013:506; Creswell 2014: 65). Relating study findings to existing knowledge also helps to demonstrate transferability of results which again is an indication of the trustworthiness of the research results (Polit & Beck 2010:326; Creswell 2014:206). The concept of “adaptation” is thus intended to serve as a point of reference through which the study findings can be supported and further articulated to increase understanding of the Ebola experience and to promote transferability of the findings.

Further, the recommendations (refer to chapter 8) of the study which focus on reducing survivors’ and caregivers’ vulnerability during Ebola outbreaks and the community’s salient fear in-between outbreaks, are also articulated on the understanding of adaptation, including how the different adaptive modes can be nurtured to increase the resilience of individuals, families and the community at large. The notion of adaptation is central to survivors’ and caregivers’ very existence and wellbeing. Survivors and caregivers, as adaptive beings, responded in various ways (refer to data display 6.1.2) with some battling to overcome associated challenges of being linked to Ebola outbreak (refer to data display 6.7.1) while others learned to cope with the realities of the illness and recovered from the negative effects of the outbreak (refer to data display 6.2.3). Others still transcended this experience and realised positive outcomes (refer to data display 6.2.2). In addition to the structure that the RAM provided, the different stimuli demanding the individual to adapt to as revealed by the current research, are also theoretically illuminated using other relevant frameworks from the disciplines of social-psychology and psychology.

## **7.2. RELATING ADAPTATION TO EXISTING THEORIES**

Relating the data to existing theory is consistent with the views of Creswell (2014: 65) who observes that in qualitative studies such as the present study, where the aim is to arrive at broad description and explanation of a particular phenomenon, relating the study findings to existing models or theories helps the researcher to arrive at some point of coherence; interconnecting thoughts and linking parts to the whole

(Creswell 2014:66). To further explicate the findings, the all-encompassing concept of adaptation is discussed in relation to three (3) theoretical constructs: the widely used Roy Adaptation Model (RAM) in nursing (refer to section 7.2.1) and the Social Identity Theory (SIT), (refer to section 7.2.2) and the Labelling Theory (LT) (refer to section 7.2.3), from the social science disciplines. A discussion of the prominent features of each theoretical framework and how they contribute to a better understanding of the adaptation processes in the context of the Ebola survivors and caregivers follows.

### **7.2.1. THE ROY ADAPTATION MODEL (RAM)**

As indicate previously the RAM is a well-researched and utilised model in the discipline and practice of nursing. The broad nature of the model accommodates all the themes and categories arrived at during the initial data analysis (see Chapter 6).

#### **7.2.1.1. Introduction and overview**

The RAM has been used in many areas of research using various research designs to understand human adaptation and how professional health care can facilitate individuals' and groups' (including families') adaptation to challenging phenomena (Fawcett & Frederickson 2009:3). In affirmation, Clarke, Barone, Hanna and Senesac (2011:343) contend that the RAM has become one of the most frequently used nursing models in nursing research, practice, and education because it outlines a generic process of adaptation that nurses and other caregivers can use in any situation where a patient encounters any change in their lived realities. The comprehensive nature of this model allows for utilisation of a single model with a set of concepts and terms, no matter what the clinical condition, level of care, composition of the particular clinical team, relevant stimuli or the level of adaptation and outcomes at any point in time (Clarke, Barone, Hanna & Senesac 2011:343).

The Roy Adaptation Model, according to Perrett and Biley (2013:337), was constructed in the 1970s and a major redefinition of its concepts followed in 1997. The RAM's original scientific assumptions were based on Von Bertalanffy's (1968) General Systems Theory as well as Helson's (1964) Adaptation-Level Theory and

was later expanded to include components that focus on the meaningfulness and unity of the universe (Hannon-Engel 2008:126). In this regard, within the context of the RAM, the individual is considered an open adaptive system made up of interrelated parts that function together in conjunction with the environment, resulting in a purposeful unified whole (Roy & Andrews 1999:30-31). The Systems theory posits that inputs (as stimuli) activate control (coping) mechanisms resulting in output (observable behaviour). In essence, RAM describes a person as an adaptive system that responds to stimuli, resulting in either adaptive (effective) or ineffective behavioural response (Roy & Andrews 1999:31; Phillips 2011:307; Dobratz 2014:53).

In the context of the current study, the stimuli being experienced by survivors (infected persons who survived Ebola) and as well as caregivers of Ebola patients are the constant threat of possible new outbreaks, fearing being re-infected as well as antisocial overtones like ostracism and stigma (Perrett & Biley 2013:337) that usually result from contracting Ebola or merely being associated with Ebola patients.

#### **7.2.1.2. The RAM's longevity and currency**

In 1995, the RAM guided De Haan's pretest-posttest quasi-experimental study to test an intervention addressing loss associated with chronic illness (DeHaan 1995:3-15). The researcher concluded that the RAM provided a good framework upon which to test interventions. In 2008, Hannon-Engel used the RAM as a basis for knowledge development in bulimia nervosa, a complex, poorly understood, chronic and debilitating disorder characterised by repeated binge eating and purging episodes (Hannon-Engel 2008:126-127). The researcher demonstrated the utility of RAM's framework as a basis for clinical research and practice and concluding that the Roy Adaptation Model has tremendous utility as a basis for knowledge, research and practice developments concerning bulimia nervosa (Hannon-Engel 2008:127-131).

Furthermore, in 2013, Ordin, Karayurt, and Wellard also explored the adaptation of transplant recipients in Turkey using the Roy Adaptation Model in a descriptive qualitative research design. The researchers concluded that RAM provides a credible framework through which the delivery of nursing care and information can be "organised" for liver transplantation recipients (Ordin, Karayurt & Wellard 2013:31-2).

In 2013, Zhang also used the RAM in a quantitative research design, to investigate how older adults make end of life decisions, with the aim that the knowledge gained would help health workers identify factors that might influence end of life discussions and shed light on strategies on effective communication to advance care planning (Zhang 2013:1-2). A model-testing design and path analysis were used to examine secondary data from 938 participants and the results showed that physical impairment, self-rated health, continuing to work, and family structure had direct and indirect effects on completion of advanced directives (Zhang 2013:4-6), further demonstrating use of RAM in clinical nursing to expand disciplinary knowledge.

Also in 2013, Perrett and Biley used results of a qualitative grounded theory study to test components of the Roy Adaptation model as framework for “negotiating uncertainty” while adapting to HIV (Perrett & Biley 2013:337). The researchers compared the study’s emergent adaptation framework to the Roy Adaptation Model. This comparison strengthened concepts such as focal and contextual stimuli, the definition of adaptation and a description of the four adaptive modes. It also provided an opportunity for the investigators to suggest areas for further development including the role of perception in the adaptation process (Perrett & Biley 2013:337-343).

These examples demonstrate the applicability of the RAM in practice settings, including its ability to cross various populations and settings as well as its usefulness in both quantitative and qualitative investigations. This further demonstrates that RAM has successfully stood the test of time and is “transformational for nursing science” as well (Clarke, Barone, Hanna & Senesac 2011: 338; 343; Dobratz 2014:53-54).

### **7.2.1.3. Assumptions of Roy Adaptation Model**

According to Polit and Beck (2010:530) assumptions are principles considered as being true that a researcher uses to ground conceptualisations, conduct analysis and document a study. Assumptions are also considered “truths” foundational to theory and research and which are accepted as such by members of these communities without having to proof their “truth”. The assumptions included in RAM are divided into three categories: philosophical, scientific and cultural, as further explicated:

The RAM's philosophical assumptions are rooted in the general tenets of humanism and are related to the concepts of "cosmic unity" and "veritvity" (Roy & Andrews, 1999, in Roy & Zhan 2001:317; Roy & Andrews 1999:35). With regard to "cosmic unity", Roy believes that people and the universe have common patterns and integral relationships, stemming from the belief that persons have a mutual relationship with the world and a God figure and that human meaning is rooted in an omega point of convergence of the universe (Roy 2009:31; Masters 2012:134). Roy posits that rather than the universe acting to maintain itself, there should be purposeful human existence in a creative universe. Informed by her conceptualisation of humanism, Roy notes that humans as individuals and groups share in creative power; they behave purposefully and possess intrinsic holism and strive to maintain integrity and to realise their need for relationships (Roy & Andrews 1999, in Hana & Roy 2001:9). Roy espouses Christian humanism (theistic humanism) as opposed to secular or atheistic humanism (Hanna & Roy 2001:9). Roy further holds the belief that God is intimately revealed in the diversity of creation and is the common destiny of creation and that individuals use human creative abilities of awareness, enlightenment and faith to have mutual relationships with the world and the God figure (Hanna & Roy 2001:9-10; Dobratz 2008:257; Boston College, School of Nursing, BCSN, 2013:2-3).

The second philosophical concept of "veritvity" arose, when Roy identified incompleteness in the philosophical assumptions of humanism, particularly in relating the individual to the community. Veritvity reflects a second set of philosophical assumptions, based on the worldview of stability, teleology, unity, and universality of truth (Hana & Roy 2001:10). Veritvity "pertains to the principle of human nature that affirms a common purposefulness of human existence" (Roy & Andrews 1999:34) and includes concepts such as unity of purpose of humankind, activity and creativity for the common good including value as well as meaning of life (Roy 1988:32-33; Roy & Andrews 1999, as cited in Hana & Roy 2001:10; Hannon-Engel 2008:126-128).

Roy's conceptualisations of *cosmic unity* and *veritvity* provide the lens through which the scientific principles and cultural assumptions that underpin the RAM are viewed (Roy & Andrews, 1999, in Hannon-Engel 2008:126-127). In the context of the current study, the actions of affected persons as survivors, caregivers and family members

for wanting to stay alive implies the value and meaningfulness of human life, partially affirming the usefulness and applicability of the RAM within real life situations.

The scientific assumptions of the RAM are based on general systems theory and adaptation level theory (Roy & Corliss 1993, in Zhan 2000:158). Systems theory allows for the conceptualisation of complex human systems to be described more simply to offer a foundation from which to examine the intricate multi-faceted and non-linear processes of being a human being (Hannon-Engel 2008:126-127). Accordingly, it is assumed that systems of matter and energy progress to higher levels of complex self-organisation (adaptation) (Roy 1997:42; Roy 2009:31). Roy and associates further assume that consciousness and meaning constitutes person and environment integration and that awareness of self and environment is rooted in thinking and feeling (Hannon-Engel 2008:127; Roy 2009:31; Masters 2012:134). The RAM further assumes that human beings as “systems” foster relationships through acceptance, protection, and interdependence and that persons and earth [universe] have common patterns and integral relations (Roy 2009:31; Masters 2012:134). Finally, from a scientific perspective, the theory holds that person and environment transformations are created in human consciousness; and that integration of human environment meanings result in adaptation (Hannon-Engel 2008:127; Roy 2009:31).

In the context of the current study, it is argued that the personal and environmental transformations as well as the integration of humans and their environment result in adaptation. For instance, as a negative example, the force that drove the locals to isolate and discriminate against Ebola survivors and caregivers and their families discussed under “public reaction towards survivors and caregivers” (refer to data display 6.5) reflects this foundational tenet of the RAM (albeit that the community’s reaction appears maladaptive). In a way these “frantic” efforts by the community could be interpreted as a way of adapting to environmental stimuli, that is the outbreak of Ebola and associated fear of infection and death. In the same way, the person and environment transformations as well as the integration of humans and their environment resulted in the adaptive behaviour of survivors and caregivers.

The cultural assumptions underlying the RAM are based on the fact that culture plays a significant part in the interpretation of the elements in the RAM. These assumptions have been extended to include a re-definition of adaptation for the twenty first century (Roy & Zhan 2001:317; Hanna & Roy 2001:9; Wills 2011:171; Masters 2012:135-6). These cultural assumptions according to the RAM emphasise that different cultural experiences influence how the major aspects/elements of the model are expressed. It is assumed that different concepts related to health and illness as espoused in different cultures may influence the conception and interpretation of the elements in the model to a lesser or greater extent (Wills 2011:171-173; Masters 2012:135-136).

The model further assumes that different cultural expressions of the elements of the RAM may lead to changes in practice activities such as nursing assessment and nursing care based on the local realities of actors. As conceptualisation of the RAM evolves within a particular culture, the implications for nursing care may differ from the conceptualisations in the original culture in which it was constructed. For instance, the culture Roy found herself in, during the time of the initial formulation and construction of the RAM (Roy 2009:31; Wills 2011:171; Masters 2012:135).

In the context of the present study, the conceptualisation of the different cultural assumptions of the RAM can in part be influenced by the harsh social cultural sanctioning survivors and caregivers and their families experienced during and in between Ebola outbreaks. The study findings indicate that the cultural beliefs and explanatory models of disease causation (refer to data display 6.6.1) and beliefs and practices to remedy Ebola infection (refer to data display 6.6.2) dictate how individuals and families were expected to deal with Ebola patients and survivors. It is these differences in the conceptualisation of what constitutes “a correct approach” that is principally responsible for the different interpretations of some of the elements of RAM and consequently what would constitute a culturally congruent mode of care.

#### **7.2.1.4. Metaparadigmatic concepts of nursing in relation to the RAM**

A metaparadigm is the most global perspective of a discipline (Masters 2012: 3). The concept is defined by Parker (2001:5) and Fawcett (2005:4) as a framework for a discipline, including the discipline of nursing that sets forth the global phenomena of

interest and the propositions, concepts, principles as well as methods of a discipline. Metaparadigmatic concepts are very broad and general and are intended to reflect agreement among members of a discipline about what constitutes the field of study of that discipline. It offers a platform upon which practitioners can develop theories and conceptual models to explain phenomena central to their practice (Walker & Avant 1995, cited in Parker 2001:6; Alligood & Marriner-Tomey 1997:224; Parker 2001:5).

While debate continues as to what should be included as being central to the discipline of nursing, most scholars agree that the central concepts the discipline deals with are person, environment, health and nursing (Parker 2001:6; Fawcett 2005:6; Masters 2012:3). In the subsequent section, these four concepts are discussed within the assumptions underlying the RAM, thus providing for the congruent structuring of the current study findings using the tenets of the RAM:

Person is defined as “an adaptive system with cognator and regulator subsystems acting to maintain adaptation in the four adaptive modes” (Roy 2009:12). The RAM describes a person or human system as holistic and adaptive in constant adaptation to environmental stimuli. The person as adaptive system is described as a whole with parts that function in unity for some purpose. The human system, the focus and recipient of nursing care, consists of individuals and human collectivities (groups, organisations, communities and the society at large) (Roy & Andrews 1999:31; Roy 2009:12). Key concepts in this regard are holism, open systems and adaptation. In the current study, person refers to Ebola survivors, caregivers and members of the local community in the study area, who were present during the latest outbreak and who acted upon the Ebola virus as such (those that survived) or acted on the manifestation of the outbreak (as caregivers and members of the local community).

Environment is defined as “all conditions, circumstances and influences surrounding and affecting the development and behavior of persons and groups with particular consideration of mutuality of person and earth resources” (Roy 2009:12). The concept also refers to the environments within and around humans as adaptive systems (Roy 2009:46). It is from the internal and external environment that three stressors (input): focal, contextual and residual arise to affect a person, depending on

their stage of development, family and cultural background. It is the changing environment that stimulates the person to create adaptive responses (Andrews & Roy 1991:18; Roy 2009:35-36). In the context of the present study, “environment” implies the physical environment including people that presents with the Ebola virus and infection, and the societal reaction of prevailing fear including the social–cultural expressions and beliefs that became apparent during Ebola outbreaks and continued in the aftermath and in between outbreaks in the communities in the study areas.

Health is defined as “a state and a process of being and becoming an integrated whole human person which reflect person and environment mutuality” (Roy 2009:12). The concept of health within RAM has evolved to mean a process by which both health and illness can co-exist, a re-conceptualisation which allows for persons who despite serious disabilities or terminal illness deal effectively with challenges (Zhan 2000:159; Masters 2012:133). Health is reflective of human adaptation (Andrews & Roy 1991:21). In the context of this study, I propose that “health” should be understood to mean the ability of survivors to adapt to and deal effectively with their physical (surviving the infection physiologically) and associated psycho-social challenges of having suffered from Ebola infection or of being associated with infected persons. Thus, health for caregivers of Ebola infected persons means the ability to deal effectively with the psycho-social consequences that arose from their association with Ebola. In contrast, health for members of the community implies the freedom from illness and ability to adapt to existence of an Ebola outbreak, including the fear of infection always associated with Ebola outbreaks in a manner that is, non-stigmatising, non-labelling, non-aggressive and non-ostracising to affected persons.

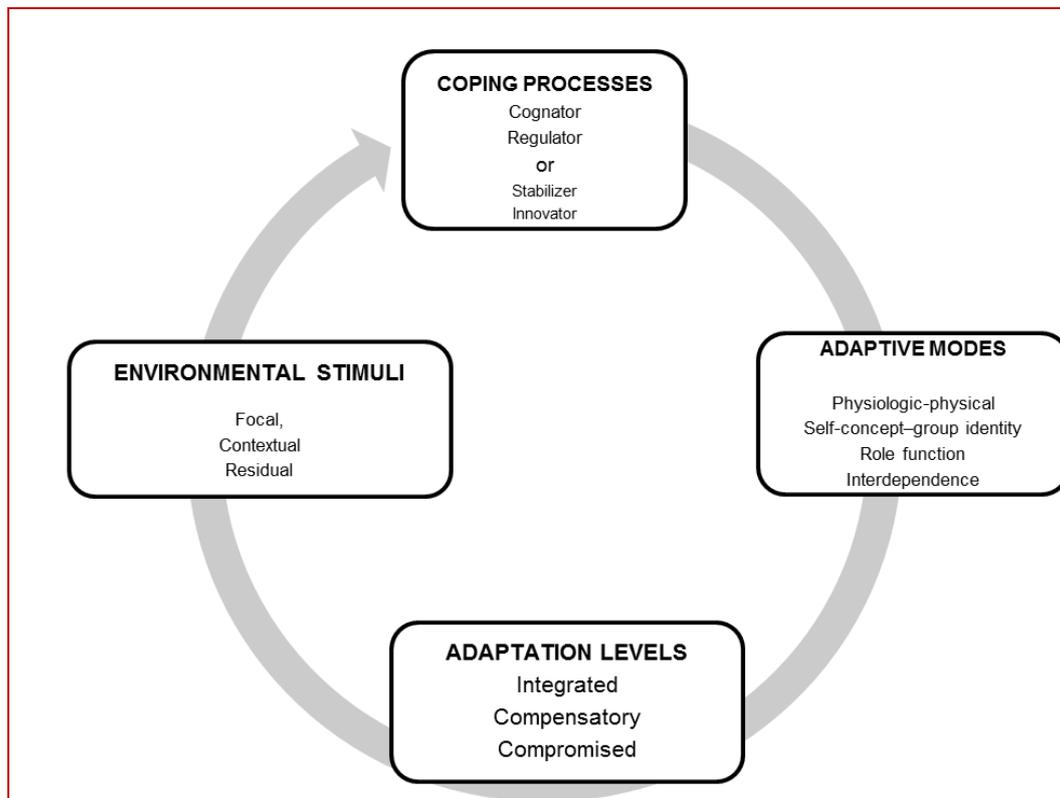
Nursing is defined by Roy as a “health care profession that focuses on the life processes and patterns of people with a commitment to promote health and full life-potential for individuals, families, groups and the global society” (Roy 2009:3). It is the science and practice that expands peoples adaptive abilities and enhances individuals’ and groups’ capacity to interact with the environment and to transform the environment. The goal of nursing according to Roy (2009:12) is to promote the adaptation of individuals and groups in the four adaptive modes, to contribute towards health, quality of life and dying with dignity. These are attained by assessing

behaviors and factors that influence adaptive abilities including environmental factors (Roy & Andrews 1999:53-55; Roy 2009:12). Roy espouses the idea that the nurse's role is to promote adaptation in situations of health and illness and to enhance the interaction of human systems with the environment, thus promoting health (Roy & Andrews 1999:55). In this study, I propose that "nursing" should be understood as "health care" in its broadest sense as Ebola outbreaks often result in multi-sector interventions and collaborations involving the whole interdisciplinary health team members as well as members of the community, including law enforcement agents.

In summary, the RAM views humans, both individually and in groups, as holistic adaptive open systems, with coping abilities that act together to maintain adaptation and to promote effective person and environmental transformations with the ultimate aim to promote "health" (Roy & Zhan 2001:317; Dobratz 2008:255; Roy 2009:12-13).

#### **7.2.1.5. Major Concepts of the Roy Adaptation Model**

Humans, both individually and collectively, are viewed as holistic adaptive systems in a transformative coping relationship with their internal and external environments, in an attempt to maintain "system" integrity in the face of environmental stimuli (Roy 2009:12; Roy & Zahn 2001:317). A stimulus is defined as any entity that provokes a response, thus triggering the need for adaptation (Roy & Andrews 1991:10; Roy 2009:34). Its origin may be within and/or outside the body. "Stimuli" or "stressors" are grouped as focal, contextual and residual in nature. Focal stimuli are stressors most immediately challenging to the person's adaptation and attract the individual's attention most (Roy 2009:35). Contextual stimuli represent all other stimuli that strengthen the effect of the focal stimulus (Roy 2009:35); whilst residual stimuli refer to all other phenomena that arise from the person's internal or external environment whose effects are not clearly measurable or known to the actors at the moment of the focal challenge (Roy 2009:36). These three types of stimuli act together and influence a person's adaptation through their coping processes (Roy 2009:33). A schematic representation of the major concepts/elements of the RAM is depicted in figure 7.1:

**Figure 7.1. Elements of the Roy Adaptation Model**

The coping processes are broadly classified as regulator and cognator subsystems for the individual and stabiliser and innovator subsystems for groups. Through these coping processes, individuals or groups as holistic adaptive systems interact with the internal and external environment, transform the environment and get transformed by the environment (Roy & Zhan 2001:317; Roy 2009:33). According to Roy, a particular aspect of the internal environment is the person's adaptation level referring to the three possible levels of the human adaptive system. These adaptation levels are integrated, compensatory and compromised adaptation (Roy & Zhan 2001:317; Roy 2009:33). These levels of adaptation can be reached with reference to the four "adaptive modes"; physiological-physical, self-concept-group identity, role function and interdependence (Roy & Andrews 1999:53; Zhan 2000:159; Roy 2009:43). A core concept of the model is Roy's belief that adaptive responses support health, which is a state and a process of being and becoming an integrated whole, reflecting mutuality with the environment (Roy 2009:12; Masters 2012:133).

### **7.2.1.6. The process of human adaption**

When a human system, in the form of a person or group, receives an environmental stimulus from internal or external sources, the stimulus serves as input and “switches” on its adaptive capability (system). The coping processes that ensue allow individuals and groups to adapt to the environmental stimulus mentally, physically, socially, spiritually and emotionally, within the regulator and cognator subsystems. The regulator subsystem responds automatically using neural, chemical and endocrine mechanisms based on the stimulus received via the senses while the cognator subsystem responds to a stimulus through four cognitive-emotional channels of perception, information processing and judgments, learning, judgment and emotions (Andrews & Roy 1991:10; Roy 2009:41; Wills 2011:171). Perception and information processing include activities such as selective attention, coding and memory while learning involves imitation, reinforcement and insight (Roy 2009:41; Masters 2012:129). Judgment includes problem solving and decision making; while individuals use defenses to seek relief from anxiety and to make affective appraisal and attachments through the emotions (Hanna & Roy 2001:10; Roy 2009:41).

The cognator-regulator and stabiliser-innovator function to maintain integral life processes. These life processes are manifested in the behaviour of the individual or group undergoing adaptation and the resulting behaviour may be integrated, compensatory or compromised (Roy & Hanna 2001:10; Tiedeman 2006:535; Roy 2009:34). According to Roy (2009:34) human behaviour is viewed as an output of the human system and usually takes the form of adaptive or ineffective responses.

Furthermore, Roy insists that although direct observation of the regulator and cognator subsystems functioning is not possible, the individual’s behavioural responses that arise from these coping processes are expressed in the four adaptive modes and these can be observed (Zhan 2000:159; Roy & Zhan 2001:317; Roy 2009:43). These can also be measured or subjectively reported and in collaboration with the person or group, it can be judged as being adaptive or ineffective response.

Through the “feedback loop” of the model, these responses serve as a feedback to the human system, which in turn “decides” whether to increase or decrease its effort to cope with the stimuli (Roy 2009:34). In essence, the feedback from the adaptive modes act as “new stimuli” providing further input for the system, thereby igniting a new set of adaptive mechanisms to cope with the newly “created” stressor (Hanna & Roy 2001:10; Roy 2009:33). It is these coping processes that allow persons as holistic adaptive systems to interact with internal and external environmental stimuli, transform the environment and get transformed, in a process that supports health and wholeness (Roy & Zhan 2001:317; Masters 2012:130; Perrett & Biley 2013:339).

#### **7.2.1.7. Relating the study findings to the Roy Adaptation Model**

In this section, salient features related to the study’s findings are explicated in terms of the key concepts of the RAM namely: stimuli, coping process, adaptive modes and resulting adaptation levels of survivors, caregivers and the local community.

##### **7.2.1.7.1. Application of the RAM to Survivors’ Adaptation**

In this section, the application of the various concepts of RAM is explicated in relation to how Ebola survivors adapted following their exposure to the Ebola virus:

- **Stimuli**

The stimuli that triggered the adaptive behaviour in survivors were multifaceted and included focal and contextual stimuli (Roy & Zhan 2001:317; Roy 2009:35). The focal stimulus consisted initially of the Ebola virus and its infection itself and the physiological symptoms/responses it triggered such as fever and haemorrhage (refer to section 3.3.7.3). This was soon overtaken by fear of death, social rejection, ostracism, stigma and severe disruption of survivors’ life patterns and other challenges associated with surviving Ebola (refer to data display 6.2.3; 6.3). These were exacerbated by the prevailing poor social health education, media exaggeration and heightened national awareness (Schwartz 1995:2; Kabanankye 2001:12). These emerging realities “forced” infected persons to adapt through physiological and

psychological and social responses. The fear of death was related to experiencing the ferocious nature of Ebola while the social rejection related to the broader community's observation of Ebola's ferocious nature leading to changes in social relationships and tolerance. With these unexpected challenges, Ebola patients became aware that their physical, social and psychological wellbeing was under attack, and this forced them to adapt using various means (refer to data display 6.7).

- **Coping processes**

These internal (focal) and external (contextual) stimuli acting together as “input factors” or “stressors” ignited infected patients' adaptive mechanisms within the regulator and cognator subsystems to maintain integrated life processes in all the four adaptive modes. These adaptive behaviours are consistent with the physical, psychological, social as well as spiritual “adaptations” undergone by the survivors (refer to data display 6.3). These coping efforts resulted in integrated, compensatory or compromised outcomes (Roy & Andrews 1999, as cited in Roy & Zhan 2001:317; Roy 2009:12). The integrated and compensatory outcomes resulted in survival due to effective adaptation (refer to data display 6.3.1; 6.3.2) while the compromised life processes resulted in death of the affected persons, due to ineffective adaptation and inadequate defences against the Ebola virus invasion (refer to data display 6.2.3.2).

- **Adaptive modes**

The first adaptive process that occurred within the “regulator subsystem” was the “*physiological-physical*” response to the infective process involving all the body cells, tissues, organs and systems, discussed under humoral and cellular responses (refer to section 3.3.7.4). Unlike those who perished from the Ebola infection, survivors' humoral and cellular immune responses was “vigorous” and “orderly” and well regulated leading to their survival (Baize et al 1999:423-6; Falzarano et al 2012:2). This physiologic reaction to the virus was automatically and unconsciously performed by the neural, endocrine and chemical coping channels, except for the adaptive processes that could be seen as signs and symptoms in the affected body organs and systems (refer to data display 6.3.2 and section 3.3.7.4)(Roy 2009:41).

The second coping (adaptive) process that occurred within the “cognator subsystem” was the “*psychological-spiritual*” response that followed in reaction to the intense fear related to the anticipated “physical death” due to the virulence of Ebola (refer to data display 6.2.3.2 and section 3.3.7.4) and “social death” due to rampant ostracism, rejection and abandonment of culturally valued practices. The “social death” was linked to survivors’ association with Ebola including the side effects of the disease on them (refer to data display 6.3.2, 6.3.3, 6.3.4, 6.3.5, 6.3.6). The responsive “actions” involved defences to reduce anxiety through activating cognitive-emotional channels of perception, information processing and judgments, learning, judgment and emotions and manifested in them seeking opportunities for self-preservation and protection (refer to data display 6.1.2.1) (Andrews & Roy 1991:10; Roy 2009:41). These “reactions” fall within the RAM’s “*self-concept*” adaptive mode whose main objective is to attain “psychic and spiritual” integrity (Roy 2009:44; Phillips 2011:307).

The study findings indicate that following appraisal of their emerging realities survivors “adapted” in the self-concept mode by actively engaging in “battles” deemed necessary to overcome the anticipated “physical” and social death” (refer to data display 6.7.1). Specifically, some sought to overcome their challenges by seeking religious and spiritual help by means of “sacramental blessings” from a priest and engaging in fervent prayers and religiosity (refer to data display 6.7.2). For some, seeking help from caring others and adopting optimistic and positive attitude helped them to adapt to their new challenges (refer to data display 6.7.3; 6.7.4). Other survivors surrendered and accepted their fate (refer to data display 6.7.5), and a few others engaged in avoidance, distancing and withdrawing from unsupportive others (refer to data display 6.7.6). These adaptive actions was to ensure survivors manifest psychological and spiritual health and live meaningfully within the two realms of life; with “freedom” or “transcendence” from these otherwise negative lived experiences.

The adaption in the “*role function*” mode which refers to one’s behaviour towards and interaction with others to realise social integrity (Andrews & Roy 1991:16; Roy 2009:44; Phillips 2011:308) manifested in survivors battling to overcome their challenges of social isolation, ostracism and stigma by among other things seeking support from caring and “supportive” others such as close friends, family members

and healthcare workers. Such efforts helped survivors to restore themselves to their “former” selves to ably perform their roles and responsibilities in the “pre-math” of Ebola consistent with their established roles and routines, say as farmers, teachers, mothers and health care workers. Roy (2009:44) insists that such adaptive actions enable survivors to “know who each of them is in relation to others”, a reaffirmation that helps survivors as members of the community to meet their primary, secondary and tertiary roles towards self, their families and the community. The desired outcome of “adaptation” within role function was for survivors to return to meaningfully perform previous roles either as farmers, mothers or nurses (Alligood & Marriner-Tomey 1997:188; Linley 2003:601-602; Roy 2009:44; Masters 2012:131).

Within the “*interdependence*” mode of “adaptation” which involves “giving and receiving of love, respect, and value”, intended to achieve relational integrity (Andrews & Roy 1991:17; Roy 2009:44), survivors were noted to seek support from caring others such as their relatives, close friends and health workers (refer to data displays 6.7.1; 6.7.3). These actions were intended to “re-establish broken relationships” that the antisocial overtones brought about as a result of the dread associated with Ebola. Hence by seeking to re-establish social linkages from supportive persons like close friends, family members, religious figures and health workers, survivors attempted to gain ground from where they could receive and give love, respect, and value and be valued by others” (refer to data display 6.7.1; 6.7.2; 6.7.3). The desired outcome of adaptation in this realm was to re-establish links with significant others and support systems to attain relational integrity (Roy 2009: 45).

- **Adaptation levels**

In terms of the adaptation levels, as Roy (2009:33) explains, the three adaptation levels of integrated, compensatory and compromised life processes prevailed. An integrated adaptation level is where the structure and functions of the human system work as a whole to meet human needs as seen in normal body functioning (Hanna & Roy 2001:10; Masters 2012:130). A compensatory adaptation level results when an individual’s adaptive capacity is “forced” to cope with a challenge (physical or psychological) and attempts to recovery and return to the integrated life processes. In

such situations, compensation aims to ensure survival, growth, reproduction and mastery despite the challenges (Andrews & Roy 1991, in Alligood & Marriner-Tomey 1997:178; Linley 2003:601). In contrast, a compromised life process occurs during inadequate compensatory processes leading to ineffective adaptive response, exposing the affected person to further deterioration of their health, resulting in death, compromised growth or failure to master the environmental transformations (refer to data display 6.1.1.2; 6.2.3.2; 6.3.2) (Alligood & Marriner-Tomey 1997:178; Roy & Zhan 2001:317; Hanna & Roy 2001:10; Roy 2009:57-58; Masters 2012:130).

In this study, infected persons who failed to adapt to the infection at the physical/physiological level perished because of inadequate immune response (refer to section 3.3.7.4). Weak and disorderly immune responses led to their death (Baize et al 1999:423-6; Falzarano et al 2012:2). This observation is also true for patients with high concentrations of Interferon-Gamma (IFN- $\gamma$ ) and increased blood concentrations of nitric oxide (Baize et al 2002:163-165; Sanchez et al 2004:10370). Feldmann and Geisbert (2012:7) validate that increased blood concentrations of nitric oxide in patients, resulting from inappropriate cellular response to Ebola virions leads to their death, by prompting premature apoptosis (programmed cell death) of bystander lymphocytes (killer cells), rapid tissue damage and loss of vascular integrity (causing leakage out of the blood vessels) which is prominent in virus-induced hypovolemic shock in haemorrhagic virus fevers such as Ebola due to the severe hypotension (Baize et al 2002:163-165; Feldmann & Geisbert 2012: 21).

In patients who managed to survive, further adaptations helped them to reduce pain, fear, and anxiety by making appraisals and attachments through emotions as and when necessary (Roy 2009:41). This “adaptation” entailed survivors consciously or unconsciously engaging various coping mechanisms to adapt to and increase their “resilience” to the various stressors such as the rampant social isolation, ostracism and stigma. In this context, resilience signifies reduced ‘vulnerability’, implying that whenever an individual is confronted with an adversity, they ably continue life with minimum negative consequences (Dyer, Patsdaughter, McGuiness, O’Connor & De Santis 2004:57; Hofer 2006:259; Davydov, Stewart, Ritchie & Chaudieu 2010:481).

The resilient survivors adapted despite their personal and social losses (Cameron, Ungar & Liebenberg 2007:285; Kim-Cohen 2007:271; Stanton, Revenson & Tennen 2007:565), ably “coping” during adversity (Skinner & Zimmer-Gembeck 2007:119; Taylor & Stanton 2007:377; Davydov et al 2010:481). In contrast, survivors who did not adapt in a resilient way were severely weakened by psycho-social challenges. They became disempowered and failed to bounce back to healthy life after Ebola. Such survivors started to avoid, distance themselves and withdrew from others (refer to data displays 6.7.6), which Roy terms *ineffective adaption* or *compromised* life process (Cadell, Karabanow & Sanchez 2001:21; Reich 2006:793; Roy 2009:33).

#### **7.2.1.7.2. Application of the RAM to Caregivers’ Adaptation**

In this section, the application of the various concepts of RAM is discussed in relation to how caregivers adapted following their exposure to the Ebola patients:

- **Stimuli**

The stimuli that triggered the adaptive behaviour in caregivers were both focal and contextual in nature (Roy & Andrews 1999, in Roy & Zhan 2001:317; Roy 2009:35). The focal stimulus consisted mainly of the fear of infection and the impending death, (refer to data display 6.1.1.1; 6.2.3.2) as well as social rejection, ostracism and stigma including being needlessly abandoned by close family members and members of their local home communities (refer to data display 6.2.3.3; 6.2.3.4; 6.2.3.5).

Caregivers were also weary of being annihilated completely by their families and members of the community because of being considered as a source of infection (data display 6.1.1.2). The contextual stimuli related to the inescapable nature of Ebola experience (data display 6.1.1.5) worsened by poor social health education, media exaggeration and heightened national awareness (Semmler 1998:149; MacNeil & Rollin 2012:1). Therefore, the immediate need for caregivers was to attain ‘adequate’ psychological adaptation to enable coping with challenges (Roy 2009: 45).

- **Coping processes**

Internal (focal) and external (contextual) stimuli acting together as “input factors” or “stressors” ignited caregiver’s coping process within regulator and cognator subsystems, resulting in either integrated, compensatory and compromised outcomes. The integrated and compensatory outcomes led to positive adaptation (resulting in adaptive behaviour) while compromised outcomes resulted in inadequate adaptation (leading to ineffective adaptive behaviours) (Roy & Andrews 1999:81; Roy & Zhan 2001:317; Roy 2009:12-13) as expressed within the RAM’s four “adaptive modes” (Roy 2009:41; Wills 2011:171-172; Masters 2012:129-130). These adaptive behaviours are consistent with caregivers’ social and psychological (emotional) “adaptations” which they underwent to overcome the numerous challenges of Ebola.

The social adaptations were to minimise the effects of social isolation, rejection, discrimination as well as stigmatisation among other consequences (refer to data display 6.2.3; 6.4.2). Caregivers also adapted emotionally to overcome despair, anxiety, sleeplessness, helplessness and stress among other challenges (refer to data displays 6.4.1; 6.4.3). Caregivers experienced the caring role as stressful, burdensome and depressing. These challenges thus made adaptation an essential element for caregivers to attain “freedom” or “transcend” from these negative feelings and regain their health (Andrews & Roy 1991:21-22; Roy & Andrews 1999:53-54).

- **Adaptive modes**

The adaptive process that occurred within the “regulator subsystem” was the “*physiological-physical*” response to the fear related to the infection which resulted in physiological reaction affecting the body through psychosomatic manifestations. In terms of the psychological (emotional) reactions, caregivers experienced sadness, anger, and anxiety among others as they anticipated Ebola infection (data display 6.1.1.4.1). The accompanying corporal reactions included stomach problems, weight loss, palpitation, chest pain, migraine; nightmares, sweating, infections and hyperventilation among others (data display 6.1.1.4.2). These reactions were reinforced whenever caregivers were reminded of Ebola and was automatically and

unconsciously performed by their neural, endocrine and chemical coping channels (Andrews & Roy 1991:19-20; Hannon-Engel 2008:128-129; Masters 2012:130-132).

In reaction to stimuli, caregivers' "cognator subsystem" leading to "psychological-spiritual" integrity effected coping in reaction to the intense fear related to the anticipated "physical death" (data display 6.2.3.2; 6.4.3) as well as "social death" due to rampant ostracism and abandonment much like survivors (data display 6.2.3.3; 6.2.3.4; 6.2.3.5). The responsive "actions" in this coping process involved much like survivors, activating cognitive-emotional channels of perception, information processing and judgments, learning, judgment and emotions (Andrews & Roy 1991:10; Roy 2009:41). These "reactions" fall within the RAM's "*self-concept*" adaptive mode whose main objective is to attain "psychic and spiritual" integrity (Roy 2009:44; Phillips 2011:307). Caregivers responded to the threat by engaging in "battles" deemed necessary to overcome the anticipated challenges through prayers and religiosity (data display 6.7.2); adopting optimism and positive attitude (data display 6.7.4) and by surrendering and accepting their fate (data display 6.7.5), while engaging in avoidance, distancing and withdrawing when deemed necessary (data display 6.7.6). The intended outcome of these adaptive actions was for caregivers to realise psychological and spiritual health and wellbeing, to enable them to live meaningful lives after and in-between outbreaks (Roy 2009:44; Masters 2012:130).

The adaption in the "*role function*" (Andrews & Roy 1991:16; Roy 2009:44) entailed caregivers seeking to overcome social isolation, ostracism and stigma by among other things seeking support from caring and supportive others including healthcare workers (refer to data display 6.2.1.1; 6.7.3). Like survivors, caregivers attempted to restore their "former" selves to ably perform their expected roles and responsibilities as members of their local community. As Roy (2009:44) dictates, such adaptive actions allowed caregivers to attain social integrity by meeting their primary, secondary and tertiary roles towards self, families and community after the outbreak.

Within the "*interdependence*" mode of "adaptation" which involves "giving and receiving of love, respect, and value", intended to achieve relational integrity (Andrews & Roy 1991:17; Roy 2009:44), caregivers much like the survivors actively

sought support from caring relatives, close friends, family members, religious figures and health workers (refer to data display 6.2.1.1; 6.7.2; 6.7.3). These “coping” actions were intended to “mend” the broken relationships the fear of Ebola had created and help caregivers re-establish vital social linkages to allow them receive and give love, respect and value to attain relational integrity during and after the Ebola outbreaks in the community (refer to data display 6.7.1;6.7.3) (Roy 2009:44; Masters 2012:131).

- **Adaptation levels**

In consonance with Roy’s (2009:33) declaration, caregivers adapted to the news of the Ebola outbreak via the integrated, compensatory and compromised adaptation levels. Caregivers who adapted well and showed resilience to the social challenges (social rejection, ostracism and stigma) and psychological challenges due to first-hand experience of sufferers’ despair and their own anxiety, sleeplessness, manifested integrated and compensatory life process characterised by positive adaptation and coping with the challenges leading to an integrated life process (Dyer et al 2004:57; Hofer 2006:259; Stanton et al 2007:565; Davydov et al 2010:481-482).

The mere fact that they were prepared to render care might be indicative of a positive adaptation; however, as so often cautioned in the literature care and caring can become very hard labour draining the caregiver of vital internal resources. Caregivers who did not adapt well continued to live compromised life processes as a result of social rejection, ostracism and stigma (refer to data display 6.2.3.3; 6.2.3.4; 6.2.3.5). Unfortunately such caregivers continued to experience unhealthy and negative psychological manifestations, among them despair, anxiety, helplessness and hopelessness among others (refer to data display 6.4.3) as a result of their inadequate integrative and compensatory abilities leading to diminished sense of wellbeing and poorer health (Reich 2006:793; Roy 2009:33-35; Masters 2012:129).

### **7.2.1.7.3. Application of the RAM to Community’s Adaptation**

In this section, the application of the various concepts of RAM is discussed in relation to how the community adapted following the emergence of Ebola infection:

- **Stimuli**

As Roy (2009:35) espouses, the focal stimuli that triggered the adaptive behaviour in the community included their perceptions based on hearsay and media reports (Schwartz 1995:2; MacNeil & Rollin 2012:1-2) as well as the fear of infection that was associated with imminent death (refer to data display 6.1.1.1). As the infection spread the social rejection, isolation, ostracism, abandonment and rejection of affected persons and stigmatisation as well as death experienced by affected persons became contextual stimuli, aggravating the focal stressor, i.e. fear and panic among the members of the community (refer to data display 6.2.3). These unusual occurrences meant members of the community had to quickly “adapt” to and surmount these realities so as to ably cope with and withstand these complexities.

- **Coping processes**

The coping processes of the community were apparent within the stabiliser and the innovator subsystems where the community’s efforts were geared towards “maintaining structures and processes for change” (Hanna & Roy 2001:10) albeit in a rather negative sense. The adaptive processes that occurred within the “stabiliser and innovator subsystems” was the response of the community to “protect” the community resources from members of the community deemed to be “unfit” as a result of their association with Ebola. The change that emanated from the community interactions was geared towards ensuring the community was maintained “alive and free from Ebola” (Roy 2009:34). This interpretation is solely deduced from participant perceptions and not from community members’ accounts as this was not the primary aim of the study. In this instance I, to some extent, already transferred findings to the general population to facilitate understanding of the contexts of these experiences.

- **Adaptive modes**

As Roy (2009:43-44) affirms, adaptation of groups within the “*physical*” mode aims to assure the resource adequacy of the community. This was seen in actions of the community to “keep away” Ebola patients, caregivers and other directly involved

persons from community resources such as watering wells, markets, shops and public transportation means in the bid to protect and guarantee the “meagre” available resources for the larger community (refer to data display 6.1.1; 6.2.3.3).

In terms of the second adaptive mode of “*group identify*”, the focus of the group as explained in Hanna and Roy (2001:10) and Roy (2009:44) was to ensure that the community lasted through the crises to preserve its identified integrity. In the presence of Ebola, this meant members of the “unaffected” community had to through shared relationships, goals, values and cultural beliefs work toward ridding the community of “negative” elements. This meant that affected persons such as Ebola patients, survivors, care givers as well as health care workers known to be closely associated with the source of infection, were to be avoided at “all costs” (refer to data display 6.5.1.2). These reactions were intended to keep the community safe (refer to data display 6.5.2.2). Hence the community “adapted” by actively isolating affected persons, openly rejecting them and discriminating against them eventually leading to the stigmatisation of such persons and families (refer to data display 6.1.1.1), leading to annihilation of directly affected persons and families (refer to data display 6.1.1.2) (Hanna & Roy 2001:10-11; Roy 2009:41-44; Masters 2012:130).

The adaption in the “*role function*” (Andrews & Roy 1991:16; Roy 2009:44) entailed the community members seeking to attain social integrity, that is intactness of their community to the level of the pre-Ebola status (refer to data display 6.5.1.1), characterised by members of the community engaging in activities in a normal and uninterrupted manner with people interacting without inhibitions. With the advent of Ebola, the adaptation in this mode meant various members of the community were socially made aware of their roles and became committed to fulfil the expected tasks so the group could achieve a common goal: that of assuring the existence of the community in the aftermath of Ebola. In order to do this, members of the community “divided” roles, some became vigilantes to “keep infected persons under check” preventing free movements in the community (refer to data display 6.5.1.2), while others became caregivers, especially those believed to have resistance to Ebola and the elderly (refer to section 3.4). Conversely, others undertook the role of healers in an attempt to rid the community of the disease (refer to data display 6.6.2). Roy

(2009:44) on her part insists that such “adaptive” actions enable community members to meet their designated roles to attain social integrity (Masters 2012:131-132).

Within the “*interdependence*” mode of “adaptation” (Andrews & Roy 1991:17-18; Roy 2009:45), the community members attacked and actively sought support from friends, family members and others to ensure the community’s need for resources, among them food, shelter, health, and security was assured (Hanna & Roy 2001:10; Roy 2009:45; Masters 2012:131). Within the study’s context and as explained under the *role function* adaptation mode, the community members worked together to ensure their community survived without being infected. Unfortunately, guaranteeing the community’s safety led to the ostracism and discrimination of directly affected persons (refer to data display 6.2.3.3; 6.2.3.4; 6.2.3.5; 6.3.4; 6.5.1.2; 6.5.1.3).

- **Adaptation levels**

In consonance with Roy’s (2009:33) declaration, community members adapted to the news of the Ebola outbreak in an integrated, compensatory or compromised manner leading to positive or negative adaptation. This implies that those members of the community who adapted well showed resilience to news of outbreaks and the psychological challenges of fear, hysteria, panic, despair, anxiety, usually associated with news of Ebola outbreaks. As Roy affirms, such community members lived compensatory life process characterised by positive adaptation and coping, resulting in an integrated life process (Stanton et al 2007:565; Davydov et al 2010:481-483).

In contrast, members of the community who failed to adapt well continued to live compromised life processes, characterised by fear, hysteria, panic, despair and persistent anxiety (refer to data display 6.5.1.2; 6.5.1.3; 6.5.2.1; 6.5.2.2) due to inadequate integrative and compensatory mechanism capabilities of such community members (Cadell et al 2001:21; Reich 2006:793; Roy 2009:33; Masters 2012:130).

## **7.2.2. THE SOCIAL IDENTITY THEORY**

The Social Identity Theory (SIT) is one of a number of ways in which psycho-sociologists explain the occurrence of prejudice among humans. It was developed by Henri Tajfel and John Turner (1979) to understand the psychological basis of intergroup discrimination (University of Twente 2013:1-2). According to Tajfel and Turner (1979, in Trepte 2006:255) people tend to categorise themselves and others as belonging to different groups and evaluate these groups to the advantage of the group to which they belong: here as survivor, caregiver or member of the community.

### **7.2.2.1. Components of the Social Identity Theory**

The SIT has three components: social categorisation, social identification and social comparison (Crisp 2010:177; Smith 2011:1-2), all focusing on features of “the group’s beliefs and practices in the individual’s mind” (Hogg & Abrams 1988:3). The theory assumes that part of the self-concept individuals have is defined by belonging to certain social groups (Trepte 2006:255). The social categorisation aspect of the theory refers to the situation where an individual sees themselves as part of a group (Crisp 2010:177; Smith 2011:1-2). Social identification means an individual in addition to categorising themselves as belonging to a particular group, takes on the norms, behaviours and attitudes of the group members (Crisp 2010:177; Smith 2011:1-2). This leads to social comparison, characterised by in-group members comparing themselves against members of the “out group” which is usually perceived to be inferior. This feeling that “we are better than them” leads to discrimination against “inferior groups”; persons associated with Ebola (Crisp 2010:177; Smith 2011:1-2).

The basis of the social identity theory is the fact that people generally desire to have positive distinctiveness from out-groups, (desire to be better than others) so as to acquire a positive social identity characterised by positive self-esteem via association with a positively valued group, usually a dominant group (Crisp 2010:177; University of Twente 2013:2). Positive distinctiveness is the combined desire to be differentiated from out-groups (inferior or undesirable groups) and to be differentiated in a way that favours the dominant, in-group. As Tajfel and Turner (1979, in University of Twente

2013:1-2) proclaim, individuals are likely to display favouritism and discriminate against others when they feel that they will benefit by adopting such behaviour. This is especially so if members of the dominant group believe that doing so will protect their interests and group characteristics (safety, health status, freedom), particularly where the out-group has undesirable attributes, such as the association with Ebola.

#### **7.2.2.2. Relating the study findings to the Social Identity Theory**

In the context of this study, the emergence of Ebola meddled with the social identity that existed in the community and this resulted in the appearance of two groups: a “dominant” group and an “inferior” group. The dominant group consisted of members of the wider community not directly affected by Ebola; while the “inferior” group comprised survivors and caregivers directly affected by Ebola. Hence, as espoused by the SIT, community members viewed survivors and caregivers as an “inferior and undesirable” group because of their association with Ebola and actively sought to differentiate themselves, in order to protect and foster their positive distinctiveness.

As informed by the tenets of the SIT, participants in this study found themselves treated as “outsiders”, or “out-groups”, no longer able to interact with and belong to the larger society that existed before the Ebola outbreak. The discrimination and prejudice that arose out of fear of Ebola annihilated and alienated survivors and caregivers, from the preferred, “pre-Ebola group” (refer to data display 6.2.3.4; 6.2.3.5; 6.5.1.2; 6.5.1.3). It is this social rejection and altered social identity and the resulting stigmatisation that created the need for adaptation. In other words, it is through resilience actions that survivors and caregivers withstood and lived with the implications of altered social identity, reduced esteem and social abandonment. In these circumstances, resilience helped survivors and caregivers to resist, cope with, recover and bounce back and for some, even grow to in the face of such threat to their survival (Skinner & Zimmer-Gembeck 2007:119-120; Davydov et al 2010:482).

### **7.2.3. THE LABELLING THEORY**

Labelling theory (LT) is an explanatory framework that accounts for the effects of stigma associated with devalued standings, such as being delinquent, homeless, mentally ill, or having an infectious disease. The LT attempts to explain individual experiences of maltreatment, violence and negative attitudes that arise out of the interaction between a marginalised group and a marginalising group (Link, Cullen, Frank & Wozniak 1987:1461; Stuber, Meyer & Link 2008: 351; Pasma 2011:122-3).

#### **7.2.3.1. Basic Tenets of the Labelling Theory**

Originating in sociology, LT was developed to explain how individual's self-identity and behaviour may be determined or influenced by the way the society in which they live classifies them (Kroska & Harkness 2008:193; Pasma 2011:122). Like the SIT, the Labelling Theory further explains the psycho-social stimuli input (focal) stimuli and secondary stimuli calling for adaptation and which in itself are because of "others" adaptive attempts, in this case, the community who feared being infected by Ebola.

As an offshoot of the sociological concept of social interactionism, LT espouses that reality as seen in the world by individuals is socially constructed implying that understanding, significance and meaning are developed not separately within the individual, but with others within the larger community (Jenkins & Carpenter-Song 2008:382; Leeds-Hurwitz 2009:892). The theory asserts that social processes like identity formation, cooperation, conflict and perceptions are products of human interaction (Jenkins & Carpenter-Song 2008:382; Leeds-Hurwitz 2009:892). The theory further declares that social construction of reality is a creative on-going process characterised by dynamic human to human interactions with intersubjective negotiation of reality (Kroska & Harkness 2008:193; Macionis & Gerber 2010:131-2).

An important aspect of such intersubjective creation of reality relates to how communities create labels that eventually come to define how individuals within the community are referred to and even get treated because of possessing a particular attribute. These labels often come either with positive or negative attributes. As Link

and others (1987:1461) substantiate, labels play an important role in how those considered belonging to “unfavourable” or “inferior” group are perceived by members of the “favourable” or “dominant” group. In fact, Jenkins and Carpenter-Song (2008:382) are of the opinion that this negative labelling is what motivates members of the dominant group to negatively label and subject members of the minority (undesirable) group to ridicule, social rejection, stigmatisation and discrimination.

### **7.2.3.2. Relating the study findings to the Labelling Theory**

In this study, the labelled group consisted of survivors and caregivers, who needed to stand strong against the dominant group’s (community’s) negative labelling (Edgerton 1993:131, in Jenkins & Carpenter-Song 2008:382). The stigma associated with such labelling requires resilience efforts to counter the threat it has on the individual’s self-concept, mental image, and their perception of themselves and their social identity (Edgerton 1993:131; Pasman 2011:122; Markowitz, Angell & Greenberg 2011:144).

When individuals have weak defences, the LT posits that being labelled, for instance as mentally sick or delinquent, may actually cause a person to become mentally ill or delinquent due to self-fulfilling prophecy and self-stereotyping (Darley & Farzio 1980, in Markowitz et al 2011:147; Pasman 2011:122). Survivors and caregivers with a weak self-concept risked being negatively affected by this “prophecy” of self-stereotyping and self-discrimination (Yang et al 2007:1527; Markowitz et al 2011:147). While substantiating on this affirmation, Link, Cullen, Struening, Shrout and Dohrenwend (1989:400-402) declare that the danger associated with the negative labelling is that it erodes one’s self-concept and makes the stereotypical attitudes about a person personally relevant to the individual, making them adopt self-stereotyping and self-discriminatory stances in the face of continued labelling. The findings revealed that some “weak” survivors and caregivers indeed adopted dysfunctional (non-adaptive) coping styles among them secrecy, non-disclosure or social withdrawal from others (refer to data display 6.7.6). This further narrowed their social networks leading to deeper isolation and reducing their chances for employment and income generation (refer to data display 6.1.1.2), thus affecting their health and wellbeing (Kroska & Harkness 2008:193; Markowitz et al 2011:146).

Another outcome of personalising stigmatising beliefs “imposed” on the labelled persons is that they may begin to expect devaluation and discrimination by the dominant group which demoralises them, lowers their self-esteem and self-efficacy and increases their chances of developing depressive disorders (Markowitz et al 2011:146; Pasman 2011:122). Although depression was not the focus of the study, I deduce that living through the widespread negative labelling, was partly possible by survivors and caregivers being resilient and embracing effective coping strategies like seeking support from others and adopting optimistic and positive attitudes (refer to data display 6.7.3; 6.7.4). I further propose that this is what aided survivors and caregivers to transcend the various challenges without becoming overtly depressed.

### **7.3. OUTCOME OF SURVIVORS, CAREGIVERS AND COMMUNITY ADAPTATION**

The concept of adaptation means responding positively to environmental changes and is defined as “the process and outcome whereby thinking and feeling people, as individuals or in groups, use conscious awareness and choice to create human and environmental integration (Roy 2009:28; Wills 2011:171; Masters 2012:129). An individual adapts by means of both innate and acquired capability. The innate capacity refer to physiological response such as the reflex like actions that are inborn and genetically programed, while the acquired adaptive capacity are those learnt over time and through experience (Roy 2009:41-42; Masters 2012:139-140).

The outcomes of adaptation and the coping processes within Roy Adaptation Model (RAM) are comparable to those espoused under the Social Identity Theory (SIT), which explains why prejudice occurs among human beings (refer to section 7.2.2) and the Labelling Theory (LT), which explains how individual’s self-identity and behaviour may be determined or influenced by the way the society in which they live classifies them (refer to section 7.2.3). A discussion of the outcomes of survivors’, caregivers’ and community’s adaptation follows with features of these 3 theories incorporated to promote a deeper understanding of the various adaptation strategies:

As indicated previously, the responses that result from regulator and cognator activity following adaptation are termed adaptive behaviours, with regard to the current discussion, outcomes. Roy insists that although direct observation of the regulator

and cognator subsystems processes is not possible, an individual's behavioural responses that arise from these, as expressed in the four adaptive modes can be observed (Zhan 2000:159; Roy & Zhan 2001:317; Roy 2009:43). Individuals' outcome behaviour can be used to assess how well they are adapting in their interaction with the internal and external environment (Roy & Andrews 1999:43; Roy 2009:31-32). This observable behavior can be adaptive (compensatory) or ineffective (compromised). An adaptive behavioural response promotes survival, growth, reproduction, mastery including human/group-environment transformations. Ineffective adaptive responses do not effectively contribute towards a person's adaptation goals (Hanna & Roy 2001:10-11; Roy 2009:57-58; Master 2012:130-131).

As Hanna and Roy (2001:10-1) much like Roy (2009:41) reiterate, these adaptations help survivors, caregivers and community members to seek relief from pain, fear and anxiety by among others making appraisals and attachments and detachments through emotions and physical distance as and when necessary (Roy 2009:41). This adaptation process entailed survivors, caregivers and community members consciously or unconsciously engaging various coping mechanisms to adapt to and increase their "resilience" to the various stressors such as the social isolation, ostracism and stigma and the associated psychological burden of fear and anxiety.

As Tajfel and Turner (1979, in Trepte 2006:255) explain within the SIT, the rampant social isolation, ostracism and stigmatisation "championed" by the community to which survivors and caregivers had to adapt and develop resilience, began when unaffected members of the community" categorised themselves as belonging to the "safe group" and the directly affected persons (patients, caregivers and survivors) as belonging to the "undesirable group" because of their association with Ebola infection. With this social categorisation, the unaffected members "worked" towards defending their community of "inferior" members to protect the "group identity" and ensure "group maintenance" (Hanna & Roy 2001:10; Crisp 2010:177; Smith 2011:1).

Such "identity formation" is supported by the LT which according to Link et al (1987:1461) play an important role in how those considered to be "unfavourable or inferior" are "perceived and treated" by members of the "majority or dominant group".

It is this negative labelling that motivated the community to ridicule, ostracise, and even dehumanise survivors and caregivers (Jenkins & Carpenter-Song 2008:382).

As previously articulated, the outcomes of individual or group adaptation is development of resilience, which signifies reduced 'vulnerability', implying that whenever an individual or group is confronted with an adversity, they ably move forward with life with minimum of consequences (Dyer et al 2004:57; Hofer 2006:259; Davydov et al 2010:481). In the current study, survivor's, caregiver's and community's resilience increased as they adapted and re-adjusted to the new reality of Ebola despite experiencing multiple personal and group losses (Cameron 2007:285; Kim-Cohen 2007:271), ably "coping" during the outbreak and in-between outbreaks (Skinner & Zimmer-Gembeck 2007:119; Davydov et al 2010:481), often becoming empowered, bouncing back stronger and even growing in the face of subsequent Ebola outbreaks (Cadell et al 2001:21; Reich 2006:793; Roy 2009:12).

However, while the majority of survivors, caregivers and community members adjusted and adapted well to the antisocial overtones (isolation, discrimination) and the psychological "pressure" that it created (anger, anxiety, fear), some of them failed to adapt and they opted for the "self or community" destructive coping mechanism of avoidance, distancing and withdrawing characterised by persistent fear and anxiety (refer to data display 6.7.6) way beyond the "expected" fear period. Such maladaptive individuals or groups call for the attention of healthcare teams to promote their health.

In view of these explications, the study findings as well as the individual needs of survivors, care givers and community members, the role of healthcare workers within the RAM and related frameworks is to promote and facilitate adoption of adaptive behaviour with the aim to increase individual and group resilience during outbreaks (Roy 2009:12; Clarke et al 2011:344). Health workers, working with the Ministry of Health and other government departments, development partners, non-governmental organisations (NGOs) including faith based organisations (FBOs) should during serious and life-threatening epidemics such as Ebola outbreaks promote individual and group resilience by enhancing positive adaptation among the most affected individuals and groups. Such efforts are vital to promote their health and well-being.

The findings indicate that the community treated survivors, caregivers and other persons such as health workers involved in direct care of Ebola patients as “outsiders”, or “out-groups”, and the community severed social and sometimes physical linkages with them, implying that such persons could no longer freely interact with their social groups as before the Ebola outbreak. To help these individuals cope with isolation and to reduce chances of them developing more serious maladies like depression and anxiety, Phemister and Crewe (2004:34) and more recently Ashley and Reiter-Palmon (2012:3) propose that efforts should be geared towards increasing their resilience. Increased resilience allows them to surmount any negative feelings that may arise because of their “unwanted differentness” (Selimbegović & Chatard 2013:757; Pinel & Bosson 2013:55), enabling them to combat diminished self-esteem and altered self-concept (Phemister & Crewe 2004:34; Markowitz et al 2011:147). It is this widespread ostracism, coupled with the negative evaluation of self, including altered social identity and the resulting stigmatisation, which created the need for fostering “adaptation” within the “self-concept-group” adaptive mode in survivors, caregivers and among the community.

In this regard, health workers’ role according to RAM would be to foster self-image through educating and counselling of affected persons (Roy 2009:44; Masters 2012:130). This view is consistent with Leininger’s (2001:362-63) postulates in the culture care diversity and universality theory, especially the belief that culturally based care can significantly contribute to human health and wellbeing and that transcultural health care can provide meaningful and therapeutic outcomes. This implies that when culturally congruent health care “actions” are delivered through the modes of “culture care preservation/maintenance” (where client’s beliefs are preserved), “culture care accommodation/negotiation” (where client’s beliefs are negotiated) or “culture care re-patterning/re-structuring” (where client’s beliefs are re-structured or re-patterned), health workers can provide culturally congruent health care which uphold client’s cultural practices and beliefs while promoting their recovery and wellbeing (Roy & Andrews 1999:81; Leininger 2001:370; Roy 2009:31). Furthermore, another perspective from which the study findings may be interpreted using the RAM lens deals with fostering adaptation efforts within the “interdependence” adaptive mode which involves giving and receiving of love, respect

and value to achieve relational integrity or the feeling of security in nurturing relationships (Roy 2009:45; Wills 2011:172). This may assist to restore social relationships and social interactions to levels before a “social stressor” emerged.

In the absence of “relational integrity” individuals experience lack of affection, they are disrespected and not accorded due value as the study participants reported (refer to data display 6.2.3.3; 6.2.3.4; 6.2.3.5). The “interdependence” adaptive mode can be enhanced by appropriate and timely family and community social education to cultivate “love”, “respect” and “value” for the affected persons and families, so that they can feel secure to relate to others. Such education sessions have the potential to make families and communities more accepting of survivors and caregivers thus ‘minimising the incidences of rejection and disrespect towards affected persons. Further, improving the capacity of say widows, widowers, caregivers or survivors through self-help projects and skills training can empower them with “technical skills” which can make it easier for them to earn respect and become more valuable members of their community (Roy 2009:45; Wills 2011:172; Masters 2012:131-132).

The findings indicate that participants experienced numerous stressors which can be categorised as equivalent to internal and external stimuli as espoused by the RAM. In view of this, fostering resilience through enhancing adaptation in the four adaptive modes is essential to ensure that affected persons survive the illness, and upon recovery they do not perceive themselves as “unworthy” and do not adopt dysfunctional coping styles which may otherwise further damage their physical, psychological, social, economic and spiritual wellbeing. This is where the notion of self-worth and community respect for all individuals need to be fostered as “in advance” (current) indicator of adaptation and resilience during future outbreaks.

Efforts to keep, foster and potentiate high level individual adaptation require interventions from within and outside the individual to protect their physiological-physical integrity by focusing on healthy lifestyles and prompt disease management processes (Roy 2009:43-44; Wills 2011:172). Such efforts also require focusing on psychological and spiritual integrity by enhancing self-concept-group identity to

achieve a sense of unity, meaning, and purposefulness in the universe by addressing issues of personal self, self-image, and moral ethical and spiritual issues. Also, current adaptive efforts should focus on maintaining social integrity of affected persons by facilitating them to freely implement their individual, family and societal roles within their home communities, while nurturing their relational integrity by fostering the giving and receiving of love, respect and value (Roy 2009:43-44; Wills 2011:172); currently in preparation for future Ebola outbreaks given their vulnerability.

#### **7.4. CONCLUSION**

In this chapter as Wertz (1985:213; 2011:160) and Creswell (2014:65) affirmed, I related the various themes and categories to the central concept of adaptation to promote deeper understanding of participants' experiences. This explication also allowed comparison of the key findings with existing models to facilitate generalisations which represent interconnection of thoughts on human adaptation. This further fulfils the expectation of qualitative research; that of bolstering existing scientific and nursing knowledge. In the next chapter, the study is summarised and guidelines to nurture survivors', caregivers' and community resilience are proposed.

**CHAPTER 8:**  
**SUMMARY OF FINDINGS, CONCLUSIONS, RECOMMENDATIONS, PROPOSED  
GUIDELINES AND LIMITATIONS**

### **8.1. INTRODUCTION**

In this final chapter, the research process is summarised, highlighting key findings, conclusions and recommendations. The discussions on the various themes, categories and subcategories as explicated in chapter six are explained within selected theoretical models and frameworks to demonstrate their trustworthiness.

### **8.2. PURPOSE OF THE STUDY**

The purpose of this study was to:

- gain a clear understanding of how living under a constant threat of Ebola is experienced, including what reactions towards affected persons symbolises.
- propose guidelines as well as perspectives that healthcare workers and policy makers may use to address the human aspects of similar epidemics in future.

### **8.3. THE GUIDING RESEARCH QUESTION**

The overarching research question that was negotiated with the participants was:

- How do you experience living under a constant threat of Ebola?

Alternatively:

- How do you experience the constant threat of Ebola?

## **8.4. RESEARCH DESIGN AND METHOD**

A phenomenological method was chosen to implement Wertz's (1983/2011) phenomenological data analysis framework. The research method served both as philosophical and methodological basis of the study and allowed description of "things" as they appear in participants' lived experiences (Finlay 2009:6; Wertz 2011:132), and this helped to arrive at "unique individual" and "universal essence" of the experience within a social cultural context (Ricoeur 1990, in Terra et al 2009:95).

### **8.4.1. Sampling**

The research study utilised purposive, convenience, and criterion sampling techniques to draw twelve (12) participants, among them five survivors and seven caregivers. Each of them consented in writing before they were allowed to participate.

### **8.4.2. Data Generation**

In-depth qualitative interviews were conducted with twelve participants who had been sampled based on the inclusion criteria and the interviews continued until data redundancy occurred. The interviews were semi-structured, contextual and digitally recorded. In addition, relevant field notes were also generated during the interviews.

### **8.4.3. Data analysis**

Data analysis was conducted at both idiographic and nomothetic levels in accordance to Wertz's (1983/2011) phenomenological data analysis framework based upon seven pre-selected themes and this eventually lead to emergence of categories, subcategories and sub-subcategories supportive of the themes. Data analysis was based on the assumptions that survivors' and caregivers' lived experiences would be expressed in manner that would provide a reality sufficiently unique to allow in-depth understanding of personal experiences. As Wertz (1983/2011) recommends, a "single super category", one that accommodates supports or gives credence to all

themes and categories was eventually selected upon final synthesis of the findings. This central and encompassing concept is “adaptation”, as expounded in chapter 7.

#### **8.4.4 Literature support**

A preliminary literature review was undertaken to open the researcher to the complexities involved in studying the experience of living under constant threat of Ebola. This review was intended to introduce the researcher to the context of the phenomenon and the socio-cultural perspectives that would eventually prove helpful for interpreting the findings. However, the main literature review was performed as a literature control to explicate the various themes and categories that emerged from the data as articulated in chapter 6 and presented in further detail in chapter 7. The review of literature covered the disciplines of nursing, psychology and psychiatry.

#### **8.4.5. Trustworthiness**

The study’s trustworthiness was assessed and ascertained in terms of its credibility, transferability, dependability and confirmability as explained in section 4.9. In order to further demonstrate the extent of the transferability of the findings, the all-encompassing concept of “adaptation” was discussed in-depth in chapter 7 and found to be generalisable and meaningful to survivors’ and caregivers’ various situations.

The concept was further discussed in relation to existing theories to not only enhance the study’s trustworthiness, but also to demonstrate how these theories support in a practical way possible interventions that can be employed to enhance survivors’ and caregiver’s resilience in the face of future Ebola outbreaks in Uganda and the region.

Further, various processes through which participants “adapted” where integrated with existing theories and recommendations that can be used to enhance survivors’ and caregiver’s *resilience* in the face of continued Ebola threat were then proposed.

## **8.5. FINDINGS, CONCLUSIONS AND RECOMMENDATIONS**

In this section, salient features of the study, namely themes and categories are summarised with reference to the all-encompassing concept of “adaptation”. Informed by these findings, pertinent conclusions are drawn and recommendations formulated:

### **8.5.1. Theme 1: Living under constant threat of Ebola**

#### **Findings:**

Participants described living under constant threat of Ebola as terrifying, characterised by numerous negative experiences including coming face to face with certain death. Survivors and caregivers reported experiencing intense fear, ostracism and stigmatisation (data display 6.1.1.1). They felt Ebola had annihilated them from their past existence and diminished their possibilities (data display 6.1.1.2). A defining feature of the traumatic experience was that the negative experiences such as social isolation lingered on for several weeks and months, even after the epidemic ended (data display 6.1.1.3) and these resulted in several psychosomatic manifestations during the outbreak and in the aftermath (data display 6.1.1.4). This led to the locals to conclude that suffering from the negative consequences of Ebola was an inescapable reality (data display 6.1.1.5). The findings also indicate that while the outbreak was frightening and traumatic, most survivors and caregivers adapted to the threat and reality of Ebola by actively seeking opportunities for self-preservation and protection (data display 6.1.2.1), which led the majority to transcend their “victimhood” state and became “empowered” individuals (data display 6.1.2.2).

#### **Conclusion:**

Living in an Ebola prone area signifies a real threat to one’s life especially during an outbreak. The evidence available shows that when such an epidemic occurs, the experience is not only terrifying, but it is life-threatening as well, because of the

possibility of death due to the high virulence of Ebola. The findings also indicate that if timely interventions are not implemented, the widespread fear, ostracism and stigmatisation may proliferate to disproportionate levels leading to severe annihilation of survivors and caregivers which in turn limits their opportunities for meaningful living within the short and long term, implying a potentially negative impact on their wellbeing. These findings imply that while Ebola is experienced as traumatic, survivor's and caregiver's adaptive capacity plays a fundamental role in mediating these negative experiences and also to a large extent, a substantial role in their self-preservation and protection efforts, including facilitating their personal journeys of transcending from being "helpless victims" to becoming active empowered members.

**Recommendation:**

In order to reduce the rampant fear, ostracism and stigmatisation and the resulting disproportionate annihilation of survivors and caregivers, it is recommended that during outbreaks constant education of the public is undertaken by health workers and trained community volunteers using mobile film vans, regional radios and through home visits. The focus of such education should be on the signs and symptoms of Ebola, procedures for protecting family members as well as appropriate referral including expectation of antisocial behaviour. The media should play a major role in educating the public about the disease to help reduce the anxiety and misinformation normally associated with Ebola outbreaks, particularly infection transmission methods. The community mobilisation efforts by the volunteers should include distribution of information, education and communication messages using posters, leaflets, brochures in local dialects for easy understanding by the community. This approach was used by the Uganda Red Cross Society during the November 2012 Ebola outbreak in Luwero District and resulted in considerable reduction of public hysteria (IFRC 2013:4-5). It is also recommended that those who contract the illness should be handled by health workers in a manner that reduces public terror and anxiety, ensuring that they do not appear terrified by Ebola patients. Furthermore, health teams should also enhance the adaptive capacity of survivors and caregivers in a holistic manner, especially cognitively by helping them find meaning in their

experience, enable them gain to mastery over their challenges as well as to restore their self-esteem through positive self-evaluation derived from psychotherapeutic interventions during and in between outbreaks. The ultimate rationale of these resilience building efforts is help to ensure survivors and caregivers are well adapted to their situations, focus pertinently on self-preservation and self-protection and are in position to move from state of “helplessness” to that of “empowerment” and “growth”.

### **8.5.2. Theme 2: Nature of Ebola Experience: unique and general experiences**

#### **Findings:**

Participants experienced the outbreak as both a positive and negative event, with the experience defined by the central role caring others played in their struggle to survive (data display 6.2.1.1). The findings also indicate that survivors and caregivers vacillated between episodes of hope and hopelessness (data display 6.2.1.2) during the outbreak period and even in the aftermath. It was discovered that survivors and caregivers had both positive and negative experiences. The positive outcomes relate to improvements in personal hygiene and protection practices (data display 6.2.2.1), self-awareness and health seeking behaviour (data display 6.2.2.2) as well as improved clinical care practices (data display 6.2.2.3). The negative outcomes were abandonment of culturally cherished practices of congeniality (data display 6.2.3.1); loss of close relatives (data display 6.2.3.2); ceaseless rejection of survivors and caregivers (data display 6.2.3.3); widespread isolation and ostracism (data display 6.2.3.4) as well as stigmatisation, shame and embarrassment (data display 6.2.3.5).

#### **Conclusion:**

These findings imply that experiencing an Ebola outbreak has both positive and negative consequences. The findings further reveal that the role of caring others, either as relatives, health workers or volunteers helps survivors and caregivers to adapt to the negative consequences of Ebola. It is further evident that experiencing Ebola is associated with episodes of optimism for favourable outcomes at one time

and experience of hopelessness and despair at another. The findings also reveal that whilst Ebola outbreaks are mostly dreaded, they can still have positive outcomes. In a positive sense, the outbreak “taught” survivors and caregivers personal hygiene and self-protection practices and increased their self-awareness and health seeking behaviour, particularly in the aftermath of the outbreak. The epidemic also resulted in improved clinical and healthcare practices of survivors and caregivers especially among healthcare workers. In the negative sense, the unprecedented deaths exacerbated abandonment of culturally cherished practices of congeniality leading to isolation, ostracism and stigmatisation of survivors, caregivers and close associates.

**Recommendation:**

Cognisant that an Ebola outbreak has both positive and negative consequences on survivors and caregivers, appropriate interventions are recommended to harness the central role of caring others in order to assist survivors and caregivers in their struggle against the undesirable consequences of the epidemic. In part, communities should be educated through social health education during and in between outbreaks using different media on the need to care for and support individuals and families affected by Ebola especially after they are certified as cured and declared Ebola free.

The researcher advances that in Ebola prone areas, personal hygiene and protection practices and increased self-awareness and health seeking behaviour, during and in between outbreaks should be fostered through continuing health teaching and encouragement by awarding certificates of cleanliness by health authorities. Ministry of Health should further encourage by means of continuing education and support supervision, health workers deployed in high risk areas to uphold universal precautions and follow infection control and prevention strategies throughout clinical exposures irrespective of whether or not there is a disease outbreak. The Ministry of Health through Developmental partners and local agencies should also continuously educate communities about the actual and potential dangers of Ebola to help reduce the “unprecedented” fear caused by misinformation and exaggeration about Ebola. It

is proposed that such community education activities should span entire outbreak periods and continuing well into the in between outbreak period albeit less frequently.

In order to ensure culturally congruent care, it is recommended that during outbreaks there is need to always uphold one of the most sacred ceremonies that is highly valued by the locals, that of burial. It is recommended that the burial teams should work with at least one family member designated to conduct some basic ritual while wearing protective clothing to enable the family feel dignity was awarded to their relative. Leininger (2001:316) describes this culture care preservation mode of health care, which means to provide congruent health care, professional caregivers should uphold client's cultural practices and beliefs as long as they promote their recovery.

As McFarland (2001:385) affirms, such therapeutic care modes fit with people's life ways and satisfy them, leading to better cooperation. It is also proposed that to ensure survivors' and caregivers' capacity to adapt and transcend episodes of hopelessness, social isolation and stigmatisation is enhanced, health workers should through individual or group psycho-education and cognitive therapy, enhance survivors and caregivers' internal strengths such as positive attitudes, self-mastery while at the same time work with others to provide external support such as availing opportunities for gainful employment and social support to increase their resilience.

### **8.5.3. Theme 3: Surviving Ebola: physical, psycho, social, spiritual implications**

#### **Findings:**

Surviving Ebola has profound effect on the wellbeing of survivors and caregivers, which may be categorised as physical (data display 6.3.2), psychological (data display 6.3.3), social (data display 6.3.4), spiritual (data display 6.3.5) as well as economic (data display 6.3.6) in nature. The physical consequences included body weakness, pain, memory loss and bladder weakness, which affected survivors' physical integrity and self-concept. The psychological effects were fear, depression, hopelessness, pain, altered body image and numbness. While, socially, there were reports of protracted ostracism and rejection and stigmatisation. Spiritually,

participants experienced increased sense of religiosity and the feeling that their survival meant they still had to “complete their mission on earth” and others attributed their survival to “reward” from God. The economic implications undoubtedly arose out of increased expenditure due to loss of property caused by response teams, costly treatments as well as loss of income arising out of the difficulties with sustaining customers especially for sufferers engaged in private business due to social stigma.

### **Conclusions:**

Whilst surviving Ebola is experienced as delightful, with most considering it as “the impossible becoming a reality”, however, survival resulted in several repercussions within physical, psychological, social, spiritual and economic realms. These negatively affected survivors’ well-being and precipitated poorer health outcomes. These experiences call for resilience building during and in between Ebola outbreaks.

### **Recommendation:**

The Ministry of Health should design special clinics for follow up of survivors to address the physical health needs related to the direct effect of the virus on the body in designated health facilities. It is further recommended that during these clinic appointments survivors and their close family members should receive psychotherapy sessions to address psychological challenges the disease may have created. These sessions, it is further suggested should also address root causes of say rejection and stigmatisation, being experienced by survivors and their families.

In another dimension, it is further recommended that the Ministry of Health and Ministry of Information and Broadcast should issue guidelines and monitor the messages of media houses for responsible journalism. This will ensure that the media is engaged in positive information sharing and creating accurate picture of the outbreak and gets involved in educating the masses about the disease, the modes of transmission and prevention as well as related information in non-frightening manner.

The health authorities should work closely with the media, by involving them early in the epidemic response efforts and providing them with correct information about the illness and epidemic control in bid to minimise the widespread hysteria and anxiety.

In order to address the social implications of the outbreak among them to reduce social isolation and stigmatisation and ensure better integration of survivors and caregivers back to their communities, continuing mass education using print, radio and electronic media is recommended, in addition to house-to-house health promotion visits in the most affected areas. After discharging survivors from isolation units, health workers should accompany them and hand them officially to the community with their certificates of wellness from the hospital, assuring the public that they are no longer infectious, and that they should be allowed to re-integrate back into the community. These should be followed by follow up visits by mobilisation teams including health workers to help assure the neighbours of survivors' recovery.

Spiritually, survivors and care givers should be encouraged to pursue interventions such as "healing" prayers which they choose to perform as long as they seem not to interfere or compromise infection control efforts. Leininger (2001:369) describes this accommodation as "culture care preservation" in the Sunshine Model of Care where recipients of care are allowed to retain care that has folk or generic care practices in order to provide culturally congruent care to individuals, families and communities.

In support, McFarland (2001:385) affirms that such care modes fit with people's life ways and often enhance their satisfaction with the professional health care system, resulting in better cooperation and overall positive health outcomes. The incorporations of culturally acceptable interventions congruent with local beliefs were well received during the latest Ebola outbreak in Luwero in Uganda (IFRC 2013:4-5).

In terms of economics, it is recommended that the Government working through the line Ministries of Finance and Health should provide meaningful financial compensation to offset the economic losses associated with epidemic control efforts

as well as the effect of negative publicity experienced by business persons affected by Ebola outbreaks. It is further recommended that the Government undertakes efforts to provide employment opportunities to such individuals and families as a form of affirmative action to help protect the economic interests of the affected populations.

To address the short and long term psychological effects, psychotherapists need to be involved during outbreaks and in between the outbreaks to participate in providing psychological care to the affected persons. After discharging the survivors from hospitals, some of the counsellors should continue with follow up home visits deep into the aftermath of Ebola to ensuring that the affected adapt well to their challenges.

#### **8.5.4. Theme 4: Caring for Ebola patients: meanings and implications**

##### **Findings:**

Participants experienced caring for affected individuals as deeply fear-inducing and stressful; knowing that Ebola is a severe and life-threatening illness. Caring for persons with Ebola meant one was drawn to “carrying” these associated burdens. The social consequences were social isolation as well as ostracism and stigma (data display 6.4.2). In contrast, psychological challenges included fear, despair, anxiety, sleeplessness, paralysis, helplessness and anorexia (data display 6.4.3).

##### **Conclusions:**

Caring for persons infected with Ebola is a deeply fear-inducing and stressful event due to the ferocious nature of Ebola. This means that in future, as part of the constant practices, early in epidemics, appropriate interventions are needed to address the deep rooted fear and stresses experienced by caregivers by timely preparing them through health education for the impending challenges in order to mitigate the negative implications of caregiving and to ensure they get adequate psychological “protection”.

**Recommendations:**

Caregivers should receive specific health education during house-to-house visits to address the deep rooted fear and stress associated with caregiving. The education should focus on basic nursing skills (universal precautions) to stave off possibility of contracting infections in the course of caregiving. Secondly, the impeding social implications among them ostracism, discrimination and stigmatisation should be addressed by “mentally” preparing caregivers to expect these consequences. Hence, caregivers should be encouraged through counselling not to internalise such stigma.

In addition to focusing on them as individuals in a reactive manner, the Ministry of Health should continue using various media to educate and urge the public not to ostracise caregivers. Further, there should be regular home visits to offer caregivers social support especially in the interim when fear, hysteria and anxiety are rampant. To address the psychological implications, individual, family and community psychotherapy sessions should be provided at the height of the outbreak as was the case in Luwero district during the November 2013 outbreak as part of the community mobilisation effort (IFRC 2013:4). Such psycho-education interventions are designed to enhance caregivers’ resilience by increasing their capacity to resist, adapt to or recover from emotional reactions to prevent them from succumbing to serious psychological problems like depression, post-traumatic stress disorder and suicide.

**8.5.5. Theme 5: Public reaction towards persons affected by Ebola****Findings:**

The findings indicate that prior to the outbreak the surrounding communities in Kibale district were well integrated, socially vibrant and individuals and families carried out routine activities in their homes, shops, and places of work (data display 6.5.1). However, when Ebola was confirmed, it precipitated fear, panic and ostracism and resulted in widespread stigmatisation of individuals and families infected, believed to be infected or who had had contact with those suffering from Ebola. The hysteria was

exacerbated by unsubstantiated media reports that amplified the ferocity of the disease, leading to abandonment of key culturally cherished practices of congeniality.

**Conclusions:**

The findings indicate that the “arrival” of Ebola upset the usual social platform of the community and resulted in the emergence of antisocial acts of ostracism and stigmatisation due to the pervasive fear and panic associated with the outbreak. These antisocial reactions appear to have been fuelled by ignorance and misconceptions about Ebola. This necessitates constant health education using the media to educate the public about the actual nature of Ebola, including how it spreads, its true picture and how to prevent it from spreading to others. This is vital because fear and hysteria seem to arise from people’s desire to protect themselves against the actual and exaggerated dangers of Ebola outbreaks (data display 6.5.2).

**Recommendations:**

In future outbreaks, interventions should focus on maintaining the “integrity” of community members by increasing their resilience to the “unsettling” nature of Ebola, by providing accurate information about Ebola, including its modes of transmission and prevention to minimise the fear and hysteria that usually surrounds outbreaks. The media should always be integrated early in the epidemic to ensure accurate and responsible reporting since unsubstantiated reporting inadvertently amplifies outbreaks, leading to extraordinary social frenzy. Preferably, such interventions should start as soon as an outbreak is declared and should continue long into the aftermath, ensuring the public is provided with accurate information to reduce the widespread misinformation and exaggeration traditionally associated with outbreaks.

### 8.5.6. Theme 6: Social-cultural beliefs and practices related to Ebola

#### Findings:

Participants reported that the community understood Ebola from two perspectives: either as a supernatural occurrence or as a natural occurrence. Those who perceived Ebola as supernatural occurrence (data display 6.6.1.1) attributed the outbreak to satanic or evil spirit attacks; punishment by deities and “bad” hearted people working through supernatural agents; results of interfamilial disagreements; and witchcraft, charm or sorcery. In contrast, those who believed Ebola was a naturally occurring disease as explained in data display (6.6.1.2) thought of it as a “normal” infectious disease that spreads through contact from one person to another. However, those who believed Ebola is “supernatural” sought supernatural healing remedies including seeking help from established places of worship like churches, mosques and healing palaces operated by locally revered prophets and prophetesses and spiritualists.

Further, those individuals and families who considered Ebola as a “normal” disease sought treatment from regular clinics and nearby health facilities and hospitals to treat symptoms like headache, diarrhoea and fever. Additionally, a third group sought help from both biomedical sources such as drug shops and clinics as well as from supernatural sources like spiritual healers, prophets, prophetesses and witchdoctors.

#### Conclusions:

The findings show the community understood Ebola as either as a supernatural or a natural entity, and this influenced their choice of treatment, depending on whether they perceived Ebola as supernatural occurrence associated with “spiritual” powers or as “normal” infectious disease requiring biomedical interventions. This has serious implications for disease control because health seeking patterns were clearly determined by an individual’s perception of what actually causes Ebola. Influenced by their perception, affected persons either choose supernatural remedies such as faith

healing from prophets, prophetesses and spiritualists or natural remedies such as antimalarials and antibiotics from clinics and health facilities. While others choose both biomedical sources such as drug shops as well as supernatural sources like spiritual healers, prophets, prophetesses and traditional healers. In order to ensure success in future epidemics, it is critical to understand the perspectives individuals hold about causes of Ebola as this directly influences their health seeking practices.

### **Recommendations:**

Informed by these findings, it is always imperative that early in outbreaks, explanatory models of causation of Ebola need to be identified to inform suitable interventions that can counter negative perceptions, while encouraging those perspectives that contribute positively towards controlling the outbreak. This is consistent with Leininger's (2001:368-369) insistence on "culture care maintenance or preservation" and "culture care re-patterning or restructuring" modes of care where caregivers are required to work with recipients of care to "preserve" positive health practices and values and "reorder" or gently "modify" those that are perceived to be harmful to their health and wellbeing. Such actions that respect and value clients cultural beliefs and values will ensure that the health messages and community education information packages are evidence-based and culturally-sensitive, and address only those concerns that are counterproductive to epidemic response efforts, thereby increasing chances of being accepted. Such culturally appropriate health information and advice when well implemented often leads to what Leininger (2001:370) describes as "culturally congruent care" which leads to better individual and community satisfaction. Understanding the dominant explanatory models also promotes identification of key stakeholders among them trusted healers as prophets, prophetesses or spiritualists, who can become "community contact points" and can be "facilitated" to encourage early and timely referral of patients to the established treatment centres. This novel recognition and collaboration can limit the spread of Ebola due to early case detection leading to timely isolation of infected persons.

### **8.5.7. Theme 7: Coping with and living in the “in between” of Ebola outbreaks**

#### **Findings:**

Participants reported that the physical, psychological, social, spiritual and economic consequences of living with, or under, constant threat of Ebola created a heavy burden that survivors, caregivers and close families had to withstand, overcome and transcend. The findings show that survivors and caregivers adopted several coping mechanisms to weather these challenges including actively engaging to overcome the challenges (data display 6.7.1); engaging in fervent prayers and prescribed religious acts (data display 6.7.2) and seeking support from caring others (data display 6.7.3). In contrast, other participants reported adopting optimism and positive attitude (data display 6.7.4); while a few others surrendered and accepted their fate (data display 6.7.5), while some resorted to avoidance, distancing and withdrawing techniques (data display 6.7.6). In mitigating these challenges, participants adopted these approaches interchangeably, using more than one coping technique at a time.

#### **Conclusions:**

The findings reveal that being affected by Ebola is a life changing experience because of the far reaching implications of the disease on both survivors and caregivers. This implies that if no need specific measures are taken, affected persons may suffer physical, psychological, social, spiritual and economic consequences for a prolonged period of time. To ensure these challenges are not overwhelming, timely interventions are recommended to increase survivors' and caregivers' capacity for adaptation and eventually to become resilient. These findings further illustrate that survivors and caregivers may adopt various coping strategies depending on their unique circumstances as they struggle to resist and overcome these challenges.

**Recommendations:**

Given that being affected by Ebola is a truly life changing experience with far reaching implications on both survivors and caregivers, appropriate interventions are needed to increase the resilience levels of survivors and caregivers during an outbreak. To increase survivors' and caregivers' capacity to adapt to the physical challenges such as visual disturbances, it is recommended that they are timely treated in the "special follow up clinics" staffed with a multidisciplinary team in designated health facilities following an outbreak. In addition to attending to the physical challenges, counsellors and specialists in psychotherapy would also address the identified psychological challenges. Further, the social workers assigned to the clinic should also help to address the social challenges being experienced including accompanying survivors to their communities as a way to lessen the ostracism. In addition, health authorities should through the constant social health education sessions prepare survivors and caregivers to expect the antisocial attitude expressed towards them, assuring them that such attitudes tend to persist but eventually go as the fear wears. In terms of spiritual remedies, it is recommended that health workers and social workers should encourage survivors and caregivers to seek supernatural or natural beliefs and practices that they believe can improve their life ways such as consultations with revered deities and other forms of spiritual practices as affirmed by Leininger (2001:369) because of its potential to lead to better satisfaction with care.

In terms of helping survivors and caregivers to overcome economic challenges, it is recommended that in the short run that Government offers satisfactory amounts of food and non-food items, as emergency relief items among them bedding, clothing, and utensils. As an intermediate and long term strategy, Government together with development partners should offset the economic losses associated with epidemic control efforts by offering meaningful compensation to affected families by replacing damaged household items as part of the epidemic response efforts. In addition, deliberate efforts to provide employment opportunities as well as monetary benefits such as soft loans should be provided to such individuals and families as a form of affirmative action to help kick start the economic recovery of the affected individuals.

It is recommended that such interventions that assist survivors and caregivers in their journey of coping with the challenges to “adapt” and become resilient should be undertaken in a “holistic” and “integrated” manner and should cover all realms of survivors’ and caregivers’ lives. Ultimately, this enables health workers to “train” and “guide” survivors and caregivers “in the path of coping, recovery and transcendence”.

## **8.6. LIMITATIONS OF THE STUDY**

Whilst the study produced credible information about the lived experiences of survivors and caregivers, it inevitably has some limitations, among them:

- The qualitative research design used means that the study documented the experience of a relatively limited number of participants and this has a negative bearing on the generalisability of the study findings to other settings, which would have been different if the study was quantitative in its approach.
- All survivors and caregivers being of female gender, while it ensured homogeneity of the group, also presented some limitations, which may be interpreted as a limitation of the study, since no male participants were involved, yet their presence could have produced markedly different findings.
- Another study limitation is that the context-specific nature of the study means analysis and interpretation of the research data depended heavily on the researcher’s choices, and yet the same data could have been interpreted differently by another and could have potentially led to different findings.

These limitations notwithstanding, the findings are reliable, valid and trustworthy, especially given that the data collection and analysis methods utilised were thorough and independently verified by a qualitative research expert at every stage of data collection, analysis and reporting. Importantly, despite these limitations, the results present some compelling evidence suggesting that majority of survivors and caregivers while admitting suffering; they surprisingly were able to overcome the negative effects of being associated with Ebola. In fact, many of them ably adjusted

to their new life as survivors and caregivers, with some even thriving and experiencing personal growth albeit within the context of psychosocial support received from close family members and friends. The knowledge gained is thus enlightening since it has humbly contributed to a deeper understanding of survivors', caregivers' and community's experiences during and in-between Ebola outbreaks.

## **8.7. RECOMMENDATIONS FOR FURTHER RESEARCH**

The findings of the current study suggest the need for further research, notably:

- Views and ideas of community members, health workers, spouses, orphans, widows/widowers and children of victims, survivors and caregivers should be explored to get holistic picture of the concept of resilience within these groups.
- Longitudinal studies to explore the experience of survivors and caregivers in the long run, including ascertaining how the concept of resilience evolves over time.
- Further research to cover a larger sample of participants from various sentinel areas to help widen and gain broader understanding garnered from current study.
- Inquiry to investigate the associated social-cultural variables to help understand how affected people modify the Ebola experience during and after the outbreaks.
- A study emphasising community empowerment is recommended especially given the importance of social-cultural factors in the appreciation of Ebola epidemics.
- Qualitative studies should be conducted to obtain more information about factors that enhance adaptation among persons directly affected by Ebola outbreaks, with participants drawn from all the regions that have experienced Ebola epidemics.
- Further studies are recommended to investigate effectiveness of the current post outbreak interventions in building the adaptive capacity of affected persons.
- In-depth studies should be conducted among volunteers, health workers and stakeholders to identify the challenges faced when building resilience of affected individuals and communities to arrive at better mitigation strategies in future.

## **8.8. RECOMMENDATIONS FOR THEORY DEVELOPMENT**

In keeping with the general aim of qualitative research regarding theory development, the researcher recommends that the concept of adaptation among sufferers of Ebola, namely survivors and caregivers be further explicated as a multidimensional and multifaceted concept, with the possibility of developing a conceptual system that can be used to enhance the adaptive capacity of survivors, caregivers as well as individuals and families who may become affected by an Ebola outbreak in the future.

## **8.9. GUIDELINES TO ENHANCE SURVIVORS' & CAREGIVERS' RESILIENCE**

The following guidelines are recommended to be used by health teams to enhance the resilience of survivors and caregivers as a strategy to assist them in resisting, coping with and adapting to their new realities including maintaining optimal wellbeing and sometimes excelling in the face of adversity. The principle of this resilience enhancing effort is to increase survivors' and caregivers' "internal" coping resources while at the same time availing "external" resources to aid their journey of coping and adaption, which are key ingredients to building resilience. If implemented in a holistic manner, these guidelines should increase survivors' and caregivers' capacity to:

- resist and withstand the challenges faced.
- cope with the challenges by enhancing their preparedness.
- recover from and bounce back to optimal level of functionality.
- adapt and maintain optimum functioning in the presence of the challenges.
- transcend beyond current challenges by taking advantage of the new realities.

### **8.9.1. Increasing survivors' and caregivers' mental resistance**

In order to increase survivors' and caregivers' ability to resist and withstand the challenges and the traumatic shocks of Ebola infection, healthcare teams should:

- Promote their wellbeing by teaching them how to be active, have healthy diets, adequate rest and to ensure they are in good physical and mental health. The rationale for a healthy body supported by evidence that individuals in good physical health are more likely to cope better with the stress and thus more likely become resilient than those in poor physical and mental health (Bilsker, Samra & Goldner 2009:2; US Department of Health and Human Services 2014:2-3).
- Through psychotherapy promote their self-esteem and encourage them to be confident, flexible, optimistic and positive. This has the potential to enable them to garner their inner strengths because such “mind sets” related to positive beliefs about oneself increases one’s adaptive capacity to buffer and protect against the challenges as well as contribute towards better adjustments and the ability to cope with the stresses of life (Turner 1999:198-199; Mind 2013:1-2).
- Encourage meaningful social interaction and integration with supportive others such as peers and family members for psychosocial support and information sharing. Interacting with supportive others enables one to utilise the benefits of social support and external resources leading to optimal physical and psychological adaptation when facing challenges (MacDermid, Samper, Schwarz, Nishida & Nyaronga 2008:16-17; Hoffman, Lent & Raque-Bogdan 2013: 240-242).

### **8.9.2. Increasing survivors’ and caregivers’ coping and adaptive capacity**

In order for survivors and caregivers to cope effectively with the various challenges related to being associated with an Ebola infection, healthcare workers should:

- Educate them early about the impending challenges to enhance their epidemic preparedness, ensuring systematic and effective action against the challenges. Such preparedness lead to what Aspinwall and Taylor (1997:417) and O’Driscoll (2013:89) describe as proactive coping, which entails forward planning, anticipating the impending stressors and developing appropriate response plans to avert negative consequences of the coming challenges as is the case with Ebola.

- Encourage faith based interventions such as healing prayer as long as they are perceived to have positive outcome on their wellbeing and coping capacity, as recommended by Leininger (2001:369) as part of culturally competent care. Using holistic and multidimensional health care approaches by integrating generic and professional modes including input from religious, kinship and cultural factors ensures that survivors and caregivers have access to a wide range of health services. This increases their chance to receive satisfying and culturally congruent care resulting in better health outcomes and coping capacity (McFarland 2001:385-386; Anderson, Scrimshaw, Fullilove, Fielding & Normand 2003:68-69).
- Provide accurate information through effective communication especially in crisis, especially during the outbreak period where antisocial overtones are manifest. Such information should include updates about the outbreak and where survivors and caregivers can obtain help and related support, because lack of information often leads to desperation, despair and dissonance (Case, Andrews, Johnson & Allard 2005:353-354; Laal & Aliramaie 2010:168-170; Usher & Grigg 2011:33-34).
- Use psychotherapeutic interventions during outbreaks and in the aftermath to discourage maladaptive coping strategies such as avoidance, distancing and withdrawing which lead to compromised life process (Roy & Zhan 2001:317; O'Driscoll 2013:89). Instead, efforts should be made by health authorities by means of psychotherapy to encourage affected persons to use adaptive mechanisms such as acceptance, positive reappraisal and seeking support from caring others (Lazarus & Folkman 1984, in Manne 2007:192; Ai et al 2010:799).

### **8.9.3. Enhancing recovery and capacity to bounce back to optimal functioning**

In an effort to increase survivors' and caregivers' ability to recover from the shock and trauma of Ebola and bounce back to optimal functioning thereafter, there is need to:

- Encourage cognitive adaptation as emphasised by Roy and Zhan (2001:320) through timely information sharing, psychotherapy and peer and family support. This helps survivors and caregivers to better understand and appreciate their

purpose in life, regain their mastery over the difficult events associated with the outbreak and restore their self-esteem through positive self-enhancing evaluation and positive thinking (MacDermid et al 2008:16; Laal & Aliramaie 2010:168-169).

- Provide holistic and need based support to enhance their coping efforts through psychotherapy and by encouraging social interaction as well as the utilisation of “external” resources. This will help them discover internal strengths such as hardiness, flexibility and optimism which tend to enhance their adaptive capacity leading to better performance in the face of continuing stressors (Laal & Aliramaie 2010:168-169; Parnabas, Abdullah, Omar-Fauzee & Nazaruddin 2013:151-153).
- Provide “crisis help centres” from where urgent holistic and integrated help can be provided whenever needed throughout the epidemic and in the aftermath. It is recommended that in these clinics health workers take immediate interventions to interrupt and reduce crisis reaction and restore affected individuals to pre-Ebola level of functioning, providing sufferers with “emotional first aid” (Dass-Brailsford 2007:97). Such integrated services points could be provided in special Ebola clinics designed to deal with immediate and long-term challenges comparable to established HIV/AIDS and teenage pregnancy clinics that offer comprehensive and integrated services leading to better health outcomes for affected individuals (Dass-Brailsford & Myrick 2010:202-204; Volkow & Montaner 2011:1411-1412).

## **8.10. CONCLUSION**

In this chapter, an overview of the research process is given to draw the reader’s attention to the various scientific steps that were followed. The salient findings are summarised and conclusions are drawn and key recommendations were made. The recommendations pertain to each of the seven themes that emerged from the study. The chapter ends with proposed guidelines that may be used to enhance resilience.

## **XX. THE RESEARCHER'S REFLECTIONS ON THE RESEARCH JOURNEY**

This study was indeed a journey...a journey of thousands of hours...right from the beginning I knew I wanted to conduct a qualitative study to understand the lived experience of people who had been directly impacted by Ebola in Uganda. So I decided to settle for survivors and study their experiences in-depth. As the journey unfolded it became clear that I needed to add another group; those who had cared for people with Ebola. And so the journey began...

As I embarked on the tortuous road of scholarship, I soon realised that the qualitative research approach I had chosen to support my study was not deep enough. With this came the first set of disappointment. Then I became confused. I was advised that I needed to look at various qualitative research traditions and see which one could best support my thesis. And so the intense reading of qualitative approaches gave rise to phenomenology. Then I said...wow...suddenly felt I had found my way. Then I wrote a section on phenomenology, which I thought was well written. When the paper came back, I was surprised by the comments of the supervisor, I was devastated. Then I sighed and told myself do I quit or stay the course? After a few weeks of pondering, I picked myself up and said I shall read very extensively and attend to the very many comments and see if I come out victorious. I made a pact with myself. I told myself I was not going to give up so easily, not just yet; and so the journey continued.

This marked a new time in my journey of scholarship. With this change things began to fall in line. Fewer and fewer comments would come with each additional chapter. Then I told myself, looks like am now making real progress. And so I became energised and began to focus more pertinently on all the comments of my supervisor, in fact very religiously to say the least. This is when I began to enjoy my studies. I then began to realise that my initial frustration was that I had not understood the value of deep thought and quality as I set out to construct knowledge within the realm of phenomenology. I was made to understand that I had to ground my thought of existing knowledge and bud off from there. This was a twist of self-discovery!

With this new perspective came new experiences and affirmations. One of the unique and surprising moments came when through the constant poking questions of my supervisor I was led to the works of Dr. Frederick Wertz of Fordham University, USA. Suddenly, both my supervisor and I were elated by the fact that we had found a theoretical framework upon which to ground my work, and most surprisingly of all, Dr. Wertz provided me the materials that were later to become foundational in my journey of enabling me complete the present study. This innocent push soon became quite astonishing. I sort of knew I was getting there, much like my supervisor now!

Then, there came another surprise, as I wrote the chapters, I realised that for me to generate knowledge within the phenomenological tradition I had to articulate my ideas very soundly and at best quite deeply. Soon I realised this depth was to convince even the worst sceptic. It was obvious this made auditability easier. And so I continued to immerse myself and kept reading and writing. As time passed, I came to appreciate that phenomenological research goes nowhere without thoughtful writing. I became aware that only by writing can one construct knowledge and in constructing knowledge we come to write in a more profound manner. This made me realise that the more I wanted to understand my topic, the more I had to read and write! And like Van Manen once wrote, the more I continued reading, the more I continued writing!

Soon I found myself interviewing participants, obviously after passing through a rigorous ethical clearance session. In this phase of my research journey, a major learning experience for me was how emotional an interview could get. I had in no way anticipated how emotionally involving some of the interviews could become, it was no less than a reality shock. On a couple of occasions, I experienced severe emotional reaction, often torn between being a researcher and being a counsellor, let alone being carried away by their stories of pain and suffering. This was a true test of scholarship; in no way intended for the fainthearted! I had to learn to deal with severe emotional reaction, especially when an interviewee broke down and cried loudly and sobbed almost endlessly. On two occasions, I caught myself almost being carried away; I nearly cried...my eyes were already teary. After the interviews it became apparent to me that phenomenological research interviews can truly be an emotion

draining event. While I knew this could happen, the extent of the reaction of some participants, especially the emotional weight this levied on me was unimaginable!

As I inched forward with the research journey, I experienced yet another surprise during data analysis phase. Despite having all the data with me transcribed, I was surprised by the fact that I spent nearly four (4) months dwelling with the data of twelve survivors and family caregivers almost on a daily basis. This level of immersion was totally new to me. The immersion appeared to never end. Occasionally the feeling that the analysis was moving nowhere would envelope me. Sometimes I wondered am I doing the right thing really. Alas, despite the apparent stagnation my supervisor kept saying: “we are getting there, keep faith”! Do you really mean it, I often mused! I couldn’t see why how his “we are getting there” would come to pass. I began to despair. I began to wonder, is there something wrong with me?

My supervisor kept assuring me; “do not despair, we have time!” I recollected that my frustration was in part because I had imagined that once I had gathered the data, data analysis would be a walk in the park! I later proved this was a terrible assumption to say the least, because this stage proved to be the most time consuming. How wrong could a young researcher like me be! As days went to weeks and weeks into months, every day, I would sit behind my laptop typing away, constantly reading and re-reading, copying, cutting, pasting, accepting changes, let alone deleting, almost incessantly. I would ask...why are we not making progress?

Then, suddenly, the cloud of despair vanished and everything seemed to flow without much hassle after the themes and categories and subcategories became clear. I started to enjoy myself especially as I wrote the results chapter. I soon discovered that I had more data to support my themes as well as categories than I actually needed. This apparent plenty abundance of information overwhelmed me on how much information was suddenly available to tell survivors’ and caregivers’ story. This was completely surprising! The ending became even more enjoyable, because with my supervisor’s suggestion each turn was easier. Finally, the thesis was completed!

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ANNEXURES

ANNEXURE A: CLEARANCE CERTIFICATE, UNIVERSITY OF SOUTH AFRICA



UNIVERSITY OF SOUTH AFRICA  
Health Studies Higher Degrees Committee  
College of Human Sciences  
ETHICAL CLEARANCE CERTIFICATE

*over* 24/01/2

HS HDC/116/2012

Date: 12 December 2012

Student No: 3514-380-0

Project Title: The lived experience of living under constant threat of Ebola: A phenomenological study

Researcher: Amandu Matua Gerald

Degree: D Litt et Phil

Code: DIS8908

Supervisor: Prof DM van der Wal

Qualification: D Litt et Phil

Joint Supervisor: -

DECISION OF COMMITTEE

Approved

Conditionally Approved

*Prof L Roets*  
Prof L Roets

CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE

Dr MM Moleki

*Dr MM Moleki*

ACTING ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

*for*

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

**ANNEXURE B: CLEARANCE CERTIFICATE, MILD MAY UGANDA****Mildmay Uganda Research ethics Committee (MUREC)**

14 May 2013

Dear Gerald,

RE: Approval of your research proposal titled: **The lived experience of living under constant threat of Ebola: A phenomenological study.**

I am glad to inform you that the proposal you submitted to MUREC was reviewed on 8 May 2013 and the committee approved it.

This approval is valid until 14 May 2014. Continuation beyond this period and changes to the protocol including data collection tools should be brought to the attention of MUREC.

You are also required to provide progress reports at an annual interval and to notify Mildmay Research Committee on completion as well as when publishing results.

Kindly proceed with your registration with UNCST.

Thank you for submitting your protocol to MUREC.

Best Wishes.

Yours Sincerely,

  
Dr. Lule John

Chair Person

Mildmay Uganda Research Ethics Committee



**Mildmay Uganda**  
PO Box 24985  
Kampala  
Uganda  
tel: +256 312 210 200  
fax: +256 312 210 205  
[www.mildmay.org/uganda](http://www.mildmay.org/uganda)  
NGO NO. S.5914 / 9191



**ANNEXURE D: LETTER OF PERMISSION FROM OFFICE OF THE PRESIDENT**



THE REPUBLIC OF UGANDA

**OFFICE OF THE PRESIDENT**

PARLIAMENT BUILDING P.O.BOX 7168 KAMPALA, TELEPHONES: 254881/6, /343934, 343926, 343943, 233717, 344026, 230048, FAX: 235459/256143  
Email: secretary@op.go.ug, Website: www.officeofthepresident.go.ug

**ADM 154/212/01**

July 17, 2013

The Resident District Commissioner  
Kibale District

This is to introduce to you **Matua Amandu Gerald** Researcher who will be carrying out a research entitled “**The lived experience of living under constant threat of Ebola: A phenomenological study**” for a period of **02 (two) years** in your district.

He has undergone the necessary clearance to carry out the said project.

Please render him the necessary assistance.

By copy of this letter **Matua Amandu Gerald** is requested to report to the Resident District Commissioner of the above district before proceeding with the Research.

A handwritten signature in blue ink, appearing to read 'Alenga Rose'.

Alenga Rose

**FOR: SECRETARY, OFFICE OF THE PRESIDENT**

Copy to: Matua Amandu Gerald

**ANNEXURE E: LETTER REQUESTING PERMISSION TO CONDUCT INTERVIEWS****UNIVERSITY OF SOUTH AFRICA DEPARTMENT OF HEALTH  
STUDIES****P.O. Box 392 Unisa, Pretoria, South Africa**

June 30, 2013

The Resident District Commissioner,  
Kibale District, Midwestern Uganda

Dear Sir/Madam,

**REF: PERMISSION TO COLLECT DATA FROM PERSONS AFFECTED BY THE JULY  
2012 EBOLA OUTBREAK**

I am a doctoral student registered at the Department of Health Studies, University of South Africa. I writing to request permission to collect data for the study entitled, "*The Lived Experience of Living under Constant Threat of an Ebola Outbreak: A Phenomenological Study*". I plan to conduct qualitative in-depth interviews with persons directly and indirectly affected by the July 2012 Ebola outbreak in Kibale district. I plan to request participants to describe in detail their lived experiences related to the Ebola outbreak.

From these interviews, I plan to develop a description of what it means to live in constant anticipation of an Ebola outbreak as well as what it means to be infected by Ebola from the perspective of those who have actually had the experience in real life. These findings will be used to recommend development of specific health care protocols to better respond to the needs of survivors and their close family members during future outbreaks of Ebola in Uganda.

Please find attached for your perusal the ethical clearance certificates from University of South Africa, UNISA, Mildmay Uganda Ethics and Research Committee (MUREC) and Uganda National Council for Science and Technology, UNCST as well as the consent form and interview guides that will be used to guide the study in accordance with the guidelines of these institutions.

I thank you in anticipation for your positive considerations.

Yours sincerely,



Amandu Gerald Matua, RN; BSN, MNSc, D. Litt et Phil (c)

**Principal Investigator and Doctoral Candidate, UNISA**

Tel: (+256) 772 522 938/0757012320

E-mail: [amandumatua@yahoo.com](mailto:amandumatua@yahoo.com)

**ANNEXURE F: LETTER GRANTING PERMISSION TO CONDUCT INTERVIEWS**

**UNIVERSITY OF SOUTH AFRICA DEPARTMENT OF HEALTH STUDIES  
P.O. Box 392 Unisa, Pretoria, South Africa**

June 30, 2013

The Resident District Commissioner,  
Kibale District, Midwestern Uganda

Dear Sir/Madam,

**REF: PERMISSION TO COLLECT DATA FROM PERSONS AFFECTED BY THE JULY 2012 EBOLA OUTBREAK**

I am a doctoral student registered at the Department of Health Studies, University of South Africa. I writing to request permission to collect data for the study entitled, "*The Lived Experience of Living under Constant Threat of an Ebola Outbreak: A Phenomenological Study*". I plan to conduct qualitative in-depth interviews with persons directly and indirectly affected by the July 2012 Ebola outbreak in Kibale district. I plan to request participants to describe in detail their lived experiences related to the Ebola outbreak.

From these interviews, I plan to develop a description of what it means to live in constant anticipation of an Ebola outbreak as well as what it means to be infected by Ebola from the perspective of those who have actually had the experience in real life. These findings will be used to recommend development of specific health care protocols to better respond to the needs of survivors and their close family members during future outbreaks of Ebola in Uganda.

Please find attached for your perusal the ethical clearance certificates from University of South Africa, UNISA, Mildmay Uganda Ethics and Research Committee (MUREC) and Uganda National Council for Science and Technology, UNCST as well as the consent form and interview guides that will be used to guide the study in accordance with the guidelines of these institutions.

I thank you in anticipation for your positive considerations.

Yours sincerely,



Amandu Gerald Matua, RN; BSN, MNSc, D. Litt et Phil (c)

**Principal Investigator and Doctoral Candidate, UNISA**

Tel: (+256) 772 522 938/0757012320

E-mail: [amandumatua@yahoo.com](mailto:amandumatua@yahoo.com)

I PLEAS THE  PLEASE GO AHEAD.

**ANNEXURE G: INFORMED CONSENT FORM FOR PARTICIPANTS**  
**UNIVERSITY OF SOUTH AFRICA DEPARTMENT OF HEALTH STUDIES**  
**P.O. Box 392 Unisa, Pretoria, South Africa**

**CONSENT FORM- ENGLISH**

**Title of the study:**

*The lived experience of living under constant threat of Ebola: A phenomenological study.*

**Telephone:** (+256) 772 522 938..... **(Principal Investigator).**

**Study purpose:**

To gain a clear understanding of how people experience the phenomenon of living under a constant threat of Ebola, especially how they perceive Ebola, what reactions towards Ebola symbolize and the public's reaction to individuals and families affected by an Ebola outbreak.

**Study procedures:**

On agreeing to participate in the study, I will be asked to complete an interview with a trained interviewer. The answers will be recorded and kept in a confidential manner. I understand that the interview will ask me to describe in detail my life experiences before, during and following the July 2012 Ebola outbreak in Kibale District in midwestern Uganda.

**Benefits:**

I will benefit from the study by obtaining some information about Ebola. My participation will enable health workers to provide better care to persons affected by Ebola and similar outbreaks in future. I understand that I will not be paid for choosing to participate in this research study.

**Risks:**

No risks will be posed to my life as a result of this study. No samples will be taken from my body. However, I understand I will be asked to give up 40-60 minutes of my time and I may experience some anxiety or discomfort while being interviewed by a trained research assistant.

**Rights to refusal or withdrawal:**

My participation is entirely voluntary and I am free to take part or withdraw at any time without being affected in any way. I understand that I may choose to answer some or all the questions.

**Confidentiality:**

The data collected during the study will be kept strictly confidential and used only for research purposes. My identity will be concealed in as far as the law allows. My name will not appear anywhere on the coded forms with the information and in reports that may arise from this particular study. I understand that paper and computer records will be kept safe and under lock and key and with password protection to enhance data confidentiality.

The interviewer has discussed this information with me and offered to answer my questions. For any further questions, I may contact, the Principal Investigator, on: (+256) 772 522 938, or, the Secretary, Mildmay Uganda Research and Ethics Committee (MUREC) on (+256) 772 682402, or the Secretary, Uganda National Council of Sciences and Technology on (+256)-41-250431.

**STATEMENT OF CONSENT/ASSENT**

.....has described to me what is going to be done, the risks, the benefits involved and my rights in regard to this research study. I understand that my decision to participate in this study will not alter my current situation including medical care. In the use of this information, my identity will be concealed. I am aware that I may withdraw any time from this study. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate. A copy of this consent form will be provided to me.

Signature of participant .....Age ..... Date .....

Signature of parent or guardian for minors .....Date .....

Signature of Interviewer .....Date .....

**CONSENT FORM- RUNYORO-RUTORO****UNIVERSITY OF SOUTH AFRICA DEPARTMENT OF HEALTH STUDIES****P.O. Box 392 Unisa, Pretoria, South Africa****FORMU YOKWIKIRI'RIZAHOO KWETERANA OMUMUSOMO GUUNU****Omutwe mukuuru gwomusomo guunu:**

Tukusoma omuringo abantu Ba Kibaale kyibatwalizemu kubera omukutina okwitibwa Ebola

**Omuramwa Gwomusomo:**

Omugaso gwo musomo ogwo guli ngu tumanye omuntu kyikumurabya kitya kuba natiina kufa Ebola. Tukwenda kumanya omuntu okukyireba otya, oba kyikugendairekitya okubeera omukutya Ebola. Kyikumanyisa kyi iwe nko muntu na famili yawe obwokuwulira ehora. Ebyo nibyo tukwenda kumanya.

**Omugenderwamu Gwomusomo:**

Bwo'kwikiriza okweterana'naitwe omu'musomo gunnu, aku'genda o'kukukaguza ebikaguzo nuwe asemerire oku'bikukaguza. Mbaire ninsaaba omugarukemu ebikaguzo ebitaitaito ebyaraba akukagwize: kandi noi'jja kukwatibwa ha rutambi. Kyonka bwokumaara kukwatibwa harutambi byo'kuba ogambiire nitwijja kubilinda kurungi muuno muuno ataloho ondi wena akubihuuliiriza. Tukwijja kukusaaba otugambireho habw'obwomeezi bwawe, ne' tekerreza yawa nkwoku ahindikire kuruga habaarukaaho buuno oburwaire obwa omuswijja gwe Ebola omu'mweezi gwamusanju omwaka gwe'nkumi ibiirin'ebiri (2012) mu Kibale District omu midwestern Uganda.

**Ebirungi byomusoomo guunu:**

Okubanza, Okwikiriza kwange kweterana hamu nainywe omu'musomo guunu nikwijja kunyongeraho o'kumanya kwange ahali'oburwaire bwe' Ebola.

Nikijja kuyamba abakoozi birwaaro lyeitu okulolera kurungi omo rundi baingi halitwe obuturaba tu'kwasirwe oburwaire bwe'Ebola omu bweire bwo'mumaiso.

Ekya kabiiri, omusoomo guunu ni'gwijja kutuyamba okumanya ebindi ne'bindi ebi'kukwataho oburwaire bwe Ebola, kyonka titukwijja kusasurwa esente yona.

**Ebi'habimu ebisobora okubaho omukweterana kwawe omumusoomo guunu:**

Hanyuma yo'musomo guunu talooho kiibi kyona ekikugya kubaho'habwomeezi bwange: kandi busaaho alikwijja kwihahoo omusaayi gwange, rundi ekicweka kyo'mubiri gwaawe kyona.

Kyonka okugarukamu ebikaguzo ebyo' musoomu guunu, ni'bijja ku'ntwarra edakiika zange hagati ye dakiika makumi'ana (40) na'nkaaga (60).

Haso'kubamu obwire nkwehurra tintenkaine 'nkumuntu obu'ebikaguzo biraba nibikaguzibwa.

**Oine´ obugabe kwikiriza rundi kuleka/kukirugamu:**

Nosoboora kwikiriza kweterana naitwe omu´musoomo guunu rundi osoboora kwanga. Okwanga kwawe nikusoboora kubaho obwire bwona, ataloho buzibu bwona mu´ngeri yoona. Ninkyetegereza kurungi nti´ninsobora kugarukamu ebikaguzo ebimu ne´bimu kandi ebindi ebintakwenda kugarukamu ni´nsoboora kubireka.

**Kulinda en´siita:**

Ebigambo ebyo´kwijja kutugambira nitwijja kubirinda kurungi muno n´kesiita yaitu kandi nibijja kukozezebwa omu´musoomo guunu gwonka. Eibaara lyange nirijja kwahurwa kurungi kandi mu´siita o´hirreho kuba niryetagwa mu´mateeka.

Ninkimanya nikwo ebi´mpandikire haru papura ne´birri omukomputya nibijja kwahurrwa kurungi muno kandi mu´nsiita.

Orutambi orutukugya kukwata nitwijja kurulinda kurungi muno mukabada eya´maani nitukozesa ekisumuruzo ekirinda ensiita.

Owaroho n´komuntu oweine obusobozi bwo´kukaguza ebikaguzo byo´musoomo guunu, abalizeho nanye ebigambo ebikukwataho omusoomo kandi yeikiriza kugarukamu ebikaguzo byange. Yagamba ngu, obundaba nyine ebikaguzo bindi byoona ebi´nkwenda kumukaguza, nterre ha siimu zinc: (+256) 772 522 938, rundi ha Secretary was “Mildmay Uganda Research and Ethics Committee (MUREC)”: (+256) 772 682402, rundi ha Secretary was, “Uganda National Council of Sciences and Technology:” (+256)-41-250431.

**EKIHANDIKO KYO´KWOLEKA KWIKIRIZA**

.....angambire ebikukwataho omusoomo guunu, ebikwijja kukorwa ebirungi byoona ebirimu, ne´biibi byoona ebirimu; kandi yansoboraho nkwo´nyine obugabe kwikiriza rundi kwanga kweterana mu´musoomo guunu.

Ninkikenga kurungi ngu´ okwikiriza kwange kutaha omu´musoomo guunu titukwijja kuhindura enyikarra yange eri;kukwataho ebirrwaro mberre nkutuga obujanjabi. Omu´kukozezebwa amakuru agatungirwe omumusoomo guunu, eibaara lyange nirijja kwahurrwa omu´nsiita. Ninkimanya ngu ninsoboora kwanga rundi kwikiriza kweterana mumusoomo guunu. Ninkyetegereza ngu okutaho omukono has fomu/akipapura kyomusomo kiinu, nikihamya ngu ebikukwataho omusoomo guunu mbyetegerize; kandi taroho a´mpabirize.

Copi ye\_ekihandiko kyo´kwoleka kwikiriza nayo´ nibagya kugimpa.

Omukono gwo omuntu´mukuru.....Emyaka.....Ebiiro byo kwezi.....

Omukono gwo muzaire rundi omulolerezi wa´baana abato.....Ebiiro byo kwezi...

Omukono gwo omuntu akagwiize ebikaguzo.....Ebiiro byo kwezi.....

## **ANNEXURE H: INTERVIEW GUIDE FOR SURVIVORS**

**UNIVERSITY OF SOUTH AFRICA DEPARTMENT OF HEALTH STUDIES  
P.O. Box 392 Unisa, Pretoria, South Africa**

### **Introduction**

Dear Participant,

Thank you very much for accepting to share your valuable experience with me [us]. In our interaction this morning/afternoon, I would like you to feel free and comfortable as you narrate your experiences relating to the past Ebola outbreak. This discussion will go on for at least an hour or until such time that you have nothing more to tell about the experience, please feel free to express yourself as you wish as your comments or experiences will not be made public

### **Biographical Information**

As we start the interview I would like to ask a few questions to know you better to help us understand the results:

- Name, Age, Gender, Occupation, Language, Telephone contact
- How you got involved with Ebola outbreak

### **Grand Tour Question**

How do you experience living under a constant threat of Ebola? Or, How do you experience the constant threat of Ebola?

### **Grand Tour Themes**

1. What was the experience like to anticipate Ebola infection?
  - What were your feelings or thoughts when Ebola broke out in this area?
2. What was the experience like to be infected with Ebola?
  - What are the most striking of these experiences....etc.
3. What is it like to survive an Ebola infection?
  - What are the most striking of these experiences?
4. What is it like to live in this community as an Ebola survivor?
  - What are the most striking of these experiences?
5. How did the public relate to you before, during and after the outbreak?
  - Why do you think, they treated you that way?
6. What are your feelings about how the public relates with you?
  - What are the most significant incidences or experiences?
7. What does having been infected with Ebola mean to you?
  - What does the illness experience bring to your mind/heart?...etc.
8. What is the public's reaction towards Ebola symbolize?
  - Why do you think people react the way they do?
9. What do you think causes Ebola? or What have you heard causes Ebola?
  - What makes a person vulnerable to diseases like Ebola?
10. What cultural/religious beliefs and practices influenced public's reaction?
  - What are the most significant of these beliefs and practices?
11. How have you managed to cope with life as an Ebola survivor?
  - What have you done to live a normal life?...what has been the result?..etc.
12. How did you feel when Ebola recently broke out in DRC and in Luwero district?
  - What were your immediate feelings and reactions....etc.

## ANNEXURE I: INTERVIEW GUIDE FOR FAMILY CAREGIVERS

UNIVERSITY OF SOUTH AFRICA DEPARTMENT OF HEALTH STUDIES

P.O. Box 392 Unisa, Pretoria, South Africa

### Introduction

Dear Participant,

Thank you very much for accepting to share your valuable experience with me [us]. In our interaction this morning/afternoon, I would like you to feel free and comfortable as you narrate your experiences related to the past Ebola outbreak. This discussion will go on for at least an hour or until such time that you have nothing more to say about the experience! Kindly, feel free to express yourself as you wish as your comments or experiences will not be made public!

### Biographical Information

As we start the interview I would like to ask a few questions to know you better to help us understand the results:

- Name, Age, Gender, Occupation, Language, Telephone contact
- How you got involved with Ebola outbreak

### Grand Tour Question

How do you experience living under a constant threat of Ebola? Or, How do you experience the constant threat of Ebola?

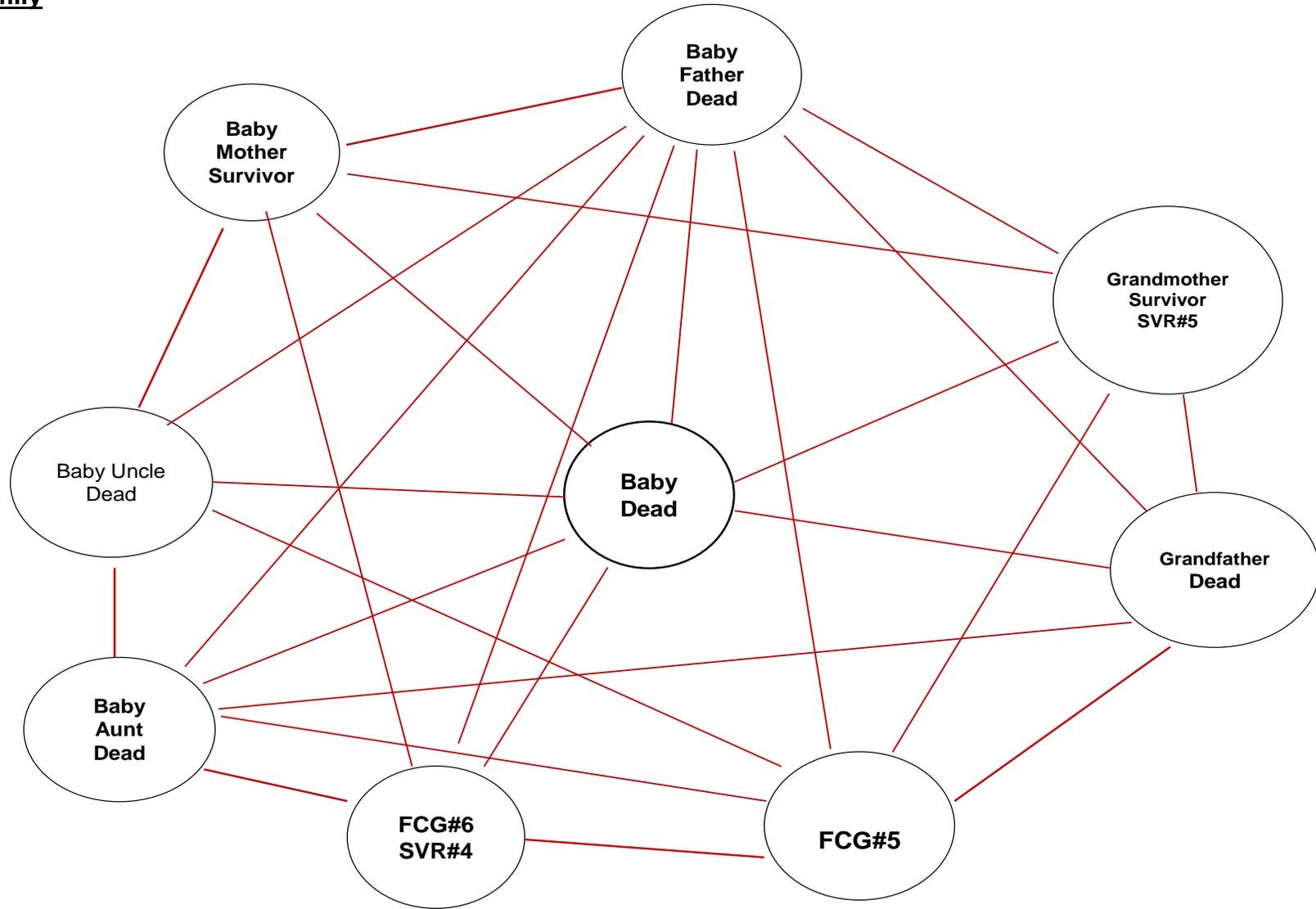
### Grand Tour Themes

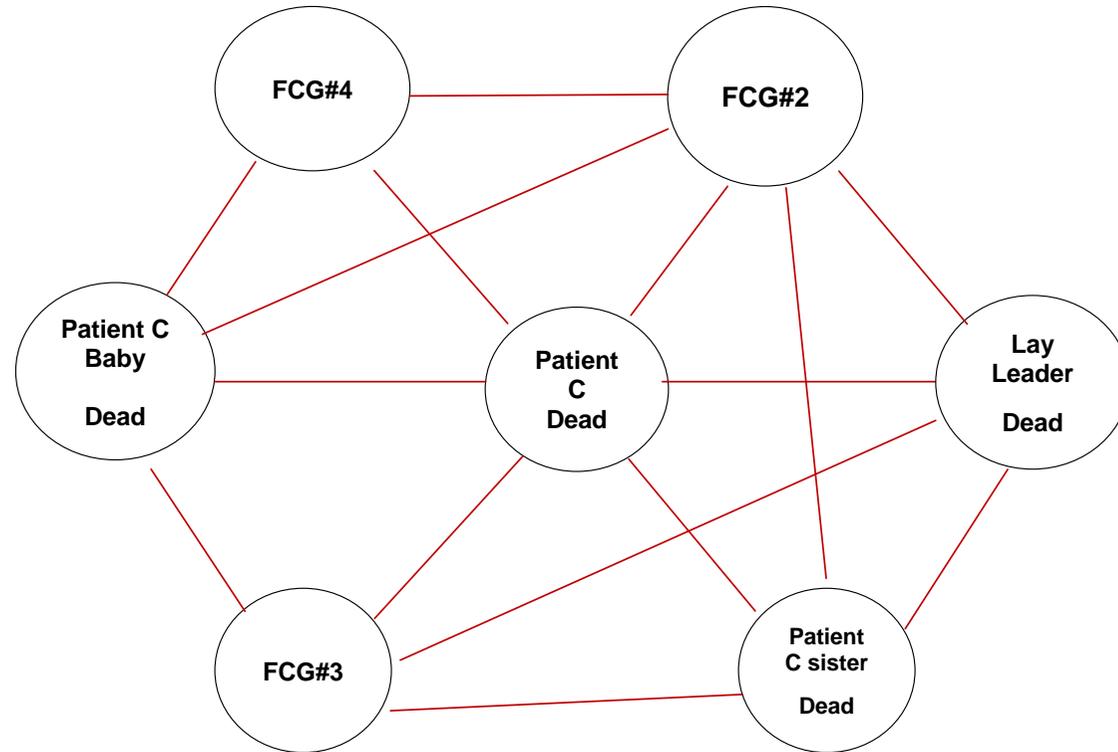
1. What was the experience like to anticipate Ebola infection?
  - What were your feelings or thoughts when Ebola broke out in this area?
2. What is it like to have a family member infected with Ebola?
  - What are the most striking of these experiences....etc.
3. What does survival of a close relative infected with Ebola mean to you?
  - What are the most striking of these experiences....etc.
4. What does it mean to be a family care giver for an Ebola patient in this community?
  - What are the most striking of these experiences?
5. How did the public relate to you before, during and after the outbreak?
  - Why do you think, they treated you that way?
6. What are your feelings about Ebola survivors living in this community?
  - What are the most striking of these feelings....et?
7. What does caring for a close relative infected with Ebola mean to you?
  - What does the illness experience bring to your mind/heart?....etc.
8. What does the public's reaction towards Ebola symbolize?
  - Why do you think people react the way they do?
9. What do you think causes Ebola? or What have you heard causes Ebola?
  - What makes a person vulnerable to diseases like Ebola?
10. What cultural/religious beliefs and practices influenced public's reaction?
  - What are the most significant of these beliefs and practices?
11. How have you managed to cope with life as a family care giver?
  - What have you done to live a normal life?...what has been the result?..etc.
12. How did you feel when Ebola recently broke out in DRC and in Luwero district?
  - What were your immediate feelings and reactions....etc.

**ANNEXURE J: EPIDEMIOLOGICAL SOCIOGRAM OF SURVIVORS AND CAREGIVERS**

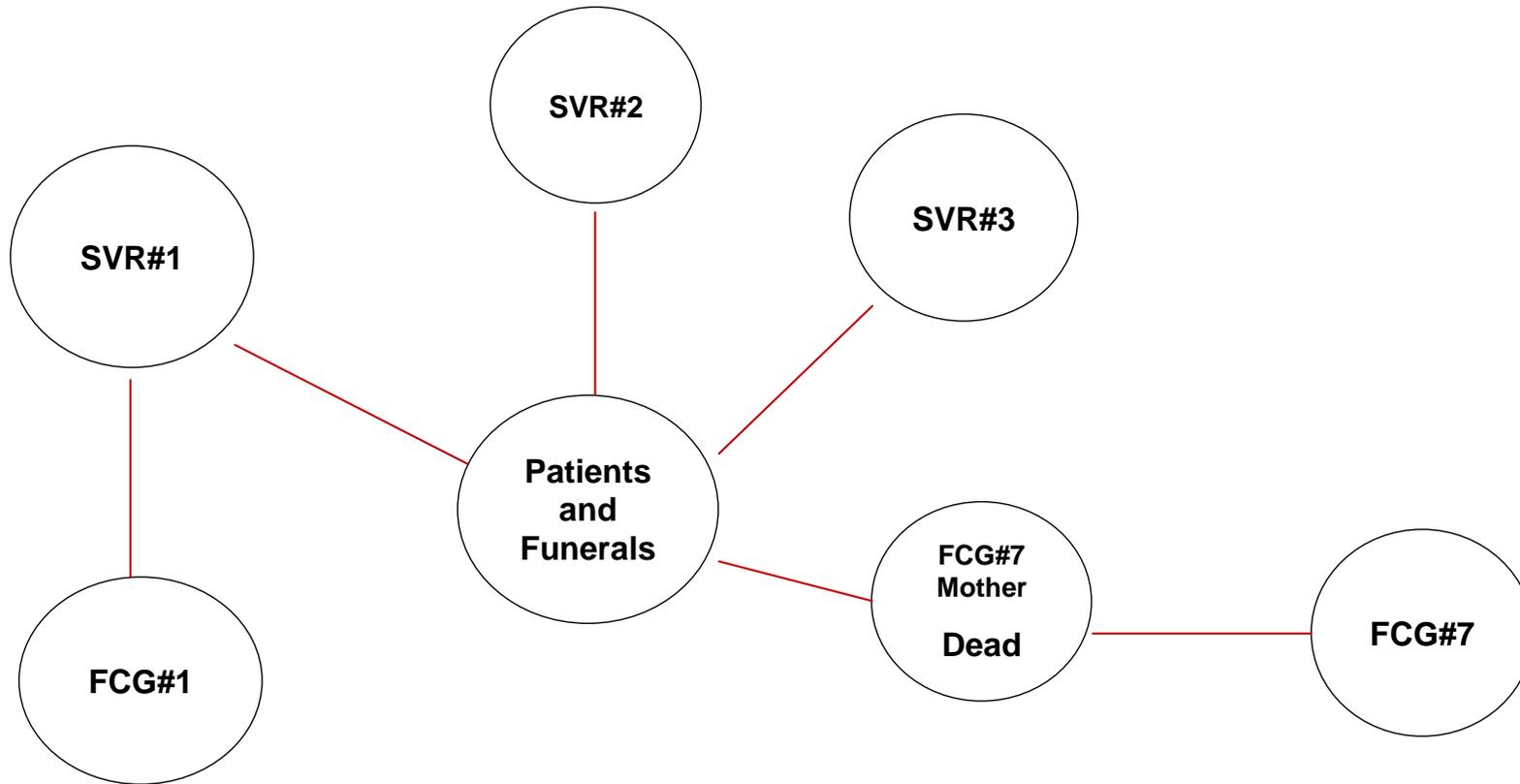
<b>S#</b>	<b>Participant</b>	<b>Type of Exposure</b>	<b>Explanatory notes to link participants to possible contacts</b>
1	Survivor 1	Hospital Exposure	Exposed to Ebola at Health Centre A from patients coming from index village in Nyamarunda area
2	Survivor 2	Hospital Exposure	Exposed to Ebola at a Health centre B from patients coming from index village in Nyamarunda area, attended to a pregnant woman
3	Survivor 3	Hospital Exposure	Exposed to Ebola at Health Centre A from patients coming from index village in Nyamarunda area
4	Survivor 4	Domestic Exposure	Exposed to Ebola by index baby, brother ( father of baby); sister in law (mother of baby); mother (Grandmother of baby) and father (Grandfather of baby)
5	Survivor 5	Domestic Exposure	Exposed to Ebola by index baby, son (father of baby); daughter-in-law (mother of baby); husband (Grandmother of baby).
6	Caregiver 1	Domestic Exposure	Exposed while caring for Survivor 1, was admitted to hospital, never sero-converted to Ebola
7	Caregiver 2	Domestic Exposure	Exposed while caring for a close friend C who later died, monitored, never sero-converted to Ebola.
8	Caregiver 3	Domestic Exposure	Exposed while caring for a close friend C who later died, was monitored, never sero-converted to Ebola.
9	Caregiver 4	Domestic Exposure	Exposed while caring for a close friend C who later died, was monitored, never sero-converted to Ebola.
10	Caregiver 5	Domestic Exposure	Exposed while caring for her father (who later died), mother (who survived) and brother who also died. She was monitored and never sero-converted to Ebola.
11	Caregiver 6	Domestic Exposure	Exposed to Ebola while caring for brother, father of the baby, and mother (Grandmother of baby) and father (Grandfather of baby). Became sick, seroconverted but survived and recovered fully.
12	Caregiver 7	Domestic Exposure	Exposed to Ebola while caring for Ebola positive mother who had got in contact with the index family weeks earlier, possibly during the funeral rites. Was monitored and never sero-converted to Ebola.

Index family



Family caregiver contacts

Health Centre Contacts and unknown contacts



## ANNEXURE K: BIOGRAPHICAL DATA OF SURVIVORS AND CAREGIVER'S

S#	Interview Code	Analysis Code	Participant Name Codes	Age	Gender	Occupation	Language
<b>SURVIVORS</b>							
1	004-09-13	SVR#1	My	35	F	Nursing Assistant	English
2	014-09-13	SVR#2	GI	28	F	Enrolled Midwife	English
3	029-12-13	SVR#3	Rs	36	F	Nursing Assistant	Runyoro
4	041-15-13	SVR#4	Al	30	F	Business Woman	Runyoro
5	042-15-13	SVR#5	Is	61	F	Peasant Farmer	Runyoro
<b>FAMILY CARE GIVERS</b>							
6	005-09-13	FCG#1	Mg	36	F	Nursing Assistant	English
7	054-18-13	FCG#2	RM	39	F	Clinical Officer	English
8	024-11-13	FCG#3	Py	48	F	Enrolled Nurse	English
9	028-12-13	FCG#4	Ce	33	F	Petty Trader	Runyoro
10	045-16-13	FCG#5	At	19	F	College Student	Runyoro
11	038-15-13	FCG#6	Al	30	F	Business Woman	Runyoro
12	040-15-13	FCG#7	Sy	24	F	Homemaker	Runyoro

## ANNEXURE L: SAMPLE OF IDIOGRAPHIC LEVEL OF DATA ANALYSIS

S.#	IPD #	MEANING UNITS	GENERAL REFLECTION [FACTS & PSYCHOLOGICAL IMPLICATIONS ]	SPECIFIC THEME BASED REFLECTION
1	SVR1.2	<p><b>Data #1</b></p> <p>I fell sick in July with persistent fever which I tried to treat but without success. I began to wonder why the fever was not resolving despite treatment. Initially starting off as an ordinary fever, the fever progressively became worse. I could not improve despite taking fever medication.</p> <p>So I decided to call a priest so that I could receive the sacraments for the sick before I went to hospital. So when they gave me the sacraments, I was firm. The following day, I decided that I would go to Kagadi hospital to see a doctor for further treatment.</p>	<p>When Mary fell sick in July, thinking of it as an ordinary fever, she took fever medications, hoping the symptoms would subside. When the fever persisted, she began to wonder why she was not responding to treatment. And soon the wonder evolved into desperation as the fever progressively became worse. Mary then begins to experience the “fear of the unknown” and uncertainty of whether she would live through this “stubborn fever”. Her confidence in survival is shaken.</p> <p>To subdue the fear, she draws on external support, based on her religious beliefs by calling on a priest so give her the sacraments for the sick before going to hospital to seek further treatment. After receiving the sacraments, Mary is confident again that she would recover.</p> <p>Mary’s sickness worries her but she becomes “strong” after the sacrament of the sick. Mary is still not aware she has Ebola.</p>	<p><b>Theme 7: Coping:</b></p> <p>Mary’s beliefs about the power of a superior being based on her religious beliefs influences how she reacts to her illness.</p> <p>In fact her belief in the power of the “sacraments for the sick” is so powerful that it turns her fear into confidence as she goes for treatment in the hospital.</p>

## ANNEXURE M: SAMPLE OF NOMOTHETIC LEVEL OF DATA ANALYSIS

PARTICIPANT DATA-THEME- EVIDENCE MATRIX– ANALYSIS OF THE GENERAL		
DATA#	THEME	SVR#1
4	Theme 1	Mary faces her diagnosis of Ebola with a great sense of optimism. Mary experiences the news of being infected with Ebola with a strong feeling of “things will be ok”. <b>Idiosyncratic</b> : Sense of optimism in the face of a negative, damaging and traumatic event
8		Mary experiences Ebola as a profound experience that upsets her physical wellbeing and her personhood. <b>General</b> : Ebola is experienced as a traumatic event. It is experienced as sudden, negative, destructive, and upsetting to ones’ physical and psychological wellbeing. The event upsets and destroys a person’s usual way of life, their possibilities and relatedness others and diminishes their personhood and negates fulfilment of their life goals and aspirations
9		Mary’s religious beliefs appear to make her perceive and experience the threat of illness including Ebola, as less threatening to her life. <b>General</b> : The belief or the actual presence of supportive other, (God, health care workers, family) lessens the negative impact of the traumatic impact of Ebola on the psychological and social wellbeing of the sufferer.
20		The presence of Ebola even remotely in the aftermath of an Ebola outbreak appears to trigger the feeling of threat of Ebola, and psychosomatic manifestations such as fear and sadness. <b>General</b> : The negative and damaging psychological effect of the traumatic Ebola experience persists and lingers on through the time and the life after the epidemic is declared officially over.
22		The threat of Ebola infection and the accompanying fear is experiences by alteration of the usual life styles whether in hospital, at home or in the community. <b>General</b> : The traumatic experience of Ebola leads to alteration of the sufferers’ usual life styles in an attempt to overcome and transcend the victimising potential of the event and to open up new possibilities for their future, their empowerment against the traumatizing effect of the infection and their overall betterment as individuals.

## ANNEXURE N: LETTER INDICATING TERMS OF EDITORIAL AGREEMENT

**Akello Doreen Omony, B. Mass Com(MUK), MA PR & PC(UK)**

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**EDITORIAL AGREEMENT**

This is to confirm that **Amandu Matua Gerald**, a doctoral student at University of South Africa requested me to perform the following tasks in relation to the thesis:

*The Lived Experience Of Living Under Constant Threat Of Ebola: A Phenomenological Study*

- a. Edit the entire thesis for editorial oversights
- b. Perform language control including sentence structures
- c. Verify the page numbers and subtitles for correctness

I undertook the responsibility with the knowledge that:

- a. This was an academic document that needed to be edited to the highest possible editorial standards.
- b. All the materials received in relation to this role were personal and confidential and were to be returned to the researcher after completing the task.

I declare that I have performed such editorial duties before and that I am well qualified to do so given my academic and professional background in Public Relations and Communication with ten years' experience in writing and editing.

Name: Akello Doreen Omony.....

Signature: .....

Date: 7.02.2014.....