Conquering Death from Ebola: Living the Experience of Surviving a Life-Threatening Illness!

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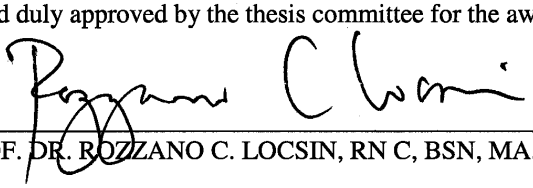
AMANDU GERALD MATUA

I, Prof. Dr. ROZZANO C. LOCSIN, Supervising Professor for Mr. Amandu Gerald Matua, student in the Master of Nursing Science (MNSc) program declare that the thesis entitled, Conquering Death from Ebola: Living the Experience of Surviving a Life-Threatening Illness was submitted and duly approved by the thesis committee for the award of the degree.



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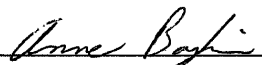

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CONQUERING DEATH FROM EBOLA: LIVING THE EXPERIENCE OF SURVIVING A LIFE-THREATENING ILLNESS

Ebola Haemorrhagic Fever, (EHF) hereafter referred to as "Ebola" first hit Uganda from the northern district of Gulu, where the effects of the disease were extremely devastating. The first outbreak occurred early in the month of October 2000. The second area to be hit was the southwestern district of Mbarara on the 23rd of October 2000 (Wanyaye, 2001; Kaguna, 2001). As of January 23, 2001, out of 425 victims of the Ebola epidemic, 211 or 49 percent survived (Onencan and Tokwiny, 2001; Mupere, Kaducu and Yoti, 2001). Seventeen of the 214, (51%) persons who perished were nurses, notably 14 qualified staff and 3 student nurses. Dr. Crispus Kiyonga, the former Ugandan Health Minister called them "national heroes." The aftermath of the devastating disease was not only having survivors; the epidemic also left behind 555 orphans in the district (Wendo, 2001; Mupere, et al., 2001).

The speculations and "hear-says" altogether added to the panic, hysteria, and fear among the Ugandan population and globally, to the extent that the World Health Organization had to issue a plea for calm and sensibility among the international community. Insufficient and often, incorrect and unsupported information about the disease, including its various ill-effects call for relentless search for knowledge in order to appropriately inform the world population about Ebola as a disease, and exercise world-wide awareness leading to its curtailment.

Ebola: The Organism

Ebola is a lipid-enveloped negative strand RNA virus belonging to the Filoviridae family of thread like viruses. Four strains of Ebola are presently known to cause human disease. These are Ebola-Zaire, Ebola-Sudan, Ebola-Cote d'Ivoire, and Ebola-Gabon; all

named after the countries where these stains were first isolated. A fifth strain, Ebola-Reston (USA), causes mild human infection but it is lethal to rhesus and macaque monkeys. Only primates are known to be infected by the Ebola virus. Presently the ecology and natural reservoirs of the virus are largely unknown (Kaguna, 2001; Zaramba, 2000; Peters, 1997). The occurrence of initial cases usually coincides with the end of the rainy season. These cases may be sporadic resulting in small outbreaks going undetected in the rural areas. However, larger outbreaks usually occur once cases have entered a health care system of low hygiene standards. Transmission is enhanced in situations where patients have increased interactions with the community, usually those of high social status who receive many visitors, or where many people are involved in burial ceremonies (Zaramba, 2000).

Ebola virus is similar to the Marburg virus morphologically and by density profiles, although it is antigenically distinct. The Marburg virus was first recognized in laboratory workers in Marburg, Germany and in Belgrade, Yugoslavia in 1967, after they were exposed to tissues and blood from African green monkeys (cercopithecus aethiops) previously imported from Uganda. Ebola was first discovered in October 1976 near River Ebola - after which the illness was named. This was in the Yombo-Nzara district of northeastern Democratic Republic of Congo (DRC), then Zaire, where it caused a tragic human epidemic (Kaguna, 2001; Peters and Le Duc, 1999).

Ebola: The Disease

Ebola is caused by infection with viruses of the genus Ebola in the family Filoviridae. The zoonotic reservoir for the virus is still unknown, however the outbreaks of EHF are associated most often with the introduction of the virus into the community by one infected person, followed by dissemination through person-to-person transmission. Ebola is a highly virulent infection associated with high rates of mortality affecting all ages and sexes. Ebola haemorrhagic fever is associated with poor prognosis and a high mortality rate

of up to 90%. Ebola is not airborne, however infected droplet spray from a patient may effectively transmit the virus if it comes into contact with mucous membranes (Zaramba, 2000).

Ebola is transmitted from person-to-person by direct contact with infected blood and body fluids such as sweat, saliva, semen, vaginal fluid, urine, and sputum. It is also transmitted through direct inoculation from contaminated instruments, such as needles, pins, and razor blades. Sexual transmission through semen has also been reported (Ekman & Priff, 1997; Kaguna, 2001; Wanyaye, 2001). The disease begins with acute fever, and diarrhoea that can become bloody (referred to as "diarrhea rogue" in French-speaking African countries) and vomiting. Headache, nausea, and abdominal pain are common complaints. Conjunctival injection, dysphagia, and hemorrhagic symptoms such as epistaxis, gum haemorrhage, haematemesis, maelena, and purpura may further develop. Some patients may show generalized maculo-papular rash on the trunk. Dehydration and significant wasting occur as the disease progresses. Frequently, at a later stage of the illness there is involvement of the central nervous system (CNS), manifested by somnolence, delirium, or coma. By the second week of illness, the patient will either markedly improve and convalesce or will develop multi-organ failure and will die in shock (Wanyaye, 2001; Zaramba, 2000).

The incubation period of Ebola ranges from 2 – 21 days, (5 -12 days in a majority of the cases), and patients are only contagious when they are symptomatic, the first symptom being fever (Kaguna, 2001; Zaramba, 2000). Survivors start to recover at approximately 2 weeks after onset of the disease. Voelker (1999) affirmed that, "an early immune response appears to be the key to surviving infection with Ebola virus" (p. 1689) when describing studies done by French researchers from the French National Institute of Health and

Medical Research [INSERM] on survivors of the 1996 Ebola outbreak in Gabon, in West Africa.

It was found that the survivors produced early increasing levels of immunoglobin G [Ig G] that were directed against the RNA virus protein coat. This showed that the attack on the protein coat was followed by clearance of circulating viral antigen and the activation of the Cytotoxic T-cell pathway. Furthermore, it was discovered that those patients who died had no Ig G response and had extremely low (nearly undetectable) levels of immunoglobin M [Ig M]. These findings seem to suggest that the differences in immune responses to the Ebola viral infection may determine whether an Ebola patient survives or succumbs to the catastrophic effects and death due to Ebola (Bonn, 1999).

Similarly, immunological studies done at the Institut Pasteur, Lille, France by Baize (1999) during the two 1996 Ebola outbreaks in Gabon, show that recovery was related to "orderly and well regulated humoral and cellular responses" (pp. 423, 424, 425 and 426). This study was based on the analysis of serial plasma samples. These analyses showed that the circulating antigen load and clinical signs early in the disease were similar, regardless of the outcome of the disease. In addition the researchers found that "patients who died generated higher concentrations of Interferon-Gamma (IFN- γ) in the early stages of infection than did the survivors, including extensive apoptosis of peripheral blood cells" (Bonn, 1999, p. 1161).

Baize, (1999) inferred that impaired humoral responses with absent specific IgG and barely detectable levels of IgM predicted failure to control virus replication and a fatal outcome occurred. This affirmation followed the comparison of the immunological responses of survivors and non-survivors. They concluded that the resolution of the infection in survivors was "probably not related to initial viral antigen load or by inference, the infectious dose" (p. 423).

The return of normal body functioning following recovery from Ebola is a very slow and striking experience. Studies done on the prognosis of such survivors show that they slowly gain appetite but remain markedly asthenic, and weight loss is striking. Late complications are common, and these are essentially musculo-skeletal problems such as joint pains. Poor appetite and prolonged psychotic disturbances have been noted (Kaguna, 2001; Wanyaye, 2001).

Aim of the Study

The purpose of this study was to describe the phenomenon "surviving a life-threatening situation". Such a phenomenon is uniquely experienced by persons who succumb to deadly diseases such as cholera, malaria, bubonic plague, and dysentery. Importantly, similar situations include circumstances that increase the likelihood of death, such as armed conflicts and vehicular accidents. Persons, who were infected with the Ebola haemorrhagic virus and survived the disease, uniquely experienced the phenomenon of surviving a life-threatening situation. Surviving a life threatening illness such as this has multifarious consequences, and the survivors' peculiar health care demands become extremely important. Describing this phenomenon facilitates understanding of these experiences, thereby influencing nursing practice.

Further, it was recognized that following the description of what it means to survive Ebola appropriate health promotion and illness prevention programs would be designed and developed. Importantly, early intervention protocols derived from this knowledge can be realised, thus alleviating debilitating health deficits among these "conquerors" of death. "The Local Council V (LC5) chairman, of Gulu District Mr. Walter Ochora, claimed that some of the Ebola survivors were suffering from blindness, loss of memory, mental problems and other disabilities (Wendo, 2001; Kaguna, 2001). Because they present unique

and complex health care demands understanding the experience of survival can facilitate the creation of interventions that will particularly emphasise requisites for care.

Description of the Phenomenon

The Concise Oxford Dictionary (1990) defines a phenomenon as "a fact, or occurrence that appears or is perceived, especially of one which the cause is in question." (p. 289). Surviving death from Ebola represents a unique experience of surviving a life-threatening situation. To understand this and similar situations, the question asked was "what is it like to live after surviving a life-threatening illness or condition"?

In Gulu, Uganda, of the 393 patients admitted with positive diagnosis of Ebola Haemorrhagic Fever (EHF), from October 8, 2000 to January 23, 2001, close to 50 per cent survived (Mupere, et al., 2001; U.S Department of Health & Human Services, (USDHHS), 2001; Onencan and Tokwiny, 2001). However, while the survival rate is encouraging, many of the survivors still show medically significant deficits to the extent that current health care management protocols do not adequately facilitate their rehabilitation. It is imperative that these experiences are affirmed as crucial to the development of programs of maintaining the health among this select and special group of people.

Significance to Nursing

The shock of Ebola epidemic is still fresh in the minds of most Ugandan citizens. Stigmatization and ostracism of the survivors and their families were rampant. Especially noteworthy was the unending discrimination that were directed toward the patients, contact persons, and their relatives, and to some extent, the medical workers who looked after the patients (Locsin and Matua, 2002). This fear of being infected became unmistakably the strongest reason for socially isolating the contact persons and above all the patients. Although the virus has been known and identified, remedies such as vaccines are yet being developed.

A survey conducted among the survivors of the 1995 Ebola epidemic in Kikwit in the DRC, indicated that fear, denial, and shame were the survivor's initial feelings (De Roo, et al., 1998). The researchers claim that nearly all the survivors had cared for a sick family member before becoming ill, and emphasized that it is clear the survivors had little or no idea that they could contract the virus from this exposure. After discharge from hospital, their families and friends abandoned the Ebola survivors much more often than they had ever anticipated. As a remedy to this unusual rejection by their closest kin and the larger society, the survivors recalled having steadfastly turned to God for compassion and solace. One of the most negative experiences that continue to linger in memories of the survivors was "witnessing other people dying in the isolation ward of the Kikwit General Hospital and the reluctance of the medical personnel to treat them" (pp. 883, 884 and 885). From these findings, the researchers recommended that during such outbreaks, unwavering attention should be given to the psychological implications of the disease. Most importantly, public campaigns should include anti-discrimination messages. They also recommended that if such outbreaks should re-emerge more psychological support should be given to Ebola patients and their families (De Roo et al., 1998).

From a human science perspective, the experiences of the survivors of this devastating life experience require understanding. These experiences are conditions or human phenomena which require nursing research" (Locsin and Matua, 2002). Schoenhofer (1994) explained that nursing research is the investigation or description of nursing phenomena grounded in a formalized conception of nursing. This implies that such studies unravel knowledge that nursing can use to execute the societal obligation to provide care to those who need it wherever they may be. Such knowledge is anticipated to foster a more humanistic approach in the care of persons who may go through similar situations; an approach that enhances the advancement of nursing practice. As a practice discipline, one of

the foci of nursing is health promotion and illness prevention of individuals throughout their lifespan. Appropriate nursing can only occur in such situations when nurses have substantial knowledge base that can influence the care of such a select and special group of people.

Nursing practice is uniquely placed in our society as being service-oriented. Knowledgeable practice, a societal expectation of nursing, can only manifest in situations when the nurses directly involved in community service are adequately empowered with up-to-date information and knowledge regarding the issues at hand. Such knowledge unveiled by way of research encourages appropriate satisfaction of societal needs.

Such research studies are efforts to sustain scientific inquiry geared towards development of nursing knowledge. These efforts are in consonance with nursing's uncompromising desire to facilitate its growth and maturity as a learned professional discipline. Such studies are concerted efforts to achieve the universal goal of knowledge generation in nursing. Additionally, such undertakings unearth new horizons that dictate nursing scholarship, thereby furthering nursing's knowledgeable practice in health care.

Theoretical Perspective Grounding the Study

In the theory Nursing as Caring (Boykin and Schoenhofer, 2001) affirm that nursing takes place in nursing situations, those shared lived experiences in which the caring between nurse and nursed enhances personhood – the process of living grounded in caring. "In the situation, the nurse draws on personal, empirical, and ethical knowing" (p.14). Living caring as nurse occurs when the nurse creates a unique approach to know persons as whole and complete in the moment, and in authentic presence enters the world of the other for the purpose of knowing the other as caring person. This process involves a constant and mutual unfolding of possibilities. It occurs continuously as while the other opens up possibilities thereby allowing the nurse to enter his or her world. In the situation of persons living as survivors of Ebola, the nurse is free to know the survivor, while expressing the beauty of

caring. Such knowledge of the encounters between the nurse and nursed facilitate knowing of self and of the other. “Every nursing situation is a lived experience” (p. 14). As such, expressing the living as survivors of Ebola enhances the appreciation of nursing as nurturing persons who live life fully grounded in caring. Since nursing situation is a shared lived experience, the findings of this study will enhance the nurses potentialities to join and bring into the relationship the life process of the other (survivor), hence enhancing his or her personhood.

Review of Related Literature

The experience of surviving a life threatening condition is one that has a long lasting impact on the survivors. Common examples of such life threatening conditions is surviving a rebel ambush, a fatal motor vehicle accident, or living through an experience of stroke. Comparable to the experience of surviving death from Ebola was the experience of surviving death at the hands of the Joseph Kony’s Lord’s Resistance Army in Gulu, Uganda.

Surviving rebel captivity is met with immense joy and a rare sense of relief. However, in general, low self-esteem, lack of confidence, and depression were some of the feelings these former LRA captives verbalized. Erenreich, (1997) a consultant for the Human Rights Watch children’s rights project, documented these experiences during a research study undertaken between May and June 1997. This study focused largely on the experiences of children formerly abducted by Kony’s LRA rebels. It found out that the children experienced immense fear, anxiety, hopelessness, helplessness, and desperation at not knowing how to escape rebel captivity. The group also gave accounts of frequent visitation by the spirits of those they had killed or watched die! They reported these experiences as being frustrating and scary!

The experience of surviving Ebola is the experience of suffering numerous and relentless physical deficiencies and distresses. Bwaka, Bonnet, Calain, Colebunders, De Roo, Guimard, Katwiki, Kibadi, Kipasa, Kuvula, Mapanda, Massamba, Mupapa, Muyembe-Tamfum, Ndaberey, Peters, Rollin, & Van den Enden (1999), established that the survivors suffered numerous physical complications. These findings were based on clinical observations of 103 patients during the damaging 1995 Kikwit EHF outbreak. These observations revealed that survivors started recovering two weeks after onset of the disease, they gradually gained appetite but most of them remained markedly weak, having lost weight drastically. These patients frequently complained of asymmetrical and sometimes migratory arthralgia (joint pains), ocular disorders, orchitis, hearing loss and pericarditis that was clinically suspected. No substantive recommendations were made regarding the care of these survivors.

Surviving ebola is a unique experience comparable to defying death. De Roo and colleagues (1998) in a study conducted among the survivors of the 1995 Ebola epidemic in Kikwit, on survivors' feelings and experiences, indicated that they showed overwhelming appreciation, joy, and gratefulness to God. In this study, survivors were told to describe their feelings and experiences pertaining to their encounter with Ebola. It was discovered that they expressed profound gratitude to all those persons including the Almighty for their survival. The researchers further unearthed that the survivors expressed joy at having survived death from Ebola. No recommendations were made about the implications for nursing persons who survived Ebola.

The simultaneous experience of anticipating death while at the same time hoping for life was a continuing theme for contact persons of patients with Ebola (Locsin & Matua, 2002). In their study Locsin and Matua allowed contact persons to describe in writing, "What was it like waiting to know?" a phenomenon much like that described by the fifteen

survivors of the Ebola outbreak in Gulu. Anticipating the worst to come while still hoping for the best appears to pervade the experiences of both contact persons and survivors. The researchers further described that the anticipation of death conjures images of strength and motivation to live on. Importantly, this anguish of anticipation seemed to urge care for self while creating the feeling of body-mind connectivity. The researchers reported that for contact persons who were workers in the hospital, each time a suspected Ebola patient was brought in they would begin experiencing "funny electrifying feelings." It was also noted that some contacts experienced headaches at the mere sight of such patients, while others reported that they immediately felt feverish whenever they thought about Ebola. The researchers recommended that these experiences needed to be understood in order to facilitate the care of such and similar persons who experience such feelings.

Based on the findings of this study, Locsin and Matua (2002) reported that these contacts suffered grave ostracism, social isolation, and ceaseless rejection from their families, friends, and members of the community. The researchers added that due to fear, previous relationships dissipated needlessly, leading to further abandonment of the contacts and their families. The researchers also documented incidences where people who used to be friendly to contact persons before the epidemic started running away from them. Similar experiences were reported by Dee Roo, et al., (1998) in a study conducted among the survivors of the 1995 Kikwit EHF epidemic.

It is noteworthy that although there was literature available on the experiences of the contact persons and the Ebola survivors, information on the care of this special and select group was significantly missing! In this report, the global trends of the EHF outbreaks are explicated, followed by the presentation of the synopsis of the recent EHF epidemic in Gulu, Uganda.

Ebola Epidemic: The Global Trends of Outbreaks

In this section, the researcher articulates the chronological order of the occurrences of Ebola. The outbreaks are usually named after the subtypes of the Ebola virus implicated in the epidemic. Likewise, the subtypes such as Ebola Sudan are named after the country or nation where a particular subtype was first isolated. Serological evidence available to scientists indicates that there was an Ebola-like infection during the famous Yellow fever epidemic in Ethiopia from 1961 to 1962. These findings were derived from retrospective analytical studies conducted on stored human sera from Ethiopia during this period. The second incidence, also revealed through retrospective analysis of human sera occurred in Zaire, now DRC in 1972. The findings of this analysis indicated that a physician developed an Ebola-like disease after performing an autopsy on a patient believed to have died of Ebola (Zaramba, 2001; Peters and Le Duc, 1999).

It is imperative to note here that, although serological analyses point toward the existence of Ebola as early as 1961, the virus was first isolated from freshly obtained human sera in October 1976 near River Ebola, after which the virus was named. This outbreak occurred concurrently in the southern Sudan towns of Nzara, Maridi, and Tembura, and the DRC Eastern Equatoria, region towns of Yambuku and Bumba (Zaramba, 2001; Khan, et al., 1999).

The next Ebola epidemic occurred in Sudan (Ebola-Sudan) between the months of June and November 1976. During this outbreak, 284 cases were involved resulting into 150 deaths, a case fatality rate (CFR), of 52%. The infection spread through close personal contact within the health facilities leaving many medical personnel infected. Another epidemic that ravaged eastern DRC (Ebola-Zaire) ran from September 1976 to October 1976. It involved 318 cases and 280 deaths occurred, representing a CFR of 88%. The spread of the disease was enhanced by close personal contact and use of contaminated

needles and syringes. It was during this epidemic that the virus was first detected from fresh human serum (Zaramba, 2001; Khan et al., 1999).

In November 1976, a Laboratory worker in Salisbury, United Kingdom was infected by an accidental needle stick injury. However, he fully recovered from the condition and was sent home. He had been infected with Ebola-Sudan strain. In June 1977, a child became infected and died in the western DRC town of Tandala. This was Ebola-Zaire subtype. A case mortality rate of 100% was recorded. Two years later, in August 1979, a recurrent outbreak occurred at the same site as the 1976 Sudan epidemic in Nzara. This time 34 cases were documented, including 22 deaths resulting in a CFR of 64%. The Ebola-Sudan strain was implicated during this outbreak (Khan et al., 1999).

In 1989, an Ebola virus isolate was recovered from monkeys (Macaca fascicularis) housed in a quarantine facility in Reston, Virginia, Texas, and Pennsylvania. These monkeys had been imported from the Philippines. Four humans, all animal handlers developed antibodies to the Ebola-Reston virus but none of them developed any overt illness. In 1990, Ebola-Reston was once again reintroduced to Texas and Virginia, USA by monkeys imported from the Philippines. Once again, four humans developed antibodies but none of them developed EHF (Khan, et al 1999; Peters, 1997). Later in 1992, Ebola-Reston was introduced to Italy into quarantine facilities in Sienna by monkeys imported from the same export facility in the Philippines that was involved in the episodes in the United States. No human cases were registered (Peters, 1997; Khan, et al., 1999; Zaramba, 2001).

In December 1994, an outbreak occurred in Gabon (Ebola-Gabon) where 44 cases were recorded and a CFR of 63% was registered. These outbreaks were in Minkouka and other gold mining encampments deep in the rain forest. Initially it was thought of as yellow fever. However, in 1995 it was later identified as Ebola (Georges-Courbot, et al., 1997).

Similarly, in November 1994, a scientist working in Taï rain forest in Cote D'Ivoire became ill during a Chimpanzee Ebola outbreak where 12 out of 40 of them died. The scientist, an autopsy worker was evacuated to Switzerland where she later fully recovered from the illness. Ebola- Cote D'Ivoire strain was implicated during this outbreak. (Georges-Courbot et al., 1997).

The following year between the months of May and June 1995, yet another devastating (Ebola-Zaire) epidemic occurred in Kikwit, DRC, located 250 kilometres east of Kinshasa the capital city. The epidemic spread through families and hospitals. Kikwit was not only affected but its surrounding locale was equally hard hit. There were 315 cases, 244 deaths, and a total CFR of 77% was recorded (Khan et al., 1997).

In early February 1996, the West African state of Gabon was once again hit by a second apparently independent outbreak since December 1994. It began in Mayibout village on the Ivindo River in the northeastern region, where 37 people reportedly perished. This was the third outbreak since 1994. It started in July 1996 in the Booue area. Patients were transported to Libreville where the provincial hospital is located. Sixty deaths accounting for a CFR of 75% was reported during this outbreak. The index case patient had been involved in treating patients infected with Ebola in Gabon, an infection he contracted while still in Gabon. He was hospitalized and the nurse who took care of him also was infected and later died. Once again in 1996, monkeys imported from the Philippines reintroduced Ebola-Reston into a quarantine facility in Texas, USA. No human cases were recorded. In the same year 1996, Ebola-Reston was identified in a monkey export facility in the Philippines. No human cases were reported (Georges-Courbot et al., 1997).

In October 2000, a massive Ebola epidemic comparable to that of the 1995 Kikwit outbreak hit Uganda's northern district of Gulu. It was from Gulu that the virus spread to two other locations notably Masindi and Mbarara districts. Infection was mainly spread

through cultural burial practices, nosocomial infection at health facilities, and cultural practices that encourage contact with corpses, notably bathing and clothing them as a sign of last respect and to bid them farewell. The Ebola-Sudan strain was isolated from the patients during the six months long epidemic. Of the 425 persons infected, 211, 49% of them survived, and a total CFR of 51% was recorded, when the World Health Organization, WHO, issued a press release to declare Uganda's Ebola outbreak officially over on February 27, 2001(WHO, 2001; USDHHS, 2001; Mupere, et al., 2001).

The most recent Ebola outbreak in the world has been reported in the West African Tropical rain forest country of Gabon where the last outbreak occurred 5 years ago in July 1996. Initial reports of a suspected viral haemorrhagic fever in Gabon reached WHO on December 4, 2001 indicating that 7 deaths had occurred in the northeastern province of Ogooué-Ivindo. A team of experts was immediately dispatched from the Gabon Ministry of Health and the Centre International de Recherches Médicales de Franceville (CIRMF), supported by military medical personnel and the World Health Organisation Sub-Regional Epidemic Response team to Ogooué-Ivindo province. The first case of Ebola was confirmed by December 11, 2001. The Ebola-Gabon subtype was isolated. A national Ebola task force was subsequently formed and an international community of experts came in to help coordinate the fight against Ebola (WHO, 2001). By December 20, 2001, new Ebola cases were reported in the neighbouring country, the Republic of the Congo. A total of 227 contacts (persons having direct or suspected contact with the blood or other body fluids of a person suspected to be infected with ebola) were being followed up. Of these, 133 of them were in Gabon and 94 of them in the neighbouring Congo. By March 14, 2002, the Gabonese MoH had reported 60 confirmed Ebola cases including 50 deaths while the Congo MoH authorities confirmed 31 cases with 18 deaths in villages within the Cuvette region, the Congo, close to the border of the Ogooué-Ivindo province of Gabon. The Ebola-

Gabon strain is responsible for the outbreaks in both Gabon and the republic of the Congo. In both countries, surveillance teams closely followed up contact persons.

As of April 9, 2002, the Gabonese Ministry of Health reported 65 confirmed Ebola cases, including 53 deaths. Presently, 53 contacts are being followed. The most recent cases were reported in villages north of Mekambo and resulted from contact with a gorilla, whose remains were found to be positive for Ebola virus when tested at the Centre International de Recherches Médicales de Franceville (CIRMF). No disease activity has been reported since the end of February in the Makokou area.

As regards the Republic of the Congo outbreak, a preliminary review of the epidemiological situation on April 1, 2002, indicated 25 confirmed cases, including 23 deaths, reported in villages in Kelle district. The last confirmed case in the area died on 18 March. The lack of community cooperation has hampered control efforts and impeded a thorough investigation. Despite these hardships WHO, Médecins sans Frontières, International Federation of Red Cross and Red Crescent Societies and other partners in the Global Outbreak Alert and response Network, in collaboration with the Ministries of Health of the Congo and Gabon are working hard to contain this epidemic (WHO, 2002).

Ebola in Uganda: A Synopsis of the Outbreak

The outbreak of this unusual febrile illness with generalized haemorrhage and alarming rates of mortality was officially reported to the Ministry of Health, (MoH), in Kampala on October 8, 2000. This report was made by both the Medical Superintendent of St. Mary's Hospital in Lacor and the District Director of Health Services Gulu District (Uganda National Health Research Organisation, UNHRO, 2001; Mupere, et al., 2001). Immediately following this pronouncement, a team of a Virologist from the Uganda Virus Research Institute, (UVRI), and the Chief Technologist of the Central Public Health Laboratories was dispatched to Gulu to make a preliminary assessment of this "mysterious"

disease. Once in Gulu, blood samples were collected from the suspected patients and the team advised that such patients be immediately isolated and barrier nursing be started forthwith. This meant that patients suspected to have Ebola had to be transferred from the general wards to special wards where they had to be isolated. In addition to isolating the suspected patients from the main ward, all those persons, such as the health team and the cleaners who would for one reason or the other have close proximity to the patients, as a must wore protective materials such as masks, double gloves, gumboots, and clothing that protected their entire bodies. Findings of the preliminary investigations indicated that the disease had begun in the month of September or even much earlier (USDHHS, 2001;UNHRO, 2001).

As of October 14, suspicion of EHF was confirmed when the National Institute of Virology, (NIV), Johannesburg, South Africa, identified Ebola virus infection among specimens from patients, including health care workers at St. Mary's Hospital, Lacor. In response to this confirmation, the Minister of Health informed all Ugandans of the outbreak, and emphasised that the population need not panic, but take precautions to avoid the infection (Mupere, et al., 2001; UNHRO, 2001). As an emergency measure, the national task force on hemorrhagic fevers reconvened. This team in consultation with Gulu district authorities, the WHO representative, and the development partners set up a comprehensive epidemic response plan. The plan included management arrangements, surveillance and epidemiology, clinical case management, social education and mobilization, and coordination and logistical support (UNHRO, 2001; USDHHS, 2001). An active EHF surveillance system was initiated to determine the extent and magnitude of the outbreak, identify foci of disease activity, and facilitate the early detection of cases. At the national political level, an inter-ministerial committee was set up under the office of the Prime Minister, to coordinate government resources against the epidemic. Local and international

experts were called to assist in the fight against Ebola. In response to this urgent call, experts from World Health Organisation (WHO), Centers for Disease Control and Prevention (CDC), USA and National Institute of Virology (NIV), South Africa, were immediately dispatched to join the fight against Ebola (USDHHS, 2001; UNHRO, 2001; Mupere, et al, 2001).

The initial targeted prevention activities included follow up of contact persons of identified cases for 22 days, establishment of trained burial teams for all potential and confirmed EHF deaths, community education, cessation of traditional healing and burial practices, cessation of large public gatherings, and updates of hospital infection control measures, including isolation wards (USDHHS, 2001; UNHRO, 2001; Zaramba, 2000).

Due to the magnitude of this outbreak, experts from Centers for Disease Control and Prevention, (CDC), Atlanta set up a field laboratory for the diagnosis of Ebola infection in St. Mary's Hospital in Gulu Lacor. Testing was done at this field laboratory supplemented by additional testing at CDC, Atlanta, and NIV, South Africa. Sequence analysis revealed that the virus associated with this outbreak was Ebola-Sudan. The laboratory tests used during this outbreak included; virus antigen detection, antibody, enzyme-linked immunosorbent assay (ELISA) tests, and reverse transcriptase polymerase chain reaction. Laboratory-confirmed case patients were defined as patients who met the surveillance case definitions and were either positive for Ebola virus antigen or Ebola IgG antibody (USDHHS, 2001; Mupere, et al., 2001).

During the third week of October 2000, an active surveillance team was established and their work was based on three notification categories: alert, suspect, and probable. The alert category was comprised of persons with sudden onset of high fever, sudden death, or haemorrhage, and the community members used this criterion to alert the health personnel. The suspect category was comprised of persons with fever and contact with a potential case-

patient; persons with unexplained bleeding, fever, and three or more of the specified symptoms (i.e. headache, vomiting, anorexia, diarrhoea, weakness, or severe fatigue, abdominal pain, body aches, difficulty swallowing, difficulty breathing, and hiccup), and all unexplained deaths. The suspect category was used by mobile surveillance teams to determine whether or not a patient required transport to an isolation ward. The probable category included persons who meet the above criteria and were assessed and reported by a physician (USDHHS, 2001; Zaramba, 2000).

As of January 23, 2001, 425 presumptive case-patients with 214 (51%) deaths attributed to EHF were recorded from three districts of Uganda: 393 (93%) from Gulu, 27 (6%) from Masindi, and 5 (1%) from Mbarara, where the other two focal outbreaks occurred initiated by movement of infected contacts from Gulu. The epidemic covered a geographical area of approximately 11,700 square miles (31,000 square kilometres) affecting combined population of about 1.8 million Ugandans. The field findings indicated that the ages of the presumptive case patients ranged from 3 days to 72 years with a median of 38 years, of these 269 (63 %) were women. The meantime from symptom onset to death was 8 days and 218 (51%) of the presumptive cases were laboratory-confirmed (USDHHS, 2001;UNHRO, 2001; Mupere, et al., 2001).

Epidemiological investigations identified the three most important means of transmission as: attending funerals of presumptive EHF case-patients where ritual contact with the deceased occurred; intra-familial transmission; and nosocomial transmission during admission to hospital. Effective collaboration between government, local and international non-governmental organisations, and development partners through the national notification and surveillance network effectively contained the epidemic (WHO, 2001). This achievement led to the pronouncement of Uganda Ebola free on February 27, 2001, by the World Health Organisation, a declaration that came 42 days after the last patient with Ebola

recovered. This duration is twice the maximum incubation period for Ebola to develop. The last Ebola patient was a 40-year-old woman who got infected from nursing her grandchild following the mother's death. On February 28, 2001, WHO, issued a press release to declare the Uganda Ebola outbreak officially over. Uganda was now an Ebola free country! The world body called for a stronger alert response to minimise the global impact of future outbreaks (WHO, 2001; Mupere, et al., 2001).

METHODOLOGY

Phenomenology as a Method of Inquiry

Phenomenology is defined in the Concise Oxford Dictionary (1990) as "the description and classification of phenomena" (p. 289). Phenomenology is a branch of philosophy grounded in the works of Husserl and Heiddegger (Van der Zalm, Jeanne, Bergum, and Vangie, 2000). It is the study of phenomena as they are experienced. Phenomenology as Husserl (1970) describes it concerns itself with the way people's language conceals and reveals phenomena. In line with the works of Husserl (1970), this philosophical method of inquiry systematically investigates the structures of consciousness without pre-supposition, in his words "going back to the things themselves"[zu den scahein], by stressing the discovery and exploration of the experience as it is revealed in the consciousness. Hence, by studying consciousness, the researcher is able to explore the nature of the experience as it is lived.

Likewise, Koch, (1999) a nurse scholar declared that phenomenology is an approach to understanding the life experiences of people, rather than discovering new knowledge. Van der Zalm et al., (2000), laid down similar claim that phenomenology illuminates the various ranges of human experiences in daily lives and seeks to describe them in such a way that these experiences are presented "as they occur in real life." This presentation of experiences as they are lived in daily life creates opportunities for understanding them. Van

Manen (1977) likewise contends that understanding [verstehen] cannot be attained by the classical empirical-analytical methods of inquiry, but rather by the phenomenological approach.

Nursing scholars and researchers consider the fundamental philosophical orientation of phenomenology as relevant to the advancement of the discipline and the profession. Nursing, as a discipline, engages with people through their experiences of health and illness. This orientation toward concrete experiences, to persons in relationship with others, to their beliefs and practices, and to endeavor to understand the meaning of persons' experiences, hold particular appeal to nursing (Benner, 1994).

Phenomenological inquiry yields knowledge that is descriptive and explanatory in nature. In practice, such knowledge augments the nurses' understanding of the meaning and relevance to the patient's daily experiences. Understanding the meaning and relevance of such experiences empowers the nurse to appropriately facilitate the well being of such and similar patients (Polit and Hungler, 1999).

The phenomenological researcher asks the question: What is the essence of this phenomenon as experienced by these people? In this approach, the inquirer investigates subjective phenomena, in the belief that essential truths about reality are grounded in people's lived experiences. The focus of this type of inquiry is therefore what people experienced about some phenomenon, and how they interpret these experiences. It is based on the belief that lived experience gives meaning to each person's perception of a particular phenomenon (Polit and Hungler, 1999; Van Manen, 1990).

Classically, in a phenomenological inquiry, the main source of data is the in-depth conversations in which the researcher and the informant are full co-participants. The researcher uses the participant's subjective information as revealed to him/her in the conversation to understand the experience as it occurred. It is only the consciousness of the

participant that can perfectly reflect his/her experience. Van Manen (1990) alludes to this by affirming that "consciousness is the only access human beings have to the world" (p. 9)--[and] it is that consciousness that forms basis to our experiences. Because of the need to obtain as much experience as possible during the conversation, the researcher guides informants as they describe their experiences without leading the discussion. Through this in-depth discourse, the researcher strives to gain entrance into the informants' world to have full access to their experiences as lived (Polit and Hungler, 1999).

Phenomenology as a method of inquiry is particularly suited for studying poorly defined or conceptualised phenomena (Polit and Hungler, 1999), such as that of "living as a survivor of Ebola". Further, phenomenology elucidates the ontological (what it means to be) nature of lived experience, an approach that unveils opportunities for health care workers and especially nurses to develop comprehensive and integral views of human experience. Understanding these experiences of persons as they go through life enriches nurses' capacities, possibilities, and potentialities to act more humanely towards others who may experience such or similar situations. Because phenomenology studies human phenomena, it is therefore the most suitable method of inquiry to appreciate the experiences of patients who survived Ebola haemorrhagic fever.

General Procedure of Phenomenological Inquiry

A number of methodological processes exist suggesting that different steps may be utilised in conducting a phenomenological inquiry. Typically, a phenomenological inquiry involves the following four basic steps: bracketing, intuiting, analysing, and describing (Polit and Hungler, 1999). Bracketing refers to "the process of identifying and holding in abeyance any preconceived beliefs and opinions one might have about the phenomenon under study"(p. 247). This concealing or "closing off" of one's own ideas and conceptions enhance data generation in its pure form. Bracketing also termed "phenomenological

reduction" aims at isolating pure phenomenon [that which is under inquiry] from what is already known about the phenomenon (Polit and Hungler, 1999).

Intuiting on the other hand refers to "the openness the researcher exerts towards the meanings attributed to the phenomenon by those persons [participants] who have experienced it"(Polit and Hungler, 1999, p. 247). The overarching goal of the intuitive process is to generate a common understanding of the phenomenon under study. Intuition calls for imagination on the part of the researcher and requires that he/she become very much immersed in the phenomenon under study.

Furthermore, Polit and Hungler (1999) stress that following the intuiting process, the researcher proceeds to the analysis phase, characterized by data coding, categorization, and the understanding of the essential meaning(s) of the phenomenon. As the inquirer dwells with the rich descriptive data, common themes often called thematic structures begin to emerge. This process of immersion in the data generated continues for as long as is needed to ensure pure and thorough description of the experiences as they are lived.

Following this phase is the description phase that manifests when the researcher comes to define and understand the phenomenon central to the study. It is in this phase that the inquirer describes the lived experience of the participant from his/her synthesis of the data generated. This final step is really aimed at communicating and offering distinct critical description in written and verbal form (Polit & Hungler, 1999).

Description of Participants

Sixteen survivors were requested to describe the lived experience of surviving Ebola, a life threatening illness. Of the sixteen participants, eleven (69%) were female and five (41%) were male. Three of the participants were qualified nurses, two were students of nursing, and the other a cleaner in one of the medical wards that admitted patients with

Ebola. One participant was a senior secondary (high school) student, another a businessman in Gulu town and the remaining eight participants were peasant farmers.

A large majority of the participants were low-income earners, except for the few who had government paid positions and those who were involved in business transactions. The male participants had an age range from 17 years to 42 years whereas the female participants had a range of 18 years to 45 years. Both men and women had a median age of 30 years, and the overall participant median age was also 30 years.

Data Generation

In this study, participants were selected based upon the established criteria of participant accessibility, and their anticipated proficiency to ably describe their experiences. Colaizzi's (1978) phenomenological approach to data generation was used to analyse the transcriptions. This approach follows the general phenomenological inquiry process. The unique feature of this approach, however, is the step that requires formulated descriptions to be validated by the participants of the study, thus providing further authenticity to the results.

Colaizzi's Phenomenological Approach

In this study, Colaizzi's (1978) phenomenological approach of data generation was utilized. The seven characteristic procedural steps used are:

1. The researcher carefully reads the verbatim transcriptions [written descriptions] of the experiences of the participants in order to become familiar with them. To facilitate this process the researcher is engaged in the process of immersion. With this process, the researcher reads and re-reads the transcribed information while at the same time listening to the tape-recorded interview information.
2. As the researcher immerses him/herself in the descriptions and understands them, giving "idiomatic expressions" in the participant's story, particular

attention facilitates further understanding of the experience. From each written description or protocol, phrases or sentences that pertain to the phenomenon under study are extracted. This step is referred to as "extracting significant statements", also referred to as thematic statements. Here repetitious statements were eliminated.

3. The third step designated as "formulating meanings" is where the meaning of each significant [thematic] statement is clarified. Formulating meanings requires the researcher to take a precarious leap from what the participants said to what they meant. In this stage caution is taken not to sever all connections from the original written descriptions when the researcher goes beyond the statements in the protocols to derive meaning from them.
4. The fourth step comprises organization of the formulated meanings from all the descriptions (protocols) into clusters of themes. In this stage, the researcher is again involved in leaping from what was given in the meanings, to identifying themes. Two sub steps are involved in this fourth step notably:

    a) The newly identified clusters of themes are referred back to the original protocols for validation. In this case, the researcher determines whether there is any information in the original written descriptions that were not accounted for in the cluster of themes. The researcher also determines whether the clusters of themes propose anything that was not implied in the original protocols. It is also during this stage that all the clusters of themes the researcher had identified are validated for correctness.

    b) The discrepancies among the various clusters are taken into account. According to Colaizzi (1978) the researcher should not ignore the themes that do not fit into these clusters.

5. The fifth step is characterized by an exhaustive description of the phenomenon being investigated. From the identified thematic statements, the researcher formulates a description of the experience as it was lived. This exhaustive description is developed from the results of the data analysis.
6. During the sixth step the researcher attempts to formulate the exhaustive description of the investigated phenomenon, in as unequivocal a statement of identification as possible. Here the researcher makes an effort to describe the phenomenon in unambiguous and explicit terms to enhance understanding of the phenomenon under inquiry.
7. To achieve the final validation the researcher gives each subject the exhaustive description of the phenomenon and asks him or her whether or not the description arrived at fully describes his or her experience. The subjects are asked if any aspects of their experience have been omitted. Any relevant data obtained from the subjects during the validation exercise is incorporated into the final product of research.

Rigors of Qualitative Research

Credibility and auditability are rigors of qualitative research much like reliability and validity are in quantitative research. In this study, attempts were made to critically observe and utilise Lincoln and Guba's (1985) four major criteria for rigor in qualitative research inquiry namely; truth value, applicability, consistency, and neutrality throughout the research process. Further, credibility was established by the participation of only the persons who actually survived the Ebola disease and are living this experience as survivors. It is only this special group of persons who are in a position to describe what it is like to survive a life threatening illness such as Ebola.

Auditability was achieved by the use of audit trails. These audit trails refer to the use of verbatim translations of the words and phrases as they are used to describe the lived experience. With these trails, the researcher is able to lay bare evidence from which he/she made a delineation of the lived experience. This way the community of scholars will be able to trace the researcher's findings.

Procedure for Data Generation

Participants were selected based on the criteria that they would be easily accessible to the researcher and his assistant, and that they would ably describe their experiences. A list of survivors was obtained from the Gulu, District Director of Health Services (DDHS). The same Director also helped to link the researcher to the Vice Chairman of the Ebola Victims Association, an organization that overlooks the affairs of the survivors, and those persons affected by the epidemic. From this list, the vice chairman, and the researcher selected credible participants using the criteria established.

Further, participation in the study was limited to persons who had survived the recent Ebola epidemic in Gulu and those who consented to participate in the study. Priority to participate in the study was given to survivors who were health care professionals, either as workers, or as students, because these survivors would ably describe their experiences. Through this purposive sampling, it was found that these health care workers and students would be easily accessible compared to other category of survivors.

Initial Process

- Approval to conduct the study was sought from the Ethics and Research Committees of Mbarara University of Science and Technology. Upon receipt of these clearances, the researcher proceeded to seek authorization from the Ministry of Health (MoH) of the Republic of Uganda. Following this approval, the next clearance had to be obtained from the Uganda National Council for

Science and Technology (UNCST). This national research council then authorized the researcher to proceed with the study after obtaining two further clearances from the District Director of Health Services (DDHS), Gulu where the study was to be conducted and the Resident District Commissioner (RDC), Gulu, the presidential representative.

- A research assistant was recruited as staff for the research study. The primary role was to translate the consent form into the local language, and translate transcriptions into English for data generation. The research assistant was a third year medical student. It was important that the translator understood the medical nature of the disease to be conscious about language nuances uniquely referencing the medical aspects of the disease as well. It was also hoped that the experience gained during the research process would allure the assistant toward valuing research and knowledge development as an undertaking in professional practice.
- The researcher instructed the research assistant, equipping him with the necessary skills that were needed to facilitate his accurate and proficient functioning, particularly during the phase of translating the audiotaped interviews.
- The study was conducted in Gulu, the worst affected district by the Ebola epidemic, following approval from the relevant authorities, notably the District Director of Health Services and the Resident District Commissioner. The researcher and his assistant were faced with a number of constraints. The process was expensive, in that the researchers had to spend additional funding in transporting the participants from their home to the sites designated for the interview. Considerable time was spent on obtaining the final consent from the

district officials to conduct the research. This delayed the commencement of the data generation process.

- Following acquisition of the clearances from the Gulu district officials, a list of survivors was then obtained from the District Director of Health Services (DDHS). From this list, the researcher and the vice chairman of the Ebola victims association selected credible participants for the study.

Interview Process

Using the consent form (See Appendix A), the researcher together with the research assistant explained the nature of participation in the study. However, to those participants who did not speak English, the research assistant used Acholi the local dialect to explain the nature of the participation in the research study. This way voluntary participation in the research study was achieved. In general, the consent form explained the nature of the study, the voluntary nature of participation, the chance to withdraw at any time during the research process without consequence, and importantly, the opportunity to influence the care of persons in similar situations. The consent form is an integral instrument that a researcher must secure before conducting a study, because it serves to indicate the terms and conditions of a participant's voluntary participation in a study (Polit and Hungler, 1999).

During the course of the interview the seating arrangement was such that the researcher, his assistant, and participants sat in a circular manner with a table between them. The tape-recorder that was used to record the proceedings of each participant's interview was placed on the table. This seating arrangement encouraged free communication between the participants and the interviewers, in addition to providing the opportunity to observe the non-verbal expressions of the participants as they described their experiences.

After the consent to participate in the study was obtained, the interview process commenced as follows:

a. The interview was conducted freely without interruption using the guide (See Appendix B). Participants were asked to clearly describe their experience of surviving Ebola. They were informed that there was no time limit to the interview.

b. The participants were asked to tell the story of their experience, particularly the time when they learned that they had survived Ebola! The interview guide (See Appendix B) provided the directions and kept the interview process focused on the topic.

c. While describing their experience, the respondents were asked to continue to recall what this survival meant to them until they had nothing left to say.

Procedure for Data Analysis

1. A manual data filing system was used to organize the data during the analysis process. All the tape-recorded descriptions were transcribed. Those interviews that were originally recorded in Acholi, the local dialect were first transcribed, and the research assistant then undertook to carefully translate them into English, the language that the researcher understands.
2. The researcher then proceeded to immerse himself in the data by reading and re-reading each participant's transcription, while at the same time listening to the tape-recorded interviews. This process was only limited to those interviews originally recorded in English. However, for those interviews initially conducted in Acholi, the local dialect, the researcher asked the assistant who has command of the dialect to read and immerse in the data. As the researcher read the translated transcriptions aloud, the research assistant was listening to the original interview and reading the

translations as well, pointing out descriptive words and phrases. This immersion greatly facilitated the emergence of significant words, statements, and passages that directly described the experience of surviving Ebola. Notations were made in the margins, and meanings (categories, or common elements) were formulated as they emerged from the significant statements. The process was repeated for each transcribed interview, and the resulting aggregate of formulated meanings were then organized into clusters of themes, which were later validated by referring back to the original transcripts to ensure that no data had been ignored or added.

3. The thematic structures/statements that emerged during the immersion process were clustered and used to exhaustively describe the experience of surviving Ebola.
4. Following this individualized description of the "experience," the researcher and the interviewer re-visited each participant to verify and validate the formulated description of the experiences. This was done by asking the question, "Is this the experience that you meant by your description"? This way the researcher was able to validate individual descriptions of the experiences for correctness. All 15 descriptions were accepted with little clarifications and minor changes. One respondent was unavailable during this verification phase and hence her description was discarded as a procedural requirement.
5. After this verification and validation exercise, the variously described experiences were collectively and carefully integrated to arrive at the description of the experience of surviving Ebola.

Limitations of the Study

Of particular importance is the limited research literature available on Ebola as a disease, and even more so is literature on the experiences of persons who have survived the illness. Such literature would provide evidence to show what studies have been done in this

area in addition to facilitating the researcher's understanding of participants' experiences. Consequently, the explication of the findings of this study in relation to the findings of other such studies on Ebola and other life threatening conditions was limited.

Secondly, language barrier presented another significant limitation to data analysis. Eight of the fifteen interviews were recorded in Acholi, the local dialect and were later translated into English. Although the research assistant, the official translator has good command of both languages, there still exists a remote possibility that he may have omitted some important cues in the survivors' descriptions. As a result, some of the richness of the survivors' descriptions may have been lost.

Lastly, the findings of this study may not represent the experience of the survivors in totality. This arises from the fact that only a small number of the survivors participated in the study, largely due to the purposive sampling method employed and because of the early emergence of the saturation point. It is therefore suggested that the findings of the study should be used cautiously.

FINDINGS OF THE STUDY

The study on the lived experience of persons who survived Ebola, a life threatening illness, was conducted using Colaizzi's (1978) phenomenological approach. Following the approved protocol for data generation, each participant was chosen using the selection protocol described on page 28. Data was generated using a semi-structured interview with each participant asked to answer the question, "What is it like living as a survivor of the Ebola Haemorrhagic Fever?" This question was translated into Acholi, the native tongue of the people in Gulu District, Northern Uganda, specifically for those participants who did not speak English. A medical student fluent in both spoken and written Acholi was hired as the official translator. The translator being a medical student was essential to generating accurate translations of the medically significant descriptions provided by participants who

spoke Acholi. Each participant was asked to describe his/her experience until there was nothing more to say about it. All the interviews were tape-recorded; consequently, the descriptions recorded in Acholi were translated into English. Code numbers were used to identify all participants of the study.

As uniquely required by Colaizzi's (1978) phenomenological approach, confirmation and verification of the interpreted descriptions were secured from all of the fifteen participants. Although each participant described the experience of surviving Ebola differently, their stories converged into two patterns: "Victors" of the Ebola epidemic and emerging triumphant, while the other pattern was as "Victims," in that Ebola had turned them into failures in life.

Within these two patterns manifested seven categorical themes with corresponding sub-themes or thematic clusters. Each of these sub-themes supports the description of the experience of surviving Ebola hemorrhagic fever. The categories are:

- Living anew beyond happiness
- Reminiscing expressions of vulnerability
- Experiencing diminishing self integrity
- Living awareness of the afterlife
- Struggling to live meaningfully
- Living frustrating alterations in life patterns
- Suffering isolation beyond measure

Descriptive Patterns of the Phenomenon

Victors

The pattern of being victors resounded expressively within the thematic categories of "living anew beyond happiness," "living awareness of the afterlife," and "struggling to live meaningfully." As victors, the participants described their experience with a heightened

appreciation of anticipating meaningful living in spite of the dreadful experience of surviving the deadly disease.

Living Anew Beyond Happiness

The theme "living anew beyond happiness" is expressly illustrated by the following four themes:

- A powerful God exists
- Gratitude over goodness and kindness
- The joy of living
- "My time had not yet come"

The thematic statement of "living anew beyond happiness" illustrates the seemingly paradoxical recognition of living after a dreadful situation.

A Powerful God Exists

The power of God was often referred to as the only reason for survival. To these survivors, it was also the manifestation of God's love for humankind. This experience of survival was described as, "beyond happiness." To others, survival occurred because of their total belief in the Almighty and His powers to heal and rid humanity of all forms of affliction including death. A participant declared that:

> I would like to say that God loves me because if surely he didn't, I would say that there was a point or time that was reached when the doctor couldn't save any body from death …so if God wasn't the one to save me, I would have also died!

Gratitude Over Goodness and Kindness

Despite the difficulties experienced during the illness, the survivors particularly expressed gratitude over God's goodness and kindness, as well as to the many health care workers, and other human support systems who enabled them to survive an illness that no

one had control over. The survivors relentlessly showed gratefulness to the health workers for enhancing the survival process and facilitating God's wish that they should live. A participant described that:

> I was very excited and happy and thanked God. I went and got saved [total devotion to work of God] and actually everything I do now I put in God's hands! …First of all I was very thankful to God, secondly I was also thankful to the doctors [read health workers] who treated me and thirdly to my mother who stood by me and was always giving me fluids for drinking.

The Joy of Living

The survivors expressed profound delight at the possibility of living a normal life once again. They were besieged by this rare opportunity, especially when they were declared Ebola free and ready to go home after several weeks of hospitalisation. The experience of survival was met with great confidence especially after being issued certificates that signify each participant as fully recovered and Ebola-free. This certificate also acted as evidence to show that a sufferer was no longer infectious and that there was no need to run away from such a person. This theme is illustrated by a participant's description: "Actually I started feeling happy because I thought I would now remain alive"!

"My time had not yet come"

It was clear from the theme clusters that these survivors had different perceptions of the survival experience. They had various reasons to explain why they survived the epidemic yet the larger majority perished in it. Of the 425 persons reported to have succumbed to the Ebola disease, 211 survived. To most of them, survival meant that their day had not yet come as one of them vividly described:

> Actually, I think I survived because the day had not yet come

> For me to die. Considering the fact that I exposed myself to even more dangers than the other people who died, including washing bed sheets having excreta of my relative who died of Ebola, plus the baby. I even breastfed the baby.

Living Awareness of the Afterlife

In this category only one thematic expression about the participants' experiences emerged. These survivors expressed having experienced frequent visits by spirits of those who had died. Survivors experienced increased awareness of living in the beyond. They recalled having repeatedly encountered images and spirits of those who had already died. They maintained that these experiences were scary and disturbing. Importantly, these seemingly real encounters enhanced awareness of living after death.

These survivors attributed this haunting experience to the spirits of friends or relatives who perished because of Ebola. This phenomenon was clearly expressed by a participant: "I was in problems because …the ghosts of all those people who died when I was still in the hospital followed me home".

Struggling to Live Meaningfully

In this category five thematic statements were evident:

- Forming a survivors' association
- Celebrating knowledge about the disease
- Struggling to gain acceptance
- Yearning for family and social support
- Paying no attention to detractors

Formation of the Ebola Survivors Association

Survivors struggled to dispel the wrath of living with Ebola. The formation of the Ebola survivors association responsible for facilitating the care of those persons affected

and previously infected by Ebola was one of the most powerful forces that propelled the survivors to overcome the numerous physical-physiological and psychological consequences of Ebola. The association took care of the families of the survivors, as well as the orphans of Ebola. Through this association, the survivors were able to deal with some of the concerns associated with general living issues, including the particular concern of continuing infection with Ebola.

Celebrating Knowledge About the Disease

Affirming the knowledge that all illnesses do not necessarily lead to death was an effective mechanism for these survivors allowing them to live meaningfully. As they celebrated knowing, they became confident that they would live through the Ebola experience. They sought various ways to acquire knowledge about the disease and its effects. As a result, survivors were able to better understand some anti-social practices they had experienced, especially the community's attitude towards their living as survivors. They insisted on self-assurance based on the conviction that survival was possible and that armed with the knowledge, living positively is possible!

Struggling to Gain Acceptance

Despite being ostracized by members of the local communities, these survivors were able to find meaning in life, and live profitably by openly discussing and defending themselves during public discussions. The survivors started "pushing for" services that they thought would improve their lives. Among other things, they demanded a special "Ebola Survivors' Clinic" in which the survivors would be treated of the physical consequences of the illness. Further, these survivors actively participated in the local social and political activities, in the struggle to prove to the doubting members of the community that a survivor was no less than a human being.

In their campaign against social isolation, survivors informed the communities that they were now immune and that they would be of great help if any Ebola outbreak re-emerged in their area. Additionally, the survivors involved themselves in person-to-person education focused on the experience of survival. These efforts were geared towards gaining acceptance by the society in which they lived.

Yearning for Family and Social Support

Living positively after the Ebola experience was a challenge that required support from others. This theme illustrates how the survivors sought and received support from families and various support systems. These were material, moral, and/or psychological in nature. Supportive influences came from family members, health workers, friends, and all those who seemed to understand the survivors' concerns.

What seemed magical was that treating survivors with respect and dignity, opposite to the well-known effects of segregation and rejection, diverted them from the painful memories of intense suffering and agony. The survivors reported that open and non-judgmental communication greatly relieved their anxiety as depicted in this participant's description:

> I was worried but it was good that those nurses were comforting us [survivors]. They said it was good I had reached the hospital and that I wouldn't die! So all of us [survivors] were just conversing with those nurses and they were just free with us. They were giving us food prepared from the hospital.

Paying No Attention to Detractors

During and after the epidemic, members of the public hurled very disturbing comments and statements at the survivors. Often times they were ridiculed, insulted, and even given derogatory nicknames such as "Ebola" The participants found ways to ascertain

that ignoring such negative statements about them and their families was an effective method that helped them get along socially. One of the participants narrated how he was able to deal with such experience at school:

> "They nicknamed me Ebola and as I talk right now, I have been at school and they [students] were calling me Ebola! Ebola! Before I was really very annoyed [upset] …[but now]. I came to final conclusion that I should take it as a normal thing…"

Victims

The other pattern of surviving Ebola is the experience of being victims. Whereas some survivors affirmed that they had emerged victorious from their encounter with the deadly Ebola virus, participants also claimed that they had become victims of the Ebola experience. They claimed that consequent to the Ebola survival experience, they have turned into failures in life, as this participant clearly exhibits in this description:

> You know after recovering from this disease we have become very weak. We cannot do any work to earn us good income. So we are requesting the government to exempt us from paying tax. Secondly because we are weak we are requesting the government to pay for our children school fees including catering for small requirements like, books, pens, and others. Another request is for government to provide us with food.

From the descriptions of the experiences, four categorical statements emerged to support "victim" as a pattern of surviving Ebola hemorrhagic fever. These are "reminiscing expressions of vulnerability," "experiencing diminishing self-integrity," "living frustrating alterations of life patterns," and "suffering isolation beyond measure."

Reminiscing Expressions of Vulnerability

In this category, five themes emerged, namely:

- Experiencing persistent fear and anxiety
- Living with realities of psychosomatic manifestations
- Heightened awareness of survival
- Persisting with disbelief in survival
- Grieving over loneliness and aloneness

Experiencing Persistent Fear and Anxiety

During the course of the illness, survivors encountered incessant fear and anxiety. Generally participants reported fear of the unknown. Often, this fear was because of not knowing what to expect, either life or death! Survivors verbalized that their fear resulted out of the approaching and imminent death from Ebola. It is a disease that exhibited itself as incurable as this participant affirmed: "But when [we] heard that it was Ebola and that it was infectious…it meant that we were going to die. It also meant the ebola disease was so infectious that once one got it he/she had to die".

The fear and anxiety that survivors experienced was also linked to the resulting vandalism to their property performed by members of the community. Almost all survivors claimed to have experienced this fear and uncertainty. Survivors' houses and personal belongings were often set ablaze or buried, citing these articles as a possible haven for the deadly Ebola virus. Another source of anxiety these survivors articulated was the possibility of leaving children and property behind unattended if they should have died.

Living with Realities of Psychosomatic Manifestations

The survivors experienced numerous episodes of psychosomatic manifestations during and after the illness. Some recalled that while in the hospitals they periodically experienced varying degrees of illness aligned with body-mind connectivity as their well being begun to improve. These psychosomatic manifestations closely mimicked the signs and symptoms of the onset of Ebola, increasing their fear and anxiety. Commonly manifested psychosomatic signs and symptoms experienced by the survivors were headaches, heartaches, sweating, and constant nightmares. The mere sight of the isolation wards that they were housed during the epidemic, or even upon hearing the word Ebola, altogether create an electrifying sensation of "accelerating and diffusing" heat dissipating quickly from head to toe and from limb to limb.

Heightened Awareness of Survival

As the survivors' conditions began to improve, participants reported that they started experiencing a heightened awareness of being a survivor of Ebola. They demanded early discharge from hospital for fear of contracting other diseases while being confined to the hospital. "I was feeling that I should be discharged to be taken home. I thought that any other type of sickness apart from Ebola could even get me there," remarked a survivor while commenting on the experience of surviving Ebola. Survivors seemed very aware of their vulnerability and used every opportunity to guard themselves against succumbing to any illness.

Persisting with Disbelief in Survival

Lingering images of suffering from Ebola alters belief in survival. The experience of being afflicted by Ebola as a disease was so horrifying that even when declared cured, some survivors continued to doubt the possibility of survival. It took them a long time to believe that surviving Ebola was actually possible. They could not believe that they would ever

survive such an illness given that majority of the sufferers had already died. The survivors were very sceptical about being completely cured, and they had a hard time comprehending that survival was possible, given the strange pattern of the disease process. Participants saw survival from Ebola as a temporary mitigation of the signs and symptoms while waiting for the return of the same later.

Grieving Over Loneliness and Aloneness

The experience of grief was common among survivors who thought of themselves as victims of the Ebola experience. They were overwhelmed by grief for a number of reasons, including the loss of some or all their children, husband, wife, or relatives. The disheartening loss of loved ones in addition to the incessant ostracism following discharge from the hospital heightened survivors' feeling of lonesomeness and aloneness. Similarly, this experience worsens the grieving process. In addition to the physical, economic, and psychosocial problems that Ebola had brought upon them, survivors also grieved over the lack of human support systems to look after them. A participant's description, "I should have been happy but what prevented me from being happy was the fact that all my children and my husband had died and even my relatives" vividly concretizes this experience of grieving over loneliness and aloneness.

Experiencing Diminishing Self-Integrity

In this category, two thematic expressions emerged. These are:

- Diminishing self worth
- Degenerating physical integrity

Diminishing Self worth

The survivors who thought of themselves as victims were grief-stricken. They agonized over the difficulties that had emerged after the Ebola experience. They were distressed that surviving the illness made them no longer able to function normally. These

survivors reported a decrease in their self-esteem and their self-respect. They imagined themselves as being worthless - no longer able to see anything fruitful in their lives. They lost self-valuation, claiming that Ebola had robbed them of every opportunity to live meaningfully.

Degenerating Physical Integrity

These survivors complained of numerous conditions of physical impairment. They spoke of generalized and unrelenting musculo-skeletal dysfunction associated with pain and disease. Some of them suffered hearing loss, while others developed blindness. The survivors asserted that because of the inescapable defects their bodies no longer function normally, as before they contracted Ebola. They also reported that following infection with Ebola, they began to experience increased susceptibility to common infections. They claimed that their bodies had become weak and non-resistant to infections to which they previously had immunity.

Living Frustrating Alterations in Life Patterns

Under this category, three thematic descriptions emerged, namely:

- Struggling with loss of abilities
- Lingering with the agony of undeserved suffering
- Living disharmony in marriage

Struggling with Loss of Abilities

These survivors reported that following discharge from hospital, they were unable to execute activities and responsibilities that they did before Ebola. They emphasized that they had difficulty providing for their families, including their children's school fees. They complained of having lost the vigor to perform those activities expected of them as source of livelihood and for continued sustenance of their families. Misery abounded in their faces

as they painfully narrated these experiences of how they had failed to work, implying that their lives had drastically worsened.

Similarly, these survivors claimed that they had lost the endurance and the resilience to work. As such, they could no longer perform activities expected of them. They gave an account of how Ebola had caused numerous changes in their life patterns. They lamented that they had to carry an additional burden of having to cope with the changes in their bodies and social lives. They cited easy fatigability, especially in performing activities that demanded energy, yet they depended largely on their ability to persevere physical exertion for their survival.

Lingering with the Agony of Undeserved Suffering

Death from Ebola was seen as punishment. Survivors felt that they had committed no crime to deserve death. They expressed self-pity for all they had to go through after being infected with Ebola. Survivors questioned their value as humans, maintaining that they were innocent despite being labeled infectious by the local community. Consequent to these pressures, they began to experience a sense of guilt, a feeling that they might have actually infected other people especially members of their family and close relatives with whom they had enjoyed close contact.

Closely related to the feeling of guilt was the psychophysical symptom of pain that resulted from the effects of the disease on the body, and the psychosocial variables that arose during the ebola epidemic. Survivors' psychological pain resulted from a number of reasons, including the possibility of their own death, the loss of loved ones, loss of property, and the unusual and patient unfriendly procedures, such as spraying the entire body with (JIK), Sodium hypochlorite solution, before their admission into the isolation ward. The survivors concluded from all these inhumane and unusual experiences that they suffered undeservedly, claiming that they did not ask to be infected, and therefore they should not

have been treated in the way they have been! This participant's declaration, "In fact I felt they shouldn't have stopped my friends from coming, because it wasn't my wish to get the infection", clearly illustrates this experience.

Living Disharmony in Marriage

Ebola not only affected the survivors' bodies, but it also affected their marriages. Participants reported that within their families sexual relationships were strained. Some survivors had difficulty fulfilling sexual desires. The survivors, especially the men reported that they had difficulty satisfying their wives sexually. In addition to being unable to sustain sexual activity beyond one round of orgasm, some described sexual intercourse as a painful experience. They grieved that since they were unable to satisfy their wives sexually they risked being divorced by their unhappy wives. The male survivors anticipated disagreement with their spouses, causing them to fear relentlessly because in addition to their inability to sexually satisfy their wives, they even failed to provide for and perform other activities as heads of their families.

Suffering Isolation Beyond Measure

Under this category, two thematic structures were delineated, namely:

- Living in social isolation
- Losing relations and disappearing friendships

Living in Social Isolation

Relatives, friends, and neighbours frequently subjected survivors to unusual social isolation and rejection. They were hurt by the manner in which these people treated them. While in hospital they were even barred from being seen by visitors including their own relatives. Back home neighbours unexpectedly stopped customary gestures, such as sharing of domestic items, communal eating, and handshake for fear of being infected.

At work, the survivors could no longer mix freely with colleagues. Even in markets, they were denied some supplies; for fear that, their money had the Ebola virus. Those in business had similar experiences; they became limited only to those customers who did not know them as survivors of Ebola. However, whenever these unsuspecting customers got to know the truth they often returned the item fearing it was contaminated with Ebola.

Losing Relations and Disappearing Friendships

The experience of fear leads relationships to dissipate needlessly. Because of being infected with Ebola, friends, relatives, and neighbours severed their relations with the Ebola sufferers. A unique observation these survivors recalled was how they were banished and shunned by their own relatives. They reflected on how they were avoided and deserted. In addition the survivors reported that they were treated based on the fanatical belief that they were "half dead", meaning that they were as good as dead and therefore not worth investing in! They were further rejected for the fear that they would infect other members of the family. This rejection was manifested in the loss of interest in the sufferers by their own relatives, evidenced in some cases by delayed or non-visitation of siblings, spouses, or relatives, and delayed or non-payment of dues accrued towards them as illustrated by the account; "…before I fell sick there was no tension in paying for my school fees. But after Ebola… I went home, but I found that there was a great change in the love they used to have for me".

Description of the Survival Experience

Based on the descriptions of the participants, the experience of surviving Ebola Haemorrhagic Fever is described as "living beyond vulnerability while experiencing the awareness of a diminishing quality of life, losing relations and friends, but struggling to live a meaningful, although frustrating life pattern of existence in isolation".

Although participants described this experience differently, they generally followed two patterns based on whether the survivor considered him/herself a victor or a victim of the Ebola experience. Survivors who believed that they had emerged victorious described the experience of surviving Ebola as, "a feeling of immense joy and excitement", often described as "beyond happiness" with gestures of gratitude and appreciation, and "the total trust in the Almighty and His powers to rid humans of all afflictions". This category of survivors affirmed that celebrating the triumph over Ebola was worthwhile, arguing that survival was a rare opportunity especially given the high mortality rate associated with the illness. Celebrating this experience is self-assuring, and it ultimately enunciates the thematic expression of the joy of living. It portrayed the feeling of having conquered death from Ebola. It was celebrating total trust in health care system and the Almighty, and the feeling of "pushing ahead" in the face of difficulties. The knowledge of surviving death from Ebola is the knowledge of strength and endurance; it is also the capacity to persevere beyond the norm. The feeling of excitement and joy is the certainty of positive or meaningful living after Ebola. It is also the experience of perceiving self as victorious, a situation that conjures the feeling of strength and enduring hope.

Conversely, those who felt victimized by Ebola described the experience as, "a short episode of happiness quickly overshadowed by fear and anxiety over the possibility of losing everything including own life, and the disbelief in the likelihood of things ever returning to normal". There was languishing over losing relatives, friends, and loved ones. The fear of losing everything including close social attachments is the fear that succinctly illustrates the experience of victimization, and the experience of loneliness and aloneness. Living through lingering thoughts of Ebola created mind-body connectivity. It precipitated the feeling that things will never return to normal. Losing control of everything, including personal property initiated the grieving process, while abandonment by everyone, coupled

with the physical effects of Ebola signified the experience of suffering beyond measure. Disbelieving everybody and trusting no one, including the Almighty was reminiscent of the survival experience. For these victims the experience of hopelessness and helplessness outweighed the feeling of hope and the endurance to continue living meaningfully. Portraying self as innocent was coping with ceaseless fear of the unknown, and the failure to live positively and meaningfully, was resigning and succumbing to the consequences of Ebola always anticipating the worst to come!

POST-HOC LITERATURE REVIEW

A post-hoc literature search was conducted focusing on aspects of the thematic structures of the experience of: hope, anticipation, hopelessness, fear, isolation, rejection, survival, and survivorship. Other thematic structures included: death, joy, anxiety, pain, suffering, life after death, and meaningful living.

Hope and Anticipation

Findings of a study conducted by Bays (1995) among survivors of stroke yielded the experience of anticipation of living while simultaneously recognizing the possibility of death. The researcher documented that the participants of this study described the phenomenon of hope as patterning with positive anticipation, active participation, forward moving process, inner sense/strength, faith in God, continuing and relative comparison, life sustaining, realistic possibilities, connectedness, loss of control, previous abilities, and mobility. Likewise, survivors of the devastating 2000 Gulu EHF outbreak who experienced the phenomenon of "surviving a life threatening condition" expressed some of these feelings/experiences. Comparable to the descriptions of the patients with stroke, survivors of the 2000 Gulu EHF epidemic expressed hope for the best in life after Ebola although they constantly anticipated the worst to come. This experience propelled them to reminisce their vulnerability to the after effects of Ebola including the possibility of death.

Survivors, especially the victims of EHF described the survival experience as losing hope in everything including the Almighty! Mahoney and Graci (1999), as cited by Locsin and Matua (2002) in their attempt to distinguish between religiosity and spirituality suggested that although the terms are used interchangeably, they are dissimilar. However, the researchers point out that there exists general agreement among scholars that spiritual experiences are meaningful learning opportunities, and that spiritual persons tend to be more hopeful than those who are not are. The thematic descriptions that strongly associate with spirituality are charity, community, connectedness, compassion, forgiveness, hope, meaning, and morality. It is noteworthy to mention that even the contact persons as described by Locsin and Matua (2002), who experienced the phenomenon of " waiting to know or see" reported similar experiences concerning their relationship with God.

Fear, Anxiety, Hope and Joy

Thibodeau and MacRae (1997) described the experience of surviving cancer as a journey from fear, pain, and darkness to light, hope, and joy. This study focused on the experiences of adult women who have survived diagnosis and treatment of localized breast cancer without recurrence for a minimum period of 3 years. The researcher added that the lived experiences, feelings, and words of these women interweave to form an unforgettable experience. The experiences of the participants in this study were consolidated into ten major categories namely: advice, coping and support, diagnosis, life changes, health care providers, health habits, relationships, religion and spirituality, treatment options, and worry about health and recurrence. Some of these experiences similarly unfolded in the stories of the contact persons (Locsin and Matua, 2002), the former captives of Joseph Kony's LRA rebels (Erenreich, 1997), and the survivors of the 2000 Ebola epidemic in Gulu, Uganda.

Survival and Survivorship

In the attempt to understand what it means to live beyond cancer, Breaden (1997) undertook to explicate the question of "survivorship" among 45 women who had survived cancer. She quotes Lifton's (1980) study describing that "survivorship" has generally been associated with catastrophic life events such as aeroplane crashes and natural disasters. She added that because of the serious nature of the illness, "cancer" and "survival" appear to be mutually exclusive. Such was the experience of the patients who were infected with the Ebola virus. Lifton, (1980) who studied survivors of the atomic bomb in Hiroshima, Japan, defined a survivor as one who "has touched, witnessed, encountered, or been immersed in death in a literal or symbolic way and has himself/herself remained alive" (p. 54). This definition provides some useful insight into the experience of survivorship in general.

Importantly, survivors of serious illnesses such as Ebola seem to share similar qualities to those described by Lifton (1980) [Atomic bomb] and Breaden (1997) [Cancer]. Like survivors of cancer and other catastrophic events, survivors of Ebola also experienced recurrent dreams and nightmares, and a sense of being increasingly vulnerable to similar or related events or illness. However, it is important to note that unlike survivors of other life threatening conditions, survivors of cancer continue to live a life of constant fear that their cancer will recur. At the same time, they have to adjust to some level of physical compromise and isolation, and difficulties in taking up life again in the community in which they live and work (Breaden 1997). Survivors of the recent Ebola epidemic in Gulu, Uganda reported similar experience of constant fear, isolation, and frustrating alterations in life patterns.

Suffering, Pain, and Loss of Control

Because of its life-threatening nature, Landmark, Strandmark, & Wahl, (2001) explicated that newly diagnosed cancer patients face a crisis that emphasizes their mortality. The researchers further explained that the experience of breast cancer is one of suffering,

pain, and death. They emphasised that it is a traumatic crisis in which relationships disintegrate needlessly, coping abilities become ineffective, and stress reactions become increasingly locked. The researchers posit that persons who experience loss of control over their situation tend to exhibit more stress related problems such as fear, depression, and somatic symptoms than those with a belief in their own ability to influence their situation. This experience is comparable to that of the survivors of the 2000 Gulu EHF outbreak where two patterns emerged, that of victors and victims. The victors exercised control over themselves and their families, as they fought hard to live a meaningful life, while the victims succumbed to the stresses of Ebola, and continued to live a life of desperation, suffering, and resignation, to loss of control in everything!

Uncertainty vs. Meaningful Living

Frank (1971) declared that individual's attitude to suffering in disease or illness determines the potential meaning of such suffering. In the same way, Landmark, et al., (2001) affirm that there exists a general agreement among other nurse scholars that each person is motivated by a search for meaning in all experiences in life, and that it is possible to find meaning in the experience of sickness, suffering, and pain. In addition they described that participants in the study that involved women with newly diagnosed breast cancer were aware of contrasts between health and suffering, and chose to live, in spite of uncertainty and confusion. In addition, the researchers reported that when the women were confronted with the traumatic experience of the cancer diagnosis, they actively involved themselves in the fight for positive living. The researchers also reported that these cancer survivors sought for meaning in their suffering, and changed their attitudes to values in their lives, working hard to retain their dignity as humans. This struggle for meaningful life is evident in the descriptions of survivors of the devastating 2000 Gulu Ebola epidemic. For the victors of the Ebola experience who journeyed from uncertainty to meaningful life, their experience

can be compared to the women (cancer survivors) who strive to live meaningful lives even after a diagnosis with cancer. The affirmation of hope and the belief that a bright future is possible even after a devastating illness enables a person to tolerate the burden of sickness and suffering, and in circumstances where the future becomes uncertain, hopelessness can be counterbalanced by the person's strong sense of hope for the best to come (Landmark, et al., 2001). This experience of the cancer survivors is comparable to that of the victors of the 2000 Gulu Ebola outbreak who believed and affirmed that survival was an experience worthwhile celebrating. As a result, they continued to live a new and a meaningful life despite the difficulties they faced.

Relating with the Deceased

Devers (1994) described that during extreme grief a person can experience an extraordinary phenomenon of relating with the deceased, adding that it is a phenomenon whereby the survivor feels he/she has had contact with the deceased. Although the phenomenon of relating with the deceased is still poorly understood, nevertheless it is not uncommon. In the study undertaken to elucidate the basic social problem and processes engaged in by those who have experienced the deceased, Devers (1994) described that these participants went through two phases of experience. During the first phase, the participants dealt with their inner world of beliefs about reality, as they worked to comprehend what had occurred. They verified the experience and tried to find concordance with their own beliefs. In the second phase they "responded to public reality", by reconciling their own private beliefs about the experience with those of society. Further, they dealt with dissonance and selectively disclosed the experience to others. Similar stories of connecting with the deceased were narrated by former captives of Joseph Kony's LRA rebels (Erenreich, 1997) and survivors of the devastating 2000 Ebola hemorrhagic fever outbreak in Gulu, Uganda.

DISCUSSION

This study was conducted to illuminate the lived experience of persons who survived Ebola, a life threatening illness, using Colaizzi's (1978) phenomenological approach. The question asked was: "What is the lived experience of persons who survived a life threatening illness such as Ebola"? Although participants described their experience of surviving Ebola differently, their stories converged into two patterns; as victors of the Ebola epidemic emerging triumphant, while the other pattern was as victims- Ebola had turned them into failures in life.

Celebrating Survival from Ebola: The Experience of Victors

Living Anew Beyond Happiness

Surviving a life threatening illness such as Ebola is an experience in the extra-ordinary realm of reality! It is an experience worthwhile celebrating. It is emerging triumphant from a life threatening condition. Survivors were visibly overwhelmed by happiness and they expressed profound joy, for they had seized an opportunity to lead a normal life once again, a possibility they least expected. Surviving Ebola manifests the existence of a powerful and loving God. As survivors attempted to find meaning in their peculiar experiences, some asserted that they survived because the right time for them to die had not yet come, while others claimed that it resulted from their strong belief in the Almighty and his powers to rid humanity of all afflictions.

A participant described that:

> …God changes [difficult situations to] easy moments…likewise it could apply to Ebola, that the moment one puts God first, even in case of any infectious disease or sickness, when you call upon God, he will surely answer you [heals you] and makes you come out …in order to make you really a living testimony…

Still another survivor articulated her reason for survival in the transcription:

> I said really, I was just wondering how I survived. I was dreaming as if I was put in a sea surrounded by lions or other animals, or violent animals, and I was among them, just seeing death…. maybe God left me because it was not my time to go [die]. So God said you remain and repent…

Survivors' ongoing appreciation of the works and efforts of all those persons who contributed directly or indirectly to their recovery symbolizes the experience of surviving Ebola. As they continued to experience a new life of happiness, they expressed gratefulness to God, health care workers, and all other persons who enhanced the survival process by showing them the realities of goodness and kindness during "the hard times" as alluded to in this description: " I have that feeling of appreciating those people who have been hard working so that I survived…It is also due to God's plan, so I have that feeling of giving thanks to God…" Similar feelings of gratitude and appreciation of health workers and other human support systems was documented by De Roo and colleagues (1998) in a survey conducted among survivors of the 1995 EHF outbreak in Kikwit, DRC. This study focused on the experiences and feelings of the survivors much like the lived experience of those persons who survived the recent EHF outbreak in Gulu.

Living Awareness of the Afterlife

As these survivors celebrated living anew beyond happiness, they began to experience increased awareness of living in the after life. Surviving Ebola is comparable to surviving death. As the survivors reflected on their experience of witnessing frequent visits by spirits of those who had succumbed to Ebola, they began to imagine the realities of the life after death. Their experience seemed to suggest the existence of a plausible relationship between survivors and the world of the dead.

Similar accounts that portray possible relationship between the living and the dead were found in the descriptions of the former rebel captives and child soldiers who escaped from Joseph Kony's LRA rebel hands in Gulu, Uganda. Rose Erenreich, a consultant for the Human Rights Watch Children's Right project (1997) gave accounts of how the former LRA rebels were being continuously haunted by the "tipu" [spirits] of those they had killed or watched dying! This study was based on the experiences of former rebel captives. A former rebel captive vividly expresses the experience of being "visited" by the dead in the description:

> Five rebels came and took us all. …They tied us with ropes …and gave us heavy loads to carry. My eldest brother escaped but the rebels caught him and they killed him. I watched him being killed. His tipu (spirit) came to me and covered me and told me, "Today I am dead." I was in shock…

Struggling to Live Meaningfully

The formation of the Ebola survivors association greatly helped to integrate and assimilate the survivors back into their previous social life. In addition to being "a mouth piece" for re-socializing the survivors, this association continues to take care of the survivors' families, the orphans of Ebola, and those persons who lost their spouses to the deadly disease. Furthermore, it helps to strengthen the survivors as they struggle to address some of the concerns associated with living after suffering a life threatening condition, as one of the participants explains:

> Ebola is a very unique disease, and very many of us died, that is why we have decided to come out with an association … to watch over orphans... to ensure that they are educated…

> in good health condition…. and to ensure that in case of any outbreak …we should come in to sensitise the community…

Another method the survivors used to adjust confidently to the effects of Ebola was by celebrating knowledge about the disease. They made an effort to obtain credible information about the disease and its effects. Because of this knowing, they were able to deal with the consequences of Ebola on their lives and the lives of their families appropriately. Armed with this knowledge to fight their way into living meaningfully, the survivors became confident that they would successfully live through the Ebola experience. As survivors' understanding about Ebola as a disease and its effects grew, they became more relaxed and began to live positively and gainfully, as this participant described: "I know since I am a medical personnel I became strong hearted. I said no! Let us stay. I started re-assuring myself that I am not going to die (laughs), some neighbours also came and comforted me…"

Struggling to be accepted in a hostile society was one of the many challenges survivors had to face. They asserted themselves as credible members of the community by using every opportunity to educate the public on what it means to survive Ebola, assuring their audiences that they were no less than human. They also informed the communities on how the survivors had become immune to the illness, and what their contributions would be in case the deadly virus resurfaced. As they struggled to assert themselves, they often asked for services that they envisioned would speed up their recovery, and integration to their previous life pattern, as this participant put forth in this transcription:

> We claimed …immediately we started pushing for special clinic, seriously we started following up seriously for a clinic. We tried even to contact the World Health Organisation …since some of them used to visit us before, they were giving us contacts…

Living anew after Ebola was forthcoming in the presence of support obtained from families, friends, and neighbours. As survivors reflected upon their triumph over Ebola, they realised that their happiness would only be a reality if they had sustained support from their families and friends. Through such support, they hoped to deal with the complexities that Ebola had brought into their lives. This support came from various sources; while in hospital it came from the health workers; at home, it came from family members and neighbours; and at work, it came from colleagues and associates. Survivors reported that:

> At the time of discharge, we [survivors] were given letters [certificates] ...[and] when the Ebola task force brought my daughter, a nurse herself after she had recovered from Ebola, then they began to advise people. They told people not to run away from us.
>
> What relieved me was that they [health workers] were visiting us on regular basis and giving us advice on how we should live our life. They told me not to hate people who had initially run away from me… and when people like you [researcher] keep coming to us, we become convinced that we have got cured.

These findings indicate that the intervention of health workers and members of the Ebola task force greatly alleviated the survivors' anguish. Treating survivors with dignity and respect, issuing certificates of good health, mass education, social mobilization, and support were efforts geared towards curtailing the disastrous effects of Ebola. These efforts were also aimed at resettling the survivors. All forms of support whether material, moral or psychosocial, visits, and re-assurance by support systems were greatly appreciated and they cumulatively combined to relax and calm the survivors.

Similar conclusions were drawn from a study done in the DRC on the survivors of the 1995 Kikwit EHF outbreak (Heymann, et al., 1999). This study set out to describe the management of the epidemic, both at the patient's bedside in Kikwit General Hospital, and in the surrounding communities. It also set out to describe the surveillance system and the management of information during the outbreak. Through their descriptions, they were able to point out the lessons learned from this outbreak, directly from the successes and failures registered during the outbreak.

Downplaying the negative sentiments and utterances directed at survivors was one of the ways through which victors enjoyed their experience of conquering Ebola. Victors were firm over their conquest over Ebola. They insisted that despite the negative and derogatory comments about them, they had to "push on" with life. They found out that they got along with people if they paid no attention to the insults and nicknames they had been given. They came to appreciate the nicknames and comments, associated with their experience of surviving ebola as "a harmless name tag", and therefore they had no reason to be emotional about it. Once they realised this, they became happy members of their communities, further enjoying their experience of surviving ebola.

The Agony of Surviving Ebola: The Experience of Victims

Reminiscing Expressions of Vulnerability

Surviving death from Ebola, a life threatening illness is a phenomenon that calls for celebration. As some survivors rejoiced over their conquest and victory over the deadly Ebola virus, some participants grieved that Ebola had victimized them and turned them into failures in life. They agonized over the difficulties Ebola had brought into their lives, suddenly turning them into social misfits. The thematic categories of "reminiscing expressions of vulnerability", "experiencing diminishing self-integrity", "living frustrating

alterations of life patterns", and "suffering isolation beyond measure," succinctly express victim's experiences of living after encountering Ebola!

Although these victims have defied the wrath of Ebola, they continue to recollect their vulnerability to the realities that came into play because of this illness. As they recall all that they have gone through, their experience of fear and anxiety over the unknown appears to persist. They continuously worry over possible death because of the unpredictable outcome of the illness. This experience of likely death from Ebola was unearthed by a participant who said that: "I wasn't even thinking that I would be able to go back to my home I was only thinking that I would be going to the burial ground straight away".

Not knowing what to expect, total cure or the re-recurrence of the infection or the manifestation of its side effects aggravated this feeling of fear and anxiety. The damage done to the survivors' belongings in their homes added to this fear, desperation, and anxiety, in addition to the possibility of leaving their children and property unattended if they should die. This seemingly unending suffering was a source of anxiety for the victim of the Ebola scourge. Arising from the gravity of this suffering, survivors attempted to find meaning in their experiences. They repeatedly asked the question, Why Me? They wondered as to why they were the victims and not others, to go through this experience of intense suffering and pain!

Younger (1995) as cited by Locsin and Matua (2002), explains that

> "Suffering is a human experience that often brings with it loneliness or alienation from others. It is paradox of human existence, in which suffering alienates the sufferer from others, making the sufferer a stranger living in his/her own world, making others hesitant to enter the

sufferers world".

A participant's description; "Actually I feel I have been left in the world alone and that makes me feel lonely. Actually, I don't have any body to talk to! I am like a person living in the trees….", clearly illustrates this experience.

Living with realities of psychosomatic manifestations was typical of living as victim after infection with Ebola. These survivors experienced numerous incidences of mind–body manifestations during and after the illness. As the survivors' condition began to improve while still in the hospital they periodically experienced varying degrees of illness aligned with body-mind connectivity. These psychosomatic manifestations closely mimicked the signs and symptoms of the onset of Ebola increasing their fear and anxiety that Ebola could return.

Commonly these victims experienced headaches, heartaches, sweating, and constant nightmares. They experienced the same signs and symptom at the mere sight of the isolation wards where they were admitted during the Ebola epidemic, or even upon hearing the word Ebola. Each time they thought about Ebola, they would get an electrifying sensation of "accelerating and diffusing " heat dissipating quickly from head to toe and from limb to limb. Locsin and Matua (2002) similarly described this experience of mind-body connectivity in a study done in Mbarara, Uganda, involving persons who had contact with patients with Ebola.

One of the experiences of being a victim of the Ebola epidemic is experiencing a heightened awareness of survival. These participants reported that as they began to improve they became very aware of their vulnerability to other illnesses. Consequently, they utilized every opportunity to protect themselves against any illness. Because of this awareness, they demanded early discharge from hospital for fear of contracting other diseases while being confined to the hospital beds. This heightened awareness of health promotion and illness

prevention was one of the reasons that made the survivors perceive themselves as victims of Ebola.

The anguish of anticipation creates awareness for self-care and the need to protect oneself. A participant claimed that: " You know at the time they started stopping us from going back [home], I developed hatred for the health workers". Survivors understood their confinement in the isolation ward as a punishment for a crime not committed. They even accused heath workers of intentionally keeping them in hospital against their will and purposely delaying their discharge. Locsin described a similar finding of heightened awareness of survival and Matua (2002) in a study conducted among contact persons in Mbarara, Uganda. Although contact persons did not express anger at the health workers for a similar experience, nevertheless they verbalized increased awareness for self-care similar to the experiences described by the survivors of Gulu Ebola outbreak.

Persistent images of suffering with Ebola altered survivors' belief in survival. The horrific nature of the disease accelerated lingering thoughts of "things" never returning to normal. A lot of effort and time was needed to transform survivors' thoughts and expectations to a positive one from an attitude of resignation from accepting death. Survivors were very pessimistic about being completely cured from an illness where scores of people had perished. Survival from Ebola was only seen as a transitory alleviation of the signs and symptoms while waiting for their return at some point in time. The transcription,

> "…[when] they told us that it [Ebola test] was negative, in fact it was difficult to believe that I had [cured from] Ebola because most of the people had died and I was questioning myself, how can it be that I survived"?

vividly affirms this experience.

Grieving over loneliness and aloneness was an experience that all the victims verbalized. They lamented over losing their loved ones to the point where life had become meaningless because they now had no support persons upon whom to rely. In addition, these victims were overwhelmed by the incessant ostracism and rejection that followed them home after discharge from hospital. These experiences worsened their feeling of lonesomeness and aloneness, and it aggravated the grieving process.

> "[Survival is] just a sorrowful moment, a strange moment you are always under tension and seeing extraordinary things happen… I mean… like a friend you talked to last evening, in the morning you find him sick and the following day he is dead…"

concretizes this experience of grieving over loneliness and aloneness.

Experiencing Diminishing Self-Integrity

Experiencing diminishing self-integrity is living the experience of dwindling self worth and degenerating physical integrity. As these grief-stricken survivors languished over the difficulties Ebola had brought into their lives, they began to associate themselves with disillusionment in life. They were obviously anxious that surviving the illness made them dysfunctional, no longer able to function normally. They reported a decrease in their self-esteem and self-respect, perceiving them as worthless- hardly with any prospect of living a meaningful life again!

More to the decrease in self worth was the outcry of unremitting musculo-skeletal dysfunction associated with pain and unease. This dysfunction also extended to other impairments such as hearing loss, memory loss, alopecia (hair loss), arthralgia (bone pain), painful testicular enlargement (orchitis), and blindness. These dysfunctions weakened survivors to the extent that they became increasingly susceptibility to common infections. A participant described that:

> I feel my head used to work better before the illness [Ebola] and [I] used not to forget easily. But these days I am so forgetful that I am fond of forgetting where I am in a particular place and [I forget about] things. I just can't remember well.

Similar "post- Ebola" physical manifestations were observed and documented among survivors of the 1994 Cote d'Ivoire (Ivory Coast) and 1995 Kikwit EHF outbreaks. The Cote d'Ivoire study was based on the clinical course of a 34-year old female ethologist who got infected while conducting autopsy on a wild chimpanzee in the Taï National Park (Formenty, et al., 1999) whereas the Kikwit study by Bwaka and colleagues, (1999) was conducted during the devastating Kikwit EHF outbreak in 1995 where 103 patients were followed up for a time period between two weeks and two months after their hospitalisation.

Living Frustrating Alterations in Life Patterns

The experience of struggling with inability to execute activities and responsibilities is the experience of living frustrating alterations in life patterns. Importantly, it is experiencing disheartening changes in ones' life where fulfilment of basic functions becomes a considerable hurdle. In addition, it is the experience of losing vigor to perform activities that are essential for meaningful existence, such as tilling farmland, and paying school fees for own children. It is also living the unwelcome transformation of experiencing realities of diminished energy and endurance to persist in any energy demanding activity. Survivors who experienced these transformations were greatly upset because they were mostly peasants and therefore largely depended on their physical strength for survival. The transcriptions: " …whereas in the past I would share in work like garden work with people at home, now I am weak and so I can't work", and "I don't have that endurance I used to have before falling sick. I have to get down with fatigue after doing even a simple job, so I

don't have strength", depict survivors' frustrations of living with the unwelcome consequences of Ebola upon their lives!

Agonizing over undeserved torment signifies survivor's expression of self-pity for all the hardships faced. The possibility of death was a disturbing reality that continued to linger in the survivors' memories, and yet it was seen as punishment for a crime not committed. Although survivors questioned their value as humans, they maintained that they were innocent, despite being labelled infectious by the local community. However, as the pressure on them grew, they began to experience guilt for possibly infecting other persons with whom they had enjoyed close contact. A participant's description," I started to think about the people at home I was particularly worried about my friends at home since we used to share the same room", undoubtedly illustrates this experience of guilt.

In addition to the feeling of guilt was the experience of pain that resulted from the many hardships Ebola had brought into survivors' lives. Notably, patient unfriendly procedures such as spraying the entire body with sodium hypochlorite solution, widespread and seemingly continuous ostracism and rejection, all hastened survivors' sensitivity to pain. In addition, the more the survivors were ostracized and banished, the more they hurt undeservedly! De Roo et al., (1998) reported similar experiences in a study done among survivors of the devastating 1995 Ebola outbreak in Kikwit, DRC.

Living disharmony in marriage is the experience of being in marriage after surviving Ebola. It is living with constant fear that the consequences of Ebola will precipitate marital disunity. Ebola spared no aspect of survivors' lives; it unleashed its ferocity on their sexual relationship as well! Of particular significance was the effect on men whereby they experienced difficulties satisfying their wives sexually. This incapacity was a source of spousal dissension, reportedly exerting considerable strain on male partners. As would be expected, male survivors who had this problem claimed that at one point, this incapacity

may disintegrate their marriages, and this greatly upset and depressed them. This feeling is well elaborated in the description:

> You can have [an] erection alright, but you cannot satisfy your woman [wife]… You cannot go beyond one [sexual encounter] and that one, is a problem to you and immediately after that one you will be shedding tears. I am telling you, it's a very terrible problem we have…Otherwise we are going to have problems with our women [wives] …we suggest that the district should get some money so that our women [wives] are sensitised!

However, it is noteworthy that no female participant mentioned anything to do with sexuality or failure to appreciate sexual activity, a phenomenon possibly explained by the strong cultural taboos that prohibits them from discussing such issues with strangers. In addition to being unable to fulfil their marital obligations, the male survivors even failed to provide for and perform other activities as heads of their families, such as paying for school fees, clothing, and medical care.

Suffering Isolation Beyond Measure

Not knowing where to turn to, lamenting over abandonment, being laughed-at, scorned, and being disowned even by very own family depicts the experience of suffering isolation beyond measure. This experience of suffering alienates survivors from all other human support systems, leaving them helpless and bewildered. Illustrating this experience was a description by a participant, who said,

> "After discharge on that very day, when I reached home, [from hospital], I found people packing up their belongings to run away. They ran away and camped [elsewhere]. The people who told me not to come back were my mother-in-law

and my co-wives",

says it all. Much like the survivors of the 1995, Kikwit, Ebola outbreak (De Roo, et al., 1998), survivors of the 2000, Gulu Ebola epidemic suffered numerous embarrassing anti-social gestures. In both of these outbreaks friends, relatives, and even members of the same family avoided survivors, making them feel isolated and lonely. Locsin and Matua (2001) reported similar feelings of being subjected to living in social isolation in a study conducted among contact persons of the Ebola epidemic in Mbarara, southwestern Uganda.

For the victims, the experience of living through Ebola meant losing friendships needlessly! The fear that survivors could still be infectious led to friends, neighbours, and at times family members to sever ties with them. Survivors were openly ostracized, banished, and despised. Often times they were referred to and treated as half dead. Even at work, they faced the same difficulty. It was not uncommon to find that customary gestures such, as handshake, communal eating, and collegial visits became a rarity. Survivors of the 1995 EHF outbreak in Kikwit, DRC, (De Roo, et al., 1998) and the victims of Joseph Kony's LRA abductions (Erenreich, 1997) reported similar feelings of social isolation, rejection, and abandonment. The "Aboke girls" [Girls abducted from Aboke secondary school] as they were popularly known, painfully reported that they were handled with suspicion, often rejected, isolated, and nicknamed "Kony girls" by their schoolmates.

CONCLUDING STATEMENTS

Living after surviving Ebola is the experience of being aware of one's vulnerability to the consequences of the illness. It is also the experience of living an altered belief in survival as a result of the gruesome consequences of the illness. Consequently, even after being pronounced recovered and fit to return home, some survivors were still in disbelief. They claimed there still exists a possibility that they may succumb to some aspect of the illness. It is this awareness of susceptibility and defencelessness to other illnesses, or the

return of Ebola itself that causes a deteriorating awareness of life. This feeling is further exacerbated by the incessant social isolation, ostracism, and abandonment survivors encounter!

Another noteworthy experience of living after surviving Ebola is the experience of losing relations and friends. Consequent to the devastating effects of the illness, survivors were seen as source of infection and therefore isolated, rejected, and often times abandoned by close friends and members of the same family. Survivors' responses to these realities of living after surviving Ebola were twofold; for the victors it was struggling to live positively and meaningfully beyond these frustrating alterations in life, however for the victims it was resignation and succumbing to the consequences of Ebola.

Challenges and Lessons Learned

The Ebola epidemic was a devastating one in which scores of lives were lost. In this section, the enormous challenges that faced the protagonists during the epidemic are presented. In addition, the lessons learned from the various efforts that led to the curtailing of the epidemic are explicated.

1. Epidemiological analyses on the disease pattern strongly indicate that the Ebola epidemic started months before October 2000. Similarly, laboratory tests to confirm cases of EHF had to be conducted in South Africa and USA, in countries clearly outside Uganda. This delayed the process of intervention. Hence, lives that would have otherwise been saved were lost while awaiting the results. This experience calls for the establishment and maintenance of a modern day Biosafety Level Four Laboratories in this region so that testing of blood suspected to contain the virus would be done rapidly if the epidemic should re-emerge as it has happened in DRC, Sudan and Gabon. It also calls for training and development of skills in surveillance, prevention and disease control including techniques in early epidemic

detection and rapid response. It is not proper to first lose citizen's lives before bringing such epidemics under control.

2. During the Six months as Ugandan and the International community experts grappled with the massive Ebola outbreak, fourteen qualified nurses, three nursing students and one medical doctor laid down their lives. This was a very expensive and sad experience for Uganda given the level of commitment these health workers had exhibited, in addition to the very low numbers of health workers in the country. Secondly it brings to light the poverty in the medical system of this country. It is widely believed that if the health care workers had ample protection they would not have succumbed to this lethal nosocomial infection. The two referral hospitals in the northern region, notably Lacor and Gulu hospitals had barely any resource to cope with an epidemic of that measure. It is therefore recommended that this last epidemic should serve as an eye opener to government and especially the Ministry of Health to always be vigilant and plan for such eventualities so that the country is not totally unprepared as it was during the October, 2000, Ebola epidemic.
3. At the political level there was an urgent need to mobilize the entire nation to pay attention to the epidemic that had far reaching implications for Uganda as a nation. This mobilization obligated the involvement of all the ministries so that resources could be quickly mobilized to fight the epidemic. The involvement of the political leaders at all levels had significant results on the war against Ebola. It is therefore recommended that in other emergencies, the involvement of politicians both at the local level, i.e. community, district, and regional, and at the national level should be employed. This approach enhances the process of timely resource mobilization, a factor that is essential to curtail the spread of deadly emergencies such as Ebola.

4. As it has been noted in previous outbreaks in the world, especially in Africa, the involvement of the international community and especially the experts on management of the disease and its effects proved very useful. The almost immediate response of WHO the worlds' health body and CDC Atlanta, USA, and many other international organizations helped to mitigate the spread of the epidemic. In addition to the biomedical treatment given to the Ebola sufferers, some of these teams were actively involved in educative-supportive activities with and for the most vulnerable population. This multifaceted approach used by Ministry of Health of Uganda and the partners resulted in the Uganda Ebola epidemic being the "best managed" outbreak to date with a mortality rate of just over 50 percent. Following these results it is recommended that government, especially the Ministry of Health, should always foster collaboration with the international development partners. These agencies, as it has been shown, have contributed remarkably to the containment of such life threatening disasters.
5. In this era of media liberalization and information technology, the health workers found themselves being constantly requested to give information on various aspects of the disease. This was a very big challenge as they were hardly prepared at the beginning. There was the looming risk of giving differing and contradictory messages to the public. However, it is with pride taking to note that the Ministry of Health was quick to notice the gap and the importance of using the media positively in fighting the war against the deadly epidemic. This experience therefore calls for the establishment of an information desk from which various media houses and the public can obtain filtered and correct information. It is recommended that this would be achieved by regularly updating the status of such an epidemic on the Ministry of Health Uniform Resource Locators (URLs, i.e. websites), which are then made

available to the public. In the same way, it should be realised that the presence of media agencies both local and international, creates an avenue for the global approach to the mitigation of the epidemic. Additionally, it has the advantage to self mobilize other international agencies that may come in voluntarily to assist in one or more aspects of the epidemic. It is therefore suggested that health professionals, particularly the Ministry of Health, must recognise the power of the media in disseminating information that may have both positive and negative impact on the disease in question. To the development partners it is recommended that they should identify with Ministries of Health of countries as it was during the Uganda Ebola outbreak. This way their powers and resources are used very constructively in the fight against Ebola and other such conditions.

6. Compared to other disease conditions, Ebola Haemorrhagic Fever is new and therefore many aspects of the disease, including the characteristics of the Ebola virus, remain poorly understood. Given the severity of the infection that Ebola causes, the scientific community is faced with an enormous task of elucidating more information about the disease. In addition the biomedical researches, there are socio-economic and political aspects of Ebola research that remains to be done. Presently most studies focus on the biomedical aspect of the disease, leaving out the sociological and phenomenological aspects of the illness. Given this situation there is a critical call to pursue research studies in various aspects of the disease, and particularly studies that will help to unearth the natural ecology of Ebola. This discovery will greatly contribute to the control and mitigation of the spread and proliferation of one of the world's most lethal viruses.

IMPLICATIONS OF THE FINDINGS

From the findings of the study, it was realized that living the experience of surviving a life threatening condition also exits in other situations. The phenomenon of "surviving a life threatening illness" is an essential nursing phenomenon that requires further understanding through further study. Because nursing is concerned with caring for persons' wholeness, such devastating occurrences pose a great challenge for not only nursing practice, but also nursing education, and nursing research.

Nursing Practice

It is noteworthy to mention here that the social, moral, ethical, and epidemiological consequences of Ebola require understanding. Because of the complex consequences of Ebola on the individual, families, and communities, it was observed that survivors were scorned following discharge from the isolation wards. Likewise, their families were ostracized, causing other families to hide their patients or people refusing to admit having had contact with a suspect or a case patient, for fear that they will also be rejected and alienated by society. Such situations have far reaching epidemiological implications as infection may continue to spread undercover unnoticed. These realities must be understood, because such knowing boosts efforts to eradicate the illness. Nursing and healthcare as a whole must squarely address this challenge.

Consequent to the intense social isolation, ostracism, and rejection faced, survivors have great difficulty returning to their homes. This phenomenon poses an uphill task of social, ethical, and moral rehabilitation, one that targets both the survivors and the communities in which they live. Members of the community have to be continuously reassured that the survivors are no longer infectious, and that they actually need more attention that ever before! This is a challenge that requires a multidisciplinary approach and nursing being central in health care ought to coordinate this struggle.

Whereas nearly half of the patients survived the Ebola epidemic, the majority succumbed to its ferocity. The Acholi people, the indigenous ethnic group that lives in Uganda's Gulu and Kitgum districts where this study was conducted, have a proverbial statement about death. "Poyo too pe rweny", meaning that " Death is a scar that never heals"! With this many lives lost within a very short time, there is little doubt that most families and survivors in Gulu are still grieving this loss, a process anticipated to continue for a long time. As the proverb connotes, the scars left by Ebola will continue to linger in the memories of those who actually survived it or those who witnessed others perish. Caring for those persons after "surviving a life threatening illness" in the face of their continued fear for the unknown, constitutes an enormous nursing responsibility.

Cognizant of the findings of the study it is evident that health promotion strategies targeting survivors should focus on enhancing their independence. Nurses need to help survivors realise that using alternative skills such as engaging in handicraft making for their well being, rather than just relying on donations and handouts that seldom come their way. Such efforts will prevent survivors from becoming beggars and destitute. Understanding these unique experiences will equip nurses with the knowledge to care for this special and select group of people, hence enabling them to live a profitable life.

The need for a sustained multidisciplinary and multifaceted approach to instil some hope in a population that has seen no peace for the last 15 years, largely because of the activities of Joseph Kony's LRA rebels, cannot be overemphasised. The six-month long epidemic added to the already high level of suffering, sorrow, and grief that this region has seen for nearly two decades. An all-encompassing caring initiative may stir hope in a population that has seen nothing good except suffering and desperation. The nurse's responsibility here is to ensure that there exists a constructive interface between the multidisciplinary team and the survivors.

Nursing Education

During the six months of the epidemic in Gulu, Mbarara and Masindi districts, the lives of 29 health workers were lost to the epidemic (Mupere, et al., 2001). This is extremely painful and costly to the healthcare system of Uganda given the low number of health workers. These committed professionals contracted the deadly Ebola virus during the course of their work, a vivid example of occupational health hazard. Arrangements must be put in place to prevent further loss of lives from such costly "accidents". One of such avenues should be updating health workers and especially nurses on the skills of infection prevention and principles of universal precautions. Further, such principles for protection of self while handling infectious materials and patients should be stressed during the entire school life of the health professional student. This way the students will have up-to-date skills to competently take care of such cases; as a result, the loss of precious lives will be prevented. Closely linked with this is the need to advocate for the provision of appropriate facilities, especially protective gear to prevent painful death of health workers as it occurred during the Gulu epidemic.

Nursing Research

Presently very limited research work has been done on the nursing care of patients with Ebola. As a result, there is an urgent need to illumine the care of such patients during their admission and following their discharge from hospital. It is evident from literature that apart from the medical management protocols of patients during the active stage of the illness, there is not much known about other modalities that may be instituted, for example, to enhance survivors' re-integration into the community. Specifically, efforts must be placed to unveil methods of delivering care to these special and select group of nursing clientele, since addressing their concerns will result in the emergence a body of knowledge that will enrich nursing's capacity to competently and ably care for these patients. With

such competent practice, nursing can lower the high mortality rates associated with the illness if it should recur.

AREAS FOR FURTHER RESEARCH

Although considerable biochemical research has been done on the properties of the Ebola virus, the volume of available research on Ebola as a whole is still very sparse. Many questions remain unanswered about this lethal virus, its properties, and other significant attributes associated with the virus. As a result, further research is needed to unearth the natural ecology of the Ebola virus, and to specifically answer the question, " Where does the Ebola virus live between epidemics?"

Secondly, one of the most devastating consequences of the 2000 Gulu EHF outbreak is the large number of orphans it created. The epidemic left behind a huge number of children totaling 555 without parents and guardians to look after them! The need to find out how these children are coping with the untimely demise of their parents and guardians cannot be overemphasised.

Another area of study should focus upon the socio-economic implications of the Ebola epidemic on the Acholi community. Knowledge derived from such and related studies will facilitate the development of essentials for the improvement of survivors' well being after their discharge from hospital. Additionally, such studies will reveal ways in which the Acholi people are coping with the devastating consequences of an illness that suddenly left them in grief.

Lastly, there is hardly any substantive data to explain why some people live through the lethal infection yet others perish within days! Knowledge of this will help health workers design modalities that will help reduce the mortality rates during the active stages of the illness. In view of this, there is an urgent need to carry out a retrospective study to

answer the question, “How did the health workers get infected”? This is a painful experience and it calls for immediate attention!

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APPENDIX A

MBARARA UNIVERSITY OF SCIENCE AND TECHNOLOGY

Department of Nursing Faculty of Medicine

Mbarara, Uganda

PROCESS CONSENT FORM

Date: _____

Dear: _____

The experience of surviving a life-threatening illness deserves understanding. May I invite you to participate in the study entitled "Conquering Death from Ebola: Living the Experience of Surviving a Life Threatening Illness."

As a person who survived this life threatening illness during the epidemic at Gulu, you are the most credible person who can relate this experience. Comments like, "I wonder what it feels like to have survived a tragic, and "life threatening condition like ebola" prompted me to study the phenomenon of "surviving a life threatening illness". Such a phenomenon is best appreciated by descriptions that answer the question, "what is the lived experience of persons who survived death from ebola?"

Your identity will be kept in confidence by using code numbers for identification. The description of your experience will be recorded on cassette tape during the interview. The interview will take about one hour or less, or until you have nothing more to say about your experience. You will be asked to mention everything you can remember about the experience.

Your participation will benefit persons who may survive a life-threatening illness or condition in future. From this knowledge, nursing care of persons, including those in similar situations as those who have survived stroke, rebel ambush, fatal accidents, drowning and especially Ebola can be developed and implemented. The benefit you will get from this participation is the knowledge that you are able to contribute to the care of future survivors of other life threatening conditions, including those of Ebola.
Your participation is crucial to the success of this study. Please indicate your approval by denoting your signature in the space provided. <u>However, please know that you can withdraw from this study at any time.</u>

If further information or clarification is required, please do not hesitate to contact me at Lacor Hospital Interns Mess or at the Department of Nursing Block, by UTL-Telephone at 0485-20007 ext 109, or on mobile phone at: 077-522-938.

Thank you very much for your continued interest in nursing.

Sincerely yours,

Amandu Gerald Matua, BNSc, MS Student
Assistant Lecturer of Nursing

_____

CONSENT FORM

My name and signature below denote my acceptance of the invitation to participate in the study entitled “Conquering death from Ebola: Living the experience of surviving a life threatening illness”. I do understand that my descriptions of the experience will be recorded, and my identity will be kept in confidence. I also understand that I can withdraw from the study at any time without penalty.

Name: _____

Signature: _____.

Date: _____

Address: _____

Witness: _____

APPENDIX A_1

MBARARA UNIVERSITY OF SCIENCE AND TECHNOLOGY

Department of Nursing, Faculty of Medicine

Mbarara, Uganda

NGEC ME YO YER KARIPE I KWAN MAN

Nino Dwe: _____

Jal / Lamego / Mego: _____

Lapwony me loyo too ki two marac maromo kelo too, bedo kwede omyero kiniang maber. Pien, amito legi ni omyero ayeri me bedo I kwan ni eni ma topic ne kilwo ni
" Loyo too ki two Ebola: Kwo inge loyo too ki two marac".

Calo dano acel ikin jo ma gin oloyo too ki two ebola ekare ma two ni opoti I Gulu, in aye itwero tito kit ma two ni obin obedo kwede.Lapeny ma dano mukene penyo calo ni "Loyo too ki two marac calo two ebola bedo nining? En aye omina tam ni myero aniang kit ma dano tamo kewde inge ciang ki itwo marac adidaa.Wek dano oniang maber kit me loyo too ki two marac bedo kwede, omyero dano macalo in aye ogam lapeny macalo ni" gin ango ma dano ma gin oloyo too ki two ebola tito?

Nyingi onyo gin mukene mekwako komi pe bino weko ngat mukene ngyeyo. Pien pe abino ki nying wo ento abini tiyo ki namba ma abi mini lok weng ma wabi loko, kwedi ii radio.Nywako lok kwedi obi tero cawa meromo acel onyo paka wang madong itito lok weng ma iromo tita. Alegi ni itit lok weng ma wii poo iye medok ikom gin ma otime ikare ma ibedo katwoyo two ebola.

Lok me ibino tito ni binyo konyo joo mukene ma bino loyo too ki two marac iyo anyim. Lok eno bene bino konyo ki me gwoko lutwo ma tye ka twoyo two ma ciango ne tek, karacel ki joo ma odwii omonyo gi, joo ma gin onongo akciden, joo ma onongo akweya inge twoyo two prece, karacel ki joo ma oloyo muny inam.Biacara me ibino nongo ne aye inge tita lok man tye ni, loki ma itito ni bino konyo meto nyec ma gwoko joo ma oloyo too ki two marac mekene calo ebola iyo anyim.

Yer ni me tito ngoo ma ibin wok iye ikara me ibedo ka twoyo two ebola pire tek tutwal wek wa niang kit ma gine bedo kwede.Coo cain ni piny kany me nyutu ni iyer ripe ikwan man. Ento, omyero inge ni bene itwero aa ki kwan man cawa mo keken

Ka imito nyeyo jami mukene onyo tye gino me pe inyango chi iromo nongo koma ii ot yat Lacor onyo ii Mbarara University. Bene iromo gona cim namba 0485-20007 onyo namba 077-522-938.

Apwoyi tutwal pi nyutu mar I ikom joo ma gwoko lutwor onyo nac.

An kipwoc.

Amandu Gerald Matua
Latin Kwan metye kakwano masta digiri me bedo lapwony madit pa lu nac.

KARATAC ME NI YEI

Nyingi ki cain ma icoyo piny kany ni nyutu ni ayer me bedo dano acel ma oyer tito ngo ma otime ikome ikare two ebola opoto I Gulu kany kwede ki kit ma an aloyo too ki two ebola. Angeyo ni ki bino mako dwona ki bene ni pe ki bino waco nyinga bot joo mukene. Bene aniang ni aromo aa ki ikwan man cawa mo keken.

Nyingi:……..

Cain ni……..

Nino dwe……..

Kabedo kame Ibedo iyee…….

Lacaden……

APPENDIX B

Interview Guide

Introduction

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.

This discussion will go on for at least an hour or until such time that you have nothing more to describe about your experiences.

Guide Questions

a. Could you describe to me what it felt like when you were told that you were likely to survive Ebola?
b. What was your reaction (experience) when you were being discharged from the Ebola isolation unit?
c. Can you please tell me the problems/concerns you have gone through during this illness and thereafter?
d. What does this survival mean to you from the time you fell sick up to now as you are discussing with me?

APPENDIX B_1

Lakony Me Penyo Lapeny Man

Acaki

Apwoyo matek tutwal me yee mebino ka nywako gin ma otime ikomi kare me ibedo ka twoyo two Ebola kwedwa. Lok ma wabiloko kidiko/otyeno eni, amito ni ibed agonya kun per ilwor gin mor keken ci ititi wa ngor me obin otime ikare ma ibedo ka twoyo two Ebola.

Nywako lok man bino mede ni oo ikare ma wii pepor gino mor keken me otime.

Lapeny me konyo kor

a) Tita kit ma iwinyo kwede ikare ma kiwaci ni imaro loyo too woko ki two Ebola?
b) Itime nining ikare ma ki kwanyi ki iwi kitanda ikama kigwoko iyee lutwo Ebola?
c) Amito itita peko onyo parr ma iwok iye ikare ma I twoyo two ni ki yoo ngeye?
d) Iniang te loyo two ni eni ni ngo ni aa ki kare ma itwo kwede me oo naka wa I cawa ni ma itika tita kit twoni?