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CONTENTS

EBOLA SHAPES SOCIETY: NO PARTNER, NO FAMILY, NO FRIENDS

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Abstract: Ebola is examined as a Critical Event which shaped the communities in Bundibugyo district. The local framing of ebola epidemic 2007-8 as a curse to the particular ethnic groups affected the social networks and individual identities within communities. Ethnographic interviews and observations among victims of ebola were used as data, and a phenomenological approach was used to guide the research process. The paper recovers the lost moments and experiences of ebola survivors. The epidemic altered the socio-cultural set-up of the community and its impact have lasted for a long time; including stigma, discrimination, trauma, poverty and the orphan problem.

Keywords: *Ebola, Bundibugyo, Constructions, Critical Events*

1. INTRODUCTION

Ebola is an infectious disease marked by fever and severe internal bleeding spread through contact with infected body fluids. It was named after River Ebola where the outbreak was first recorded (MacNeil et al., 2010; Okware, 2015; Piot, 2012; Towner et al., 2008; WHO, 1978). Ebola causes multi-organ system failure that leads to death among human and apes (CDC, 2010; Kratz et al., 2012; Muyembe-Tamfum et al., 2012). There is no cure for ebola except for the euphemistically labeled supportive therapy (Lamontagne et al., 2019). Recent experimental vaccine studies have shown some promise (Abramowitz, 2017; Annie Wilinson, 2017). Common symptoms of ebola include very high fever, diarrhea, vomiting associated with red eyes and a measles-like rash. Even though 50 – 90% of the people infected with ebola lose their lives (Breman et al., 2016; Peters & LeDuc, 1999; Shoemaker et al., 2012; Towner et al., 2008) few end up surviving the attack.

When there is an outbreak of Ebola, the emphasis is put on medical management of suspected victims and confirmed cases in isolation wards using supportive therapy and reducing further spread of infection through ebola surveillance. Even after the outbreak effort is on the continuous follow up by

medical teams to acquire blood sample from ebola survivors for vaccines development purpose. Yet, the exclusion that is averted to the survivors and their families is left unattended to. This undermines survivor's integration back into the communities. Not much is documented about the experiences and integration for ebola survivors. Anthropological research on epidemics, especially on ebola, has tended to focus on the shared framing of epidemics grounded in the local social realities (B. Hewlett & Hawlett, 2008; B. S. Hewlett, 2016; Wilkinson & Leach, 2014). Research has revolved around the importance of local knowledge in guiding the epidemic responses, and anthropologists have advocated for the need to engage with the local actors in delivering a response in order to avoid conflicts and resistance which come from the local communities. Much of anthropological work on ebola has explored conflicts within communities emanating from resistance between the local communities and the response teams including the international community's (B. S. Hewlett & Hewlett, 2007; Jones, 2015; Wilkinson & Fairhead, 2017). Research has also dealt with the conflict created by the outbreaks but less has been covered in the kind of conflicts between local communities which emerge in the aftermath of the epidemic. This paper discusses the untold sufferings by ebola survivors which continues to unfold long after the epidemic was declared over. The suffering was based on how the different ethnic groups in the same community framed and labeled the epidemic, with each ethnic group blaming the other for responsibility for the cause of the outbreak. Goguen and Bolten (2017) discuss how the primary after-effects of ebola became a political conflict between local communities rather than the medical effects of the survivors. The manner in which the two different communities constructed the epidemic led to awakening hitherto dormant historical power-struggles over village boundaries. The epidemic generated controversies on who should be blamed for the cause and the action taken (Harper & Parker, 2014b; Leach & Hewlett, 2010; Leach & Tadros, 2014).

Local populations perceive epidemics differently from the public health experts, especially when it comes to defining the epidemic, its causes and the appropriate action needed to resolve it. This framing and blame-game generate conflict and resistance from the local population (Farmer, 1996; B. Hewlett & Hawlett, 2008; B. S. Hewlett, 2016; Leach & Hewlett, 2010). Harper and Parker (2014a) have attributed such controversy and contestations on the geographies and politics of blame (Finnstrom, 2009; Goguen & Bolten, 2017; Harper & Parker, 2014b; Leach & Tadros, 2014).

There have been attempts to make the disease more understandable to the local community. Public health experts in some cases tried to translate biomedical models of the disease into local concepts with the hope of stopping transmission (Fairland, 2015; Goguen & Bolten, 2017; Kalra et al., 2014). Yet, people rejected the message as they opted for local constructions. In translating biomedical constructions, the effort is placed on the knowledge of production, circulation, and consumption about the epidemic. However, Goguen and Bolten (2017) argue that the focus should be broadened to include the non-production, obfuscation, and rejection of knowledge in the context of an outbreak.

The study presents the living experiences of the epidemic survivors and people's reactions towards individuals and families affected by the epidemic. The study analyzes how the construction of the epidemic divided people using geographical and ethnic boundaries, which exist in the district. These divisions have continued to affect ethnic relations and boundaries, perpetuating the social suffering, stigma, and fear of and among the survivors. The study argues that the kind of construction of an epidemic creates a lasting impact on the survivors and those families which lost their loved one. The study also argues that the medicalization of the survivors through the continued extraction of their blood samples for further examination is a new form of epidemic perpetuation. It fuels the construction, enforces exclusion, and enlarges the social distance between the survivors and the community. This exclusion started with naming the epidemic and the kind of care and treatment which was given to the victims of ebola by the biomedical staff. People who were considered to be infected were put in isolation wards and quarantines, and relatives were denied access to them. After recovery, the survivor continued to face medical examinations and screening, where researchers take blood samples for continued investigation. This form of medicalization turns out to be a new form of medical violence towards survivors and their families as it fuels suspicion and the consequent social exclusion.

2. BUNDIBUGYO DISTRICT

Bundibugyo District is the research target for this study. The district is relatively isolated from the other districts of Uganda. It lies west of the Ruwenzori Mountains, bordering the Democratic Republic of Congo. Most of the district area is occupied by tropical forests which form part of the Semliki and the Rwenzori national park. The soils and the climate are suitable for food production and the continued survival of inhabitants. The people mostly live in villages headed by clan elders and leaders. The clan elders are responsible for the social well-being of the members, including their illness and death. For example, it is a clan leader's responsibility to know the cause of any illness or

death of any member. Villages are organized according to clans, each clan having a different location consisting of segments of one of the ridges with a stream on either side, forming two of the boundaries. Typical traditional villages are made of people related to one another in a patrilineal line, all claiming a common ancestry.

There are diverse ethnic groups in Bundibugyo, each with its own unique customs and norms. The major ethnic groups are Bamba and Bakonzo, and the smaller ethnic groups include Batwa/Basua and Babutuku/Bambuti. Bakonzo occupies mainly the mountain-top, while their counterparts the Bamba live in the lower lands of the mountain. Even though all the groups live together, even inter-married each other especially in the lower lands, they still maintain some distinctive features which distinguish them from one another. Language is one of these distinguishing features. The Bakonzo are the dominant group in the region stretching from Kasese to Bundibugyo and Eastern Democratic Republic of Congo (Mbalibulha, 2008; Pennacini, 2008).

There was an ebola epidemic outbreak in Bundibugyo district in western Uganda in 2007 – 2008. Many of the people who died in different parts of the mountain remain undocumented, however. Records show that more than 140 people were infected, and out of which 40 people were recorded as having died (Kratz et al., 2012; Leach, 2008; MacNeil et al., 2011; Roddy et al., 2012; Towner et al., 2008). For three months, local people were wondering what kind of epidemic was killing them, and there was a lot of uncertainty regarding the cause and spread of the epidemic. Fear paved the way for the local people to resort to their time-tested traditional health-seeking knowledge to mitigate the mysterious epidemic. One of the mitigations was a cultural practice of 'social distancing'. People avoided coming into contact with anyone from the families of the infected individuals. The government declaration of the epidemic as an ebola outbreak did not alter people's earlier perceptions of the epidemic. Instead, it buttressed the people's local framing of the epidemic and the strategies to deal with it. Local people failed to explain the outbreak, and they assumed the epidemic to be a curse.

While Ebola has received a lot of attention today, however, much of the coverage and attention happens during the outbreaks until it is declared over. The story of the ebola outbreak focusses on the biomedical specialist as the heroes who treat ebola victims but the suffering of the ebola victims remain unexplained. More information is needed on the survivor of the outbreak within the communities after a long time. The memories and experiences of

survivors are neglected, the descriptions of these memories enable to establish ebola as a critical event which shapes society.

This paper discusses the constructions of the mysterious epidemic as a curse to particular families of an ethnic group. It endeavors to explain how that kind of construction affected the survivors and those who lost their loved ones. The question that those affected and afflicted asked themselves was, 'why me, why us?' This construction was particularly applicable in this epidemic because ebola killed people from one ethnic group, namely the Bakonzo while their counterparts the Bamba and others in the district remained largely unscathed. Only one none-Mukonzo individual was recorded to have died, yet there are no major cultural, ecological and social differences among these ethnic groups.

3. THEORETICAL FRAMEWORK

The constructionism epistemology is used to inform the theoretical perspective of this study. Constructionism is a view that all knowledge is constructed in and out of the interaction between human beings and their world, and advanced within a cultural setting (Crotty, 1998). Knowledge and many aspects of the world are not real, they only exist because people give them a reality through social agreements. Even findings from biomedical or other sciences do not result from a reading of nature; they are instead constructions based upon agreements (Aronowitz, 1991; Crotty, 1998; Gaines, 1991; Good, 1994). Ebola is considered to be a cultural construct, created by the interaction between people and their relations to the expectations of society. Kleinman (1980) argues that patient and health workers have different explanations of illness. The biomedical personnel and the local people within a cultural context of an Ebola outbreak usually have a variant cultural model for the epidemic. However, what is important to note is that the model people select influences the kind of treatment they seek to deal with in an epidemic. The treatment and care for Ebola would be based on the negotiation between the various cultural model's people hold in a specific cultural context. However, the local people and biomedical personnel cultural model are always different. In many instances, the biomedical support imposes their model and they leave no room to negotiate for the cultural models inherent in the community.

Kleinman, Eisenberg, and Good (1978) observe that illness behavior is a normative experience governed by cultural rules (Kleinman, 1980). He adds that individuals learn and approve every particular illness in specific ways. Moreover, while these variations exist, the biomedical explanations and procedures on Ebola remained rigid, similar and universal, like in all other areas where the outbreak took place. The responses of the natives to the epidemic were influenced by their belief systems; it is the belief system which

shaped and influenced the people's views of the epidemic. As observed by (Robert A Hahn, 1995; Robbert A Hahn & Kleinman, 1983) individual mind, social relations and societal organization greatly affect the process of sickness. In addition, the cultural environment, in a similar way, also affects the pathogens and medicines (Robert A Hahn, 1995), because culture as a system of knowledge. It consists of shared information (D'Andrade, 1981). Therefore, the communities' interpretation and framing of the epidemic were grounded in the cultural belief system.

This paper deals with a case of ebola event outbreak in Bundibugyo district of Uganda. Two distinct theoretical lenses are utilized. Veena Das's (1995) *Critical Events*, Das (1995) argues critical moments can be describable within the framework of anthropology. Das (1995) considers a *Critical Event* be an event which changes society. According to (Das, 1995)after the critical event happens, a new mode of actions come into being in a society which redefines traditional categories, equally important are the new forms which are acquired by a variety of actors in the community and the nation. Das further argues that the terrains on which a critical event took place crisscrossed several institutions, moving across families, communities, the state, and multinational corporations. Therefore, a description of ebola outbreak as a critical event helps to form an ethnography which makes an incision upon several institutions, so that their mutual implications in the events are foregrounded during the analysis. Critical events approach to the study of ebola enables to arrive at the truth of the victims through the daily suffering, daily humiliations and every day's experiences being violated.

Ebola is a critical event in which the traditional concepts of health-seeking knowledge and behaviors were altered in the community. Practices such as, identifying an epidemic, visiting the sick, giving care, death and funeral rituals, and communal support rendered to a person (s) or a family after recovery of or losing a family member were transformed in the course of one Critical Event, namely ebola outbreak in Bundibugyo district. Ebola as a critical event devastated the lives of the infected people and destroyed and distracted the communities of the survivors. However, the victims pick themselves up and try to live again in the same communities. What does it mean to live in a community that was destroyed by a critical event? How do people reconstruct their lives in the very place of destructions? This paper does not describe the people experience during the outbreak, but the focus is on what happened to the victims of ebola after the outbreak. According to Das (2007) community is constructed through agreements and can also be torn apart by a refusal to acknowledge some parts of the community as an integral part of it.

Another relevant perspective of this study is on the anthropology of knowledge by Fredrik Barth (2002). Fredrick Barth (2002) says knowledge is what people use to understand reality and interpret experiences. According to Fredrick Barth (2002) knowledge has three basic features: a distinctive domain of knowledge, called the "corpus of knowledge", the means and media by which knowledge is "transmitted", like the educational systems, through experts, through rituals, through general socialization, through written or oral means and the "arenas" in which the activities of the domain of knowledge are conducted. This general perspective on knowledge is useful in focusing on this study. The local understanding of Ebola is considered to be a particular form of knowledge. This knowledge patterns and frames or influences the understanding and explaining the beliefs concerning Ebola in a given community. Therefore, culture then determines the conditions of the outbreak and the perceptions of the individuals towards Ebola. Culture greatly influenced how people perceived, experienced and coped with the epidemic. Explanations and expression about the epidemic were based on specific social positions occupied by individuals and the social system of meaning they employed. As the epidemic spread in the district, communities within also shaped the experiences of the outbreak itself. It was shaped in processes embedded in the complex community milieu. As it advanced, it was interpreted in the intimate part of the social system of meaning and rules of behaviors which are culturally constructed.

4. METHODOLOGY AND METHODS

This paper is part of a Ph.D. fieldwork research, which was conducted using participant observations for twelve months between 2016 and 2017 in Bundibugyo. The research topic was *The Constructions of Ebola in Bundibugyo Uganda*. The researcher? focused on lived experiences of the epidemic doing an in-depth study of natural settings. Using qualitative research paradigms and phenomenological approach, data was gathered using ethnographic interviews, discussions, and observations. Informants were asked to describe their lived experiences in details, supported by field notes. These descriptions were analyzed to arrive at experiences relevant to the phenomenon of the epidemic from a viewpoint of the survivors. The use of the phenomenology approach allowed to go back to the events of the epidemic outbreak, to discover and lay bare what lies hidden in survivor's experiences to emerge and manifest in their descriptions. The interpretive phenomenology inquiry allowed to reflect on the survivor's experiences, explicate their lives, hence enabling to unravel the meaning of lived experiences. According to Das (2007), survivor's pain experiences are created and distributed by the social order, located in individual bodies but bear the stamp of the authority upon the

docile bodies of its members the society. Therefore, pain and suffering are not simply individual experiences which arise out of the contingency of life and threatens to disrupt a known world, they may also be experiences which are created and distributed by the social order itself. The lives of particular persons and the community are deeply embedded in events, and the events attach itself with tentacles into everyday life and hold itself into the necessities of ordinary life (Das, 2007). During ethnography, one of the researchers was in a position to enter everyday life situations of those who suffered through filed work relationship. In presenting and discussing the findings, informant's identities and privacy are protected by using pseudonyms and removal of any information which may serve in identification.

5. FINDINGS AND DISCUSSIONS

Ebola epidemic started in a remote isolated village in Mt. Ruwenzori in Bundibugyo district in the early days of the month of August 2007 (Kratz et al., 2012; MacNeil et al., 2011; MacNeil et al., 2010). The epidemic was named *Bundibugyo Ebola Virus Disease* (BEVD)[1]. However, the epidemic did not receive an official name, instead, it was called different names depending on the dynamics of the outbreak. Some people in the community called it 'the mysterious illness in the mountain' while others called it 'the disease from the mountain in Kikyo'. Kikyo is where a medical facility (Health Center III) is located, and it is this facility which first reported the mysterious illness to the district authorities. Kikyo is a small town located deep in the mountain, 25 km away from main Bundibugyo town. It is a place dominated by one ethnic group, the Bakonzo. That is why the epidemic was later called the Bakonzo epidemic. But as the epidemic continued, people with relatives in Kikyo contracted the epidemic as they went to give care and attend burial rituals. When Bakonzo with relatives in Kikyo began to die in a similar way like the relatives they had attended to and/or buried, the name of the illness changed to

[1] According to the rules for taxon naming established by the International Committee on Taxonomy of Viruses (ICTV), the name Bundibugyo virus is always to be capitalized, but is never italicized, and may be abbreviated (with BDBV being the official abbreviation). Bundibugyo virus (abbreviated BDBV) was first described in 2008 as a single member of a suggested new species *Bundibugyo ebolavirus*, which was suggested to be included into the genus *Ebolavirus*, family *Filoviridae*. The name Bundibugyo virus is derived from *Bundibugyo* the name of the chief town of the Ugandan Bundibugyo District, where it was first discovered.

Kikyoyosis. The epidemic was named *Kikyoyosis* as an illness which kills people in Kikyo and their relatives elsewhere. The name *Kikyoyosis* came to mean not only where the epidemic came from before spreading, but also what it was. This name reflected the people's imagination of the epidemic with a mystical attachment. The name constructed the epidemic as a curse towards particular families of Bakonzo, and this curse stayed even when the individuals were declared healed by the biomedical doctors.

Kabiira and Muhindo, who were two of my informants, explained what they went through during the outbreak of ebola, and what they still have been facing ten years after the outbreak. Kabiira was a student then in senior five, she never continued with school. She is now a single woman living alone in a small one-room house (*muzigo)* in town and is still looking for a job. She went to the village to help her mother with the garden. She also sales some of the supplies they produced in the market. Muhindo is a widow living as a peasant farmer in the village not far from the town center. During the outbreak, she used to stay in the main town of Bundibugyo, where she used to own a small shop selling cold drinks such as drinking water packed in homemade plastic bags *(kavera),* passion juice and second-hand clothes. Now she relocated to a nearby village away from the main town.

In 2007 it was clear that once someone got the ebola, that person would die because there was no cure or vaccines. Patients were only given supportive care and treatment according to the most evident signs and symptoms (B. L. Hewlett & Hewlett, 2005; B. S. Hewlett & Amola, 2003; Piot, 2012). That is exactly what Kabiira received from the Ebola Isolation Ward as she embarked on a slow, painful recovery process. Kabiira's family was condemned for having brought the diseases to town. Indeed, her father was the first to be sick or known to have been diagnosed and died of ebola in town. But according to her, ebola had killed many people already in the village by the time her father got it.

I do not want to even hear or talk about the epidemic, people say my family is cursed, my father brought the curse to the village. But it is not true the poor man did not know; he was just too kind to take care of the sick relatives. What is hurting me most now is, even after many years, people still avoid me, I can't find a job or a man to marry me. People still point fingers at our home; as a home with curses because it was the source of the epidemic to the town. I am grateful to God I am alive today. The same way I cannot explain why my family and myself became sick, I cannot tell as well how I recovered. I thank God to be alive, I am just lucky, although I am still puzzled and suffering from the effects of the epidemic. *(An ebola survivor interviewed by the researcher at Bubandi 2017)*

Unknowingly, Kabiira contracted the epidemic while helping her father. It was after the death and burial of her father that she also fell sick. , In the beginning, her most elderly sister Musoki and then the entire family became sick and admitted in the hospital of Bundibugyo. The family problem of illness started when her father went to visit a sick relative. As it was the norm, when someone is sick, the relatives are obliged to visit the person. When visiting the sick, they sit close, touch and talk with the sick to give comfort and care. So, her father went to visit a sick relative in Kityo village with a strange disease.

This was not the usual sickness where relatives go to take care of the sick people who are admitted in the hospital, visitors were not allowed, and even bringing food, nor herbs and spiritual treatment and nourishment were all banned. Those admitted had no one to talk to or to send because their family members had no physical contact with them.

When I got admitted to the hospital no one came to visit me, no one was allowed to come to visits, I stayed isolated in the hospital. I stayed quietly to wait for my death. I thought every night that I would never make it to the next morning, I was thinking about death. The only way to leave the hospital was when they take you for burial. *(An ebola survivor interviewed by the researcher at Bubandi 2017)*

After discharge from the hospital, neighbors and friends did not visit the homes of survivors nor did people welcome the survivor in their homes. While getting work to earn a decent income is an uphill task in Bundibugyo, the survivor's dilemma was compounded by the stigma, which they and their families endure in the village on a daily basis. The terror and the shame for ebola are so rooted in the community to the extent that survivors were not only abandoned by relatives but also rejected by the church.

I am shunned and avoided by everyone including some of our relatives, something very unusual in our culture. Just as I was separated during our fight with Ebola, I emerge to find ourselves secluded in the village. In the hospital I was sad, depressed and traumatized assuming I was going to die, now once cured, and returned from the hospital, a hero's welcome was not there for me. For more than four months, I couldn't walk away from home, talk nor work with anyone, I was dead and done. I was physically living but socially and culturally dead. I am actually *a living dead*. No partner, no family member, no friends want to associate with me; that time I could not buy or sell. Because no one could touch the money I had touched, nor could anyone buy products from me. I was avoided, some people would even turn away when they see me on the path heading towards them. I lived to hope for the church's rescue; since

my father was one of the senior leaders in the local church. As a pastor's child, I took it for granted, receive love, empathy, rehabilitation, and care from the church members where my father was a faithful and famous elder, but I was wrong. No amount of explanation and counseling convinced church members to accept me as a pastor's daughter or member anymore.

(An ebola survivor interviewed by the researcher at Bubandi 2017)

When Kabiira says she is *a living dead* or being part of the 'living dead' (Mbiti, 1991), it has to do with how the community socio-culturally interacts with the dead and those who lost their loved ones and how this related to ebola survivors. Being infected with ebola posed a serious threat to the life of the people in the community. For the Bakonzo who have survived the ebola epidemic and still live within the communities dominated by the Bamba, they are treated as outcasts: people with a curse on their heads. This is what Kabiira calls 'being physically living but socially and culturally dead´, Ebola cut them off from their social networks and community support when they lost all their friends. They were left alone with no social, cultural and spiritual support.

Social networks involve solidarity, hospitality, sharing, and obligatory frequent interactions. Living in the community is like a large family because a normal social network involves almost everybody in the community. This network ensures socio-cultural and spiritual nourishment. Difficult times normally enable people to make new friends and even mend broken relationships, but in the case of ebola, the relationships were broken instead. The ebola survivors no longer belong to the community as it was before. The survivors are now socially not accepted in the community. Belonging to the community would guarantee the survivors support and social security, which means mutual dependence. So, efforts are normally done to make sure broken bonds are amended. When there is belonging, there is an exchange of hospitality and solidarity, tested and reaffirmed through difficult times. People are obliged to support or take care of their friends during difficult situations. This solidarity produces satisfaction and social acceptability expressed through mutual visits, especially when sick or going through difficult times. Real friends are those available especially in time of need like the ebola situation.

The ebola survivors were not visited when they were in the hospital, nor when they recovered and were discharged from the hospital. People still do not visit them as it was before the outbreak. Before the outbreak, visiting one another or visiting someone sick or facing great difficulties brings great satisfaction. This is no longer the case in the event of ebola. According to custom, it is a shame and hurts to have no one visiting you when you are hurting in the village. When Kabiira was visited the first time, she made sure the researcher entered the house and had something to eat. After the conduct of interview with Kabiira, she escorted the researcher up to the river at the end of the village. She

then disclosed that when people visit her home it gives her life again. The underlying purpose of accompanying the researcher for Kabiira was to be seen with the guest (the researcher) in order to let others know that she was no longer a health threat. Indeed, people in the village are able to see she still has friends who come to visit her despite them neglecting her.

For Muhindo the situation was rather different, she lost a husband, a son and a daughter. She remained with the task of taking care of her family, including her grandchildren, alone. Muhindo expresses how she was tired of researchers especially those who took her blood and do nothing to her situation. She says medical teams go to her home every six months to collect blood samples but they never take time to understand the kind of problem she was going through. She narrated her tragic story of how her entire family was infected, and later how the community hitherto neglected her.

My husband died, my daughter died, my brother-in-law died and my brother also died. Only me and my second daughter survived. In the hospital, I was a caregiver to all my family members, because all were very ill with me. At one point, I was so weak I collapsed. I do not recall what happened afterward. What I remember when I woke up, I realized my daughter had passed on and had already been buried. I thought I was going to die, but I still wanted to live at least for my children. So, I did everything possible to live. When I was discharged, it was difficult for me, because while in the hospital I was left to die alone and indeed I thought I was going to die. However, I survived, but after recovery, I was left to die. All the social relationships and support was far from me.

Suffering from this epidemic is very difficult but living as a survivor is very painful as well because it has a lifetime effect and life is never normal again. Muhindo and her family members got infected when they went with the children to the village in the mountain to join my husband to bury a relative. The husband had gone prior to giving care and support to his sick brother who by this time had died. Among the Bakonzo in case a man falls sick, the wife has to call the brother of her sick husband to come and confirm the illness but also declare the sickness to the other relatives to come and investigate the cause of the sickness and to decide the kind of treatment to give to the sick person. Muhindo's husband was part of those who investigated the illness and the death of his brother. The husband also participated in the funeral rituals like the washing of the dead body before burial. "I and my entire family stayed for four days after the burial to mourn and thereafter performed funeral ceremonies and rites. Upon our return home, my husband became ill and died

shortly". After his death, the doctors began to investigate the illness because he had similar symptoms with the late brother whom he had attended in the village. One week after the burial of her husband, everybody in her home got sick. They were all admitted to the Bundibugyo hospital. Muhindo says in the hospital the family never received much help at first. It was not until the medical team from Kampala came that her family received medical attention. While the epidemic started in early August 2007, the medical team from Kampala came in at the end of November 2007.

Suffering from rejection and exclusion from the community began during admission in the hospital when fear and death engulfed the entire district especially the hospital. There was little help from the government. I think the government did not want to declare the outbreak because of CHOGM (Commonwealth Heads of Government Meeting) in October 2007. The queen of England was coming to Uganda to attend CHOGM, so I assume the government thought news about an outbreak may disrupt her visit and the entire CHOGM activities. By the time the medical team from Kampala came, many people had died and others were in a critical state. My daughters died and were buried when I was still in the hospital. I did not mourn or participate in burying them, nor was there any relative to attend the burial. *(An ebola survivor interviewed by the researcher at Bubandi 2017)*

When the epidemic started, local people initially associated it with witchcraft. This boiled down to spiteful inter-ethnic exchanges between the Bamba and the Bakonzo with the latter accusing the former of bewitching them. However, the Bamba framed the epidemic as a curse by the gods to Bakonzo, calling it *Kikyoyosis*. This inflamed the relations and raised political stakes in the district to the present day, including the mass killings of the year 2012 in Bundibugyo (Reuss & Titeca, 2016). There was panic among the people as everybody seemed not to know what was happening. The symptoms were very traumatizing, the caregivers and the visitors to the patients became traumatized, leading to fear. The fear of an epidemic generates antisocial behavior similar to those experienced by survivors and their close relatives during the 2000-2001 outbreak in Gulu (B. S. Hewlett & Amola, 2003). This led to the rejection of the survivors and the close family member from the communities. Except for close family members or relatives, many people within the community distanced themselves from the victims. They assumed the epidemic was a curse to the affected families from the gods. This rejection did not stop during or after the outbreak but has carried on causing the harmful experience to the survivors. It has destroyed their sense of belonging, their self-esteem, and meaningful life living.

The neighborhood is no longer good like it was before the outbreak. The survivors are excluded by friends and cannot participate in small talk, discuss

any serious subject, or keep up with the local news and gossip. People just keep pointing fingers at them, calling them cursed, and accusing them of bringing ebola to the village. There was never a situation when people in the community would forget or neglect their neighbors as it was during and after the outbreak. People no longer demonstrate solidarity with survivors as friends and neighbors at village rituals and ceremonies. Traditionally, showing solidarity with friends at funerals and other occasions were very important. This is done primarily by attending and providing financial and spiritual support. It is a great honor when many people come to one's funeral vigils and accompanying rituals. Muhindo says she did not attend the burial of her daughter neither did the relatives, however. Kabiira also says very few people came to observe her father's funeral. Satisfaction used to be gotten through sharing life's everyday experiences including having a voice in the village, being granted space to speak with the neighbors and many such mundane needs. Neighbors in the villages provide emotional, material, spiritual and practical support for one another, but after the ebola outbreak, this was robbed away.

Solidarity has to do with inter-dependence, it also means living in a community rather than living in isolation. If in the neighborhood a family loses their loved one and they do not receive the solidarity from their neighbors and friends, this leads to emptiness, which causes more suffering than the loss of their loved ones. This implies perhaps the deceased did some evil things in life which they were not aware of, or perhaps the whole family is thought of negatively in the neighborhood. The physical presence of friends and relatives in such circumstances is utterly important in demonstrating their ties and solidarity with the family. Ebola was more than just a disease, for while suffering brings solidarity, the ebola outbreak instead estranged and divided people.

Like in many communities, epidemics are considered exotic, coming from another community or country, (Graboyes, 2010; Leach & Tadros, 2014) however, the blame-game occasioned by the epidemic in Bundibugyo was based on the ethnic divisions within the district. Ebola in Bundibugyo was a disease for Bakonzo families. The Bakonzo infected bodies became a threat to the lives of other people in the community. Bakonzo bodies were considered to carry disease across the community, so boundaries were created and enforced. This was to ensure the people in the community were not exposed to the danger which might come from the infected family. They installed controls in the villages to ensure individuals from families and clans who were infected do not affect other families. The epidemic made people lose their individuality and personality. Infected people were treated as cursed bodies because they

were labeled with a mysterious epidemic considered a curse to the land. It is not that survivors were a problem but their bodies were suspected to be carrying not just an epidemic but a curse. Survivors were 'socially dis-embodied', stripped of their humanity, and removed from their communities. Overnight they became 'social ghosts' and treated as unwelcome aliens. Even after the government named the epidemic as ebola, this did not change the situation. To the community, there was no difference between the infected persons and the virus itself. A strange virus bound to affect other members of the community must be avoided, so they treated the survivors in a way they treated the virus.

The epidemic was used to enforce and awaken the dormant ethnic conflicts among different groups in Bundibugyo. According to Fredrik Barth (1969) some of the characteristics of an ethnic group is considered to designate populations which are largely biological and share fundamental cultural values in overt unity of cultural form, make up a field of communication and interactions, and has a membership which identifies its set up, and is identified by others as consisting of categories distinguishable from others of the same order. Ethnic boundaries will always exist despite the flow of persons across them says Fredrik Barth (1969). Fredrik Barth (1969) talks of those none ecological cultural and social components which create diversity among people who live together. The epidemic outbreak is considered as one of those factors. Even though Bamba and Bakonzo have lived together and even intermarried for centuries when a mysterious epidemic came, the Bamba blamed it on Bakonzo. Ethnic categories provided an organization vessel on which framing of the epidemic was forged. Therefore, being a Bakonzo implied being contaminated with a curse, it means to be judged as cursed by Bamba. They created boundaries which canalized the social life of the epidemic survivors within the complex organization of behavior and social relations.

Lastly on a larger scale giving the name of a district *Bundibugyo* to a disease *Ebola*; *Bundibugyo Ebolavirus* stigmatized the district and the population from that district to a certain level. The name Bundibugyo as a name for the district is now linked to an Ebola virus of *Bundibugyo Ebolavirus* internationally, the name has become the trademark for the district of Bundibugyo. Indeed, the word *Bundibugyo* internationally represents a disease rather than a district where people live. While there may be the good epidemiological basis for the names given, but that does not consider the labeling and the stigma which people from the particular district (s) or country (s) carry with them because they had an event of Ebola in their life history. Especially when the natives travel outside the district or country, they carry with them stigma attached to a virus. There are some instances when some countries refused the names of epidemics. For example, Mexico refused *Mexican Flu* and it was called *A (H1N1) flu*. Similarly, names like *Swine Flu* were rejected. Vigsø (2010)

suggests the naming of an epidemic after the country gives an impression that a particular country is blamed for the diseases and this stigmatizes people of that specific country or region. Countries like Mexico were able to resist the name, but the marginalized people of Bundibugyo are still blamed for the epidemic which has affected their reputation, and which makes them appear primitive with strange behaviors that is why they get a strange disease like Ebola.

Once a person whose body had Ebola ceased to have private space, instead, his body was subject to public scrutiny; it becomes a threat to the lives of those who may come in contact with it. As a result, the body was subjected to the rules set by the biomedical experts. Response to ebola by public health experts is based on the biomedical knowledge which views ebola as a disease with an individualist approach. The biomedical texts look at the ebola as a virus in the laboratory or disease in the hospital among patients. Follow-up after the outbreaks is on tracking the virus in the victims of the survivor. Efforts in the district are put on how to prevent the next outbreak, focusing on effective ebola surveillance. Ebola was not only as a disease affecting individuals but an illness which affected the social networks of the community. Therefore, treatment to ebola should not focus on the biomedical individualist approach to a diseased in the body of the sufferer but to include healing to the entire community which faced the outbreak. Ebola was not just a disease but an ideology that separated and controlled those who were infected. After the ebola event, the Bakonzo families which live in the Bamba dominated communities still considered ebola as a curse that the Bakonzo deserved. The suffering of the survivors was left unattended too and the voices of the victims were not heard. The media attention only took place during the outbreak until it was declared over.

5. CONCLUSIONS

Listening to survivors lived experiences do not only provide evidence-based information that is needed for future reference in research and policy but also brings, joy, hope and resilience to the survivors themselves. They get an opportunity to share their heroic survival of a deadly disease which in the end brings healing.

The epidemic played more on social networks and kinship ties widened social distances and strengthened ethnic boundaries based on boundary politics and geographical proximity. Caring for the sick, as well as death and burial rituals

became the causal agents of ebola in Bundibugyo, unmaking historically founded norms and practices.

The caregivers who were mainly relatives became the main victims of the epidemic. Even after years, there is still a lingering stigma; as people are not comfortable associating with survivors. Ebola is not just an epidemic which comes and goes, but a pandemic which affects the community structure to the core. After surviving the ebola, the survivors are cast into the harrowing crucible of social avoidance. Where the survivors would normally have expected comfort and solace through the social networks, the after-effects are possibly more painful.

The local constructions ebola determined the continued dynamics of the epidemic outbreak and after-effects to the survivors. Ebola did not only destroy the internal organs of the body of the infected persons but also altered the socio-cultural set up of a community in which it occurred and its impact has lasted for a long time; including stigma, discrimination, trauma, poverty and the orphan problem. Therefore, Ebola is dislocated from being an epidemic that affected individuals who suffered and got treatment in the community to a pandemic which continued to create new identities within society.

Ebola treatment was largely informed by biomedical knowledge which demonstrated that once a person was declared healed, the recovered person would freely regain the day to day life as before the event of ebola. However, the event of ebola was incision to the community's cultural institutions of interpreting and framing an epidemic. The local framings of ebola as a curse caused untold suffering to ebola survivors in the communities. The modalities of recovery for ebola survivors were molded on biomedical knowledge. The biomedical knowledge did not address community concerns and the cultural framings of the epidemic, instead, it conflicted with traditional health-seeking knowledge and practices.

Ebola event has led to the medicalization of the ebola survivors which is interpreted as a new form of violence. The continued medical examination, blood screening is not only a form of medicalization but actually a new form of violence towards people.

More work needs to be done on the victims of ebola after a long time not just of the biological blood tests but on the societal acceptance of ebola survivors. Ebola survivors should be supported beyond the period of the outbreak and find effective ways that are culturally appropriate to re-integrate them in the community once discharged from ebola isolation control center

The epidemic response should go beyond biomedical interventions to include cultural-based innovations. Because Ebola event is an illness within the community, which does not only affect individuals but also shaped the entire

community. Therefore, post-treatment should involve not only the victims but the entire community. Ebola is not only pharmaceutical or biomedical problem, as it has been defined by biomedicines but rather characterized by a range of social-cultural, political and economic challenges.

Lastly, the international taxonomy of virus should stop naming viruses based on the names and countries because this led stigma of the local populations which come from those areas like the *Bundibugyo ebolavirus* puts sigma of the local people of Bundibugyo district.

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