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SCHOOL OF PUBLIC HEALTH

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POST-EBOLA SYNDROME AMONG EBOLA VIRUS DISEASE SURVIVORS IN MONTSERRADO COUNTY, LIBERIA

BY

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DECLARATION

I, HIMIEDE WEDE WILSON, do hereby declare that except for the referencing of other people's work which I have duly acknowledged, this work is the result of my own original research and that this dissertation, either in whole or in part has not been presented to any other University elsewhere for another degree

SIGNATURE_____

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Dr. ERNEST KENU (Supervisor)

DATE 29.09.16

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DEDICATION

To my parents Cllr. William H. Wilson and Ms. Gilda N. Merchant for their endless support both morally and financially. My uncle MacDonald B. Freeman Jr. and my lovely siblings Millicent, Hannah, Roosevelt, Sie and Gilda for their encouragement to push forward in obtaining higher education. May God almighty blessed you all.

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DEFINITION OF TERMS

Post-Ebola Syndrome - Health-related problems Ebola virus disease survivors are enduring after laboratory result has proven negative of EVD.

Survivors - A patient who subsequently recovers, after being confirmed positive with a result of RT-PCR testing for Ebola virus on anybody fluid ("WHO | Ebola virus disease," 2015).

Short-term PES - Health related symptoms manifesting between 1-10 months upon discharge from an Ebola treatment Unit.

Chest pain - Pain survivors experienced in the chest when lifting up something. This pain in some survivors never ceases with pain killer.

Unusual Tiredness- Weakness of the body that prevent survivors from carrying out normal work.

Eye problem - Problems of the eyes which includes itching, hurting, redness and blurred vision

Menstrual problem - Problem of the menstrual cycle which includes cessation and irregular bleeding.

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DEFINITION OF TERMS Cont'd

Itching& Peeling of skin -	The presence of rashes /skin diseases on the skin of survivors and peeling of the hands and feet of survivors.
Hair loss -	The heavy breaking of hair from the head when combing up.
Depression, Anxiety & poor sleep -	A state in which survivors feel frightened, pity themselves because they were denied access to basic needs, avoided or when survivors experienced flashbacks of their stay and how their relatives and other patients died in the ETU.
Survivors Tracker -	Someone whose duty at Partnership for Research on Ebola Vaccine in Liberia (PREVAIL) is to monitor survivors on a weekly basis. They are to remind survivors of next appointment date and monitor survivors for complications that may arise.
Social mobilizers/ Communicator	Someone that visit the homes of survivors trying to make them feel they are a part of society once again. Also, communicators go to the community and create awareness in communities of best health practices that should be carry out.

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LIST OF ABBREVIATIONS

CDC -	Centers for Disease Control and Prevention
ETU-	Ebola Treatment Unit
EVD -	Ebola Virus Disease
FGD -	Focus Group Discussion
PCM -	Paracetamol
PES-	Post- Ebola Syndrome
PHEIC -	Public Health Emergency of International Concern
PREVAIL-	Partnership for Research on Ebola Virus in Liberia
RT-PCR-	Reverse Transcriptase-Polymerase Chain Reaction
WHO –	World Health Organization

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ABSTRACT

Introduction

An increased number of survivors have emerged from the 2014 West African Ebola Virus Disease outbreak. Fifty percent of survivors have reported a combination of physical and psychological symptoms termed Post-Ebola Syndrome. However, these physical and psychological symptoms reported by survivors during convalescence is not well understood. This is due to the high case fatality rates of previous outbreaks, fewer patients surviving and the existence of limited literature that has contributed to the phenomenon of Post-Ebola Syndrome. Also, 58% of survivors in Liberia resides in Montserrado County. A county of which the magnitude of Post-Ebola Syndrome among EVD survivors is unknown. Therefore, the study aim was to estimate the prevalence of Post-Ebola Syndrome among EVD survivors in Montserrado County.

Method

An assessment was conducted to determine the prevalence, types, onset, duration and socio-economic challenges of Post-Ebola Syndrome among survivors .The study adopted a cross-sectional design. Quantitative data was collected using semi-structured questionnaire while, qualitative data was collected using an interview guide. A total of 300 respondents were stratified by the health districts and randomly selected from the seven health districts in Montserrado County. During the study data were collected for the following variables; Ebola survivors demographic, prior and post- Ebola health history, and socio-economic status.

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Result

Prevalence of Post-Ebola Syndrome among study participants was 91.3% (274/300). The commonest symptoms were reported from the following systems of the human body; Neurological System 35% (eyes problem 44%, headache 50.7%, sleep disorder 21.3%, unusual tiredness 25.7%) and Musculoskeletal System 34% (abdominal pain 22.8%, chest pain 21.6%, muscles pain 32.8% and joints pains 59%). The onset of Post-Ebola Syndrome occurred more frequently between the first 1-12 weeks after discharged from a treatment unit.

Symptoms were intermittent and persist up to 12 months after discharged from a treatment center. Fifty- five percent (165/300), of Ebola survivors, were unemployed and 72% (197/274) of those with Post-Ebola Syndrome had accessed health care. Of those accessing health care, 50% (99/197) have never improved with treatment due to inadequate drugs, limited health facilities and lack of hired specialists, while 11.6% (23/197) had somehow improved. Fifty- eight percent (173/300) of survivors had been stigmatized upon discharge from the ETU.

Conclusion: Prevalence of Post-Ebola Syndrome in Montserrado County, Liberia is high. Due to the newness of Post-Ebola Syndrome in Liberia, there is a need for the Ministry of Health, Liberia and its Partners to provide adequate drugs for appropriate health conditions, and hired specialists for the commonest reported symptoms at facilities rendering health services to EVD survivors.

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CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Ebola virus is a zoonotic disease that affects both humans and animals. The disease can cause acute illness that can be fatal if left untreated. The Ebola virus disease (EVD) has an average case fatality rate of 50% (WHO, 2015). The first outbreak of this disease was two simultaneous outbreaks occurring in Democratic Republic of Congo former Zaire and Sudan in 1976. The Congo outbreak occurred in a village near the Ebola River from which the disease got its name (WHO, 2015). The virus comes from the family filoviridae. It has three genera; Cueva virus, Marburg virus and Ebola virus. Five species of the virus have been identified namely: Zaire, Bundibugyo, Sudan, Reston and Tai forest (Tamfum et al., 2016). The species associated with the largest outbreak in Africa are the Zaire Ebola virus, Bundibugyo Ebola virus, and Sudan Ebola virus. The Zaire strain of Ebola virus is the species responsible for the 2014 outbreak in West Africa (WHO, 2015b).

The disease is known to be transmitted from animals found in the rain forest. Human transmission occurs when broken skin comes in direct contact with blood, secretion, organs or other bodily fluid of infected people and surfaces contaminated by infected fluid (WHO, 2015). The disease usually presents clinical features such as high fever, headache, arthralgia, myalgia, sore throat, malaise with nausea at the onset and persists further with continuous fever failing treatment with antimalarial drug or antibiotics, intense fatigue, followed by diarrhea and abdominal pain, anorexia, vomiting, and pseudo-remission.

At Pseudo-remission stage of infection, the patients feel better and seek food. The patient health status begins to improve and may recover at this stage and therefore survive the disease (Tamfum et al., 2016).

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The Ebola Virus Disease outbreak of 2014 is the largest in history accounting for 28,646 cases as of 30th March 2016 (WHO, 2016a). The outbreak started in December 2013 in a village called (Gueckedou) in the Republic of Guinea with the death of a two-year-old boy. On 13th March 2014, the Ministry of Health of Guinea alerted the World Health Organization of the strange illness and deaths in Guinea (WHO, 2015b).

In Liberia, the first two cases of Ebola virus disease were confirmed on 30th March 2014 in Foya district, Lofa County near the border with Guinea. In the month of April, the outbreak stabilized in the Country. The second wave of EVD began in June with a sharp increase in the number of cases. The 2014 EVD outbreak also spread to other countries such as United States, United Kingdom, Spain, Senegal, Nigeria, Mali, and Italy. On August 8th, 2014 the World Health Organization declared the Ebola epidemic in West Africa a Public Health Emergency of International Concern [PHEIC] (WHO, 2015).

By September 2014, Liberia had recorded the highest number of almost 2,000 cases. By the end of 2014, the outbreak in Monrovia subsided. On May 9, 2015, the World Health Organization declared Liberia free of Ebola after two incubation periods of 42 days without a new case (WHO, 2015). In between June to July 2015 the third wave of Ebola virus disease outbreak broke out in Liberia. The outbreak was confirmed in Margibi County with two (2) deaths reported (CDC, 2016). On 3rd September 2015, Liberia was declared free of Ebola virus disease by the World Health Organization. The fourth wave of the Ebola Virus Disease occurred in Montserrado County with three confirmed (3) cases in November 2015 (WHO, 2015b).

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A recent wave of EVD in Liberia was reported in the first week of April 2016. Three cases were confirmed of which one died (WHO, 2016c).

Patients who survive the disease are faced with health conditions that may persist for a long time after being diagnosed negative of the virus. These health conditions have been termed Post-Ebola syndrome [PES] (Igonoh, 2016).

Post-Ebola Syndrome (PES) is a group of physical and psychological symptoms affecting Ebola Virus Disease survivors. These symptoms range from short-term (12 months) to long-term [≥24 months] (Vetter, Kaiser, Schibler, Ciglenecki, & Baush, 2016). Some of these symptoms include headache, joint and muscles pain, extreme fatigue, menstrual cessation, clouded vision, hair loss, and deafness (WHO, 2016b).

Due to these challenging health problems, until after a year, Ebola survivors are unable to restart their former work. It increases both economic and health burden of communities and Nations. It also increases economic hardship on the households of these survivors as finances are limited. Currently, there is a five-year study being conducted by a Liberia-United States partnership-based research group (PREVAIL) to determine long-term consequences of EVD among survivors, determine whether survivors develop immunity that will protect them from future Ebola Virus disease and evaluate whether earlier EVD infected persons can transmit infection to close contacts and sexual partners (NIH, 2015). Upon returning home from the ETU, there have been some International and local organizations aiding survivors with cash and assorted items for a maximum of six months. Since the peak of the Ebola Virus Disease outbreak in Liberia, a survivor's network has emerged. The network has been further decentralized into sectors with supervisors assigned in the various counties of Liberia. To improve survivors livelihood, there are regular meetings conducted by each county.

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These meetings are held to enable survivors to explain their prevailing situation to supervisors and to ensure unity within the network. Furthermore, EVD survivors in Montserrado County have been asked by the Ministry of Health, Liberia to seek health care at two government hospitals in the county and a non-profit clinic being operated by the Medicine San Frontier, Liberia for a period of two years (WHO, 2016d).

1.2 Problem Statement

Survivors of the 2014 West African Ebola Virus Disease epidemic are predisposed to many health and non-health related problems. Although the phenomenon of PES has been identified following previous EVD outbreaks, due to the high case fatality rate of previous outbreaks that resulted in fewer survivors, little research has been conducted. It is still not well understood the health problems survivors experienced during recovery post-Ebola. More than 50% of survivors experience symptoms such as visual problem, joint and chest pains, headaches, extreme fatigue and depression (WHO, 2016b). These symptoms have made it tough for survivors to take up their prior lives for practically a year or more. Poor health seeking behavior coupled with limited access to quality healthcare and health personnel's fear complicates the management of Ebola Virus Disease (ACAPS, 2015). According to Schaffner (2016), the existence of poverty and poor prior nutritional status could be influencing Post-Ebola syndrome. Other factors include age, viral count, Ebola virus disease supportive treatment and high concentration of disinfectant (Nanyonga et al, 2016; WHO, 2016). Also, many survivors are enduring stigmatization by communities and family members (Barry & Amola, 2003). The 2014 Ebola Virus Disease outbreak also reduced Liberia's economy and public finances growth from 5.9 pre-Ebola to 2.0% in 2014 (Marquez, 2016). These factors are worsening economic hardship and limiting access to healthcare.

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Though a five-year study is ongoing in Liberia, up- to-date the estimated number of EVD survivors in Montserrado County with health and non-health related problems are unknown and not documented. The study was conducted to document the prevalence of PES among EVD survivors in Montserrado County, Liberia, types of symptoms, onset, and duration of symptoms and socio-economic challenges of PES among EVD survivors.

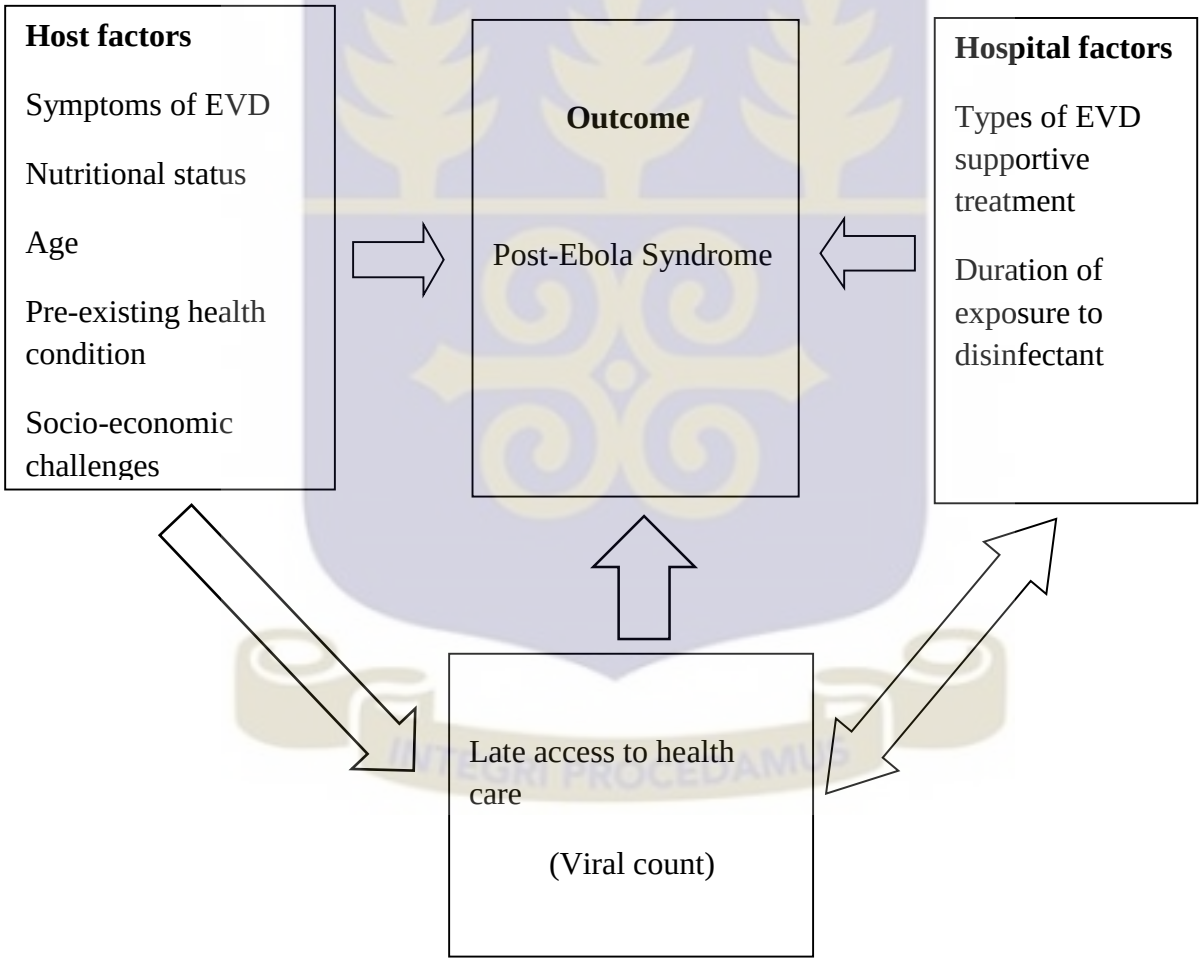

Figure 1: Diagram of Conceptual Framework on Post-Ebola Syndrome

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1.3 Conceptual Framework on Post-Ebola syndrome

Factors that could be associated with PES can be divided into the host factors and hospital factors. Host factors include: Severity of EVD which can be measured by viral count, nutritional status, age, pre-existing health conditions, and socio-economic challenges. Hospital factors consist of EVD supportive treatment, duration of exposure to disinfectant and access to health care.

Host Factors

Symptoms of EVD – The disease displays clinical features with an onset of fever after 2-21 days incubation period. EVD is described by an unclear "flu-like condition with fever, headache, fatigue, muscles pain, sore throat, follow by GIT symptoms such as nausea, vomiting, diarrhea and abdominal pain". Patients also present rash, symptoms of impaired liver and kidney function, with some cases experiencing internal and external bleeding, hiccups, conjunctivitis, desquamation and jaundice (WHO, 2015). These symptoms could persist in survivors from an acute to a chronic stage after a patient sample has proven negative for the virus by RT-PCR.

Nutritional Status- The state in which essential vitamins and minerals such as vitamins B, C, K, A, E, folic acid, calcium, and iron are lacking in the daily diet is termed poor nutritional status. Other factors to consider under poor nutrition are the prior nutritional status, characteristics and duration of infection which can result in loss of appetite in a patient recovering from an infection and the diet taken during recovery (BPAC, 2016). These factors can impair resistance to infection resulting in a PES susceptible person.

Age-could be associated with PES as the younger a patient is, it is most likely their immune system is stronger unlike, an older person whose immune system deteriorates with age. Other factors that exacerbate age are diet, exercise, personal habits, and psychosocial factors. These factors influenced a patient resistance to a disease (Gavazzi & Krause, 2002).

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Pre-existing health conditions- Liberia is a country recovering from 14 years of civil unrest. Poor health seeking behavior as a result of the economic hardship coupled with fewer competent health practitioners and inadequate health infrastructure has resulted in many curable diseases recording high morbidities. Due to this reason, ill people are mostly fond of attending pharmacies/drug stores. Where they buy medication without prescriptions or seek care from a Physician assistant, Nurse or Nurse-aid in a community without properly being diagnosed by a recognized health facility. This could have resulted in an individual harboring a chronic disease unknowingly and the infection of EVD that might have exacerbated PES (ACAPS, 2015).

Hospital factors

Duration of exposure to disinfectants- Long exposure to disinfectant was due to the severity of EVD as a result of high viral load. Disinfectant used in Ebola treatment center, on a corpse, and on ill patients was chlorine. It consisted of three standard concentrations 0.5 % (inanimate objects), 0.05 % (ill patients) and 1% (corpse). Chlorine is a poisonous substance that causes symptoms in the blood, heart, skin, lungs, eyes, nose, throat and gastrointestinal tract (NIH, 2016). Probably it may be one of the causes of Post-Ebola Syndrome.

Types of supportive treatment-There were no proven treatment available for Ebola Virus Disease. Notwithstanding, various treatment protocol were developed for supportive care, which is the pillar for treating EVD. Supportive care composes of administration of oral medication, oral rehydration fluid, nutritional supplements and psychosocial support. The dosage of these treatments varies depending on the severity of disease (viral count). PES could mostly likely be as a result of supportive care through the irregular dosages used during the severe stage of EVD.

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Late access to health care- Access to health care during the epidemic was in two folds.

Hospital factor: An individual being conscious of their exposure time and sought care early but due to the limited available beds in the ETUs between July-September, patients were denied treatment. Thereby resulting in a patient seeking care late when they were severely ill (WHO, 2014). Late access to health care which resulted in high viral count also, increase a patient duration of exposure to disinfectant. Which maybe one of the causes of PES.

Host factor: An individual (host) who experienced symptoms of EVD but not knowing they were diseased. Hence, they stay at home taking treatment for symptoms that appears like one of malaria until they were severely ill before reaching an ETU. Also, when an individual was conscious of their exposure schedule but refuse to accept they were infested with EVD for which reason they stay at home and reported to the ETU late.

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1.4 Justification

Ebola Virus disease 2014 outbreak in West Africa, was the largest since the first outbreak that occurred in 1976. The outbreak which started in December 2013 in Guinea also extended to other countries in West Africa such as Liberia, Nigeria, Mali, and Sierra Leone. The outbreak recorded 28,646 cases. Liberia, one of the hardest hit Countries recorded about 10,675 cases and 4,809 deaths (WHO, 2016a). A little over 1,541 survivors have been line listed by the Ministry of Health Liberia (WHO, 2016d). Montserrado County in Liberia recorded the highest number of cases and survivors. Survivors in Montserrado County accounts for 58% of survivors in Liberia (WHO, 2016d). These survivors after leaving the Ebola treatment center are still experiencing health related problems that is termed Post-Ebola syndrome (Racaniello, 2016). This study will provide a clearer picture of the prevalence of PES among EVD survivors in Montserrado County post-discharge from an ETU, rather than anecdotal findings that have been reported. Also, the study will reveal the burden posed by these survivors on the health care system in Montserrado County. The evidence of this study will inform policy makers to establish and maintain access to healthcare for survivors, and to develop livelihood programs that will improve survivors living standards if the need exists.

INTEGRI PROCEDAMUS

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1.5 Objectives

1.5.1 General Objective:

To assess Post- Ebola syndrome among Ebola Virus Disease survivors in Montserrado County Liberia.

1.5.2 Specific Objectives:

1) To determine the prevalence of post-Ebola syndrome among Ebola survivors in Montserrado County.
2) To determine types of post-Ebola syndrome affecting survivors
3) To determine time of onset of Post-Ebola Syndrome among survivors
4) To determine the duration of the types of symptoms among survivors.
5) To determine the socio-economic challenges of PES on survivors

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CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Epidemiology of Ebola Virus

Ebola virus is a pathogen that was initially documented in 1976 as the causal agent of hemorrhagic fevers in the Democratic Republic of Congo and Sudan. The virus is from the filoviridae family of only two members. Members of this family cause acute febrile illness that is fatal. The serotypes of each genus have distinctive features which often result in high death rate during outbreaks. The most lethal difference of these is the Ebola Zaire subtypes. Human cases arise through close contact with infected primates (Portela, 1998). With its presence in the human population, the virus spreads from human to human transmission when broken skin comes in direct contact with blood secretion, organs or other bodily fluid of infected people and surfaces contaminated by infected fluid (WHO, 2015). Below is a table showing the distribution of Ebola Virus Disease outbreak since its first occurrence in 1976 (Table 1)

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Table 1: Epidemiology of Ebola Virus Disease from 1976-2014

Year	Location	Species	Cases	Deaths	CFR
1976	South Sudan	SUDV	284	151	53.2%
1976	DRC	EBOV	318	280	88.1%
1979	South Sudan	SUDV	34	22	64.7%
1994	Gabon	EBOV	52	31	59.6%
1995	DRC	EBOV	315	250	79.4%
1996	Gabon	EBOV	60	45	75.0%
2000	Uganda	SUDV	425	224	52.7%
2001	DRC/Gabon	EBOV	122	96	78.7%
2002	DRC	EBOV	143	128	89.5%
2007	DRC	EBOV	264	187	70.8%
2007	Uganda	BDBV	149	37	24.8%
2012	Uganda	SUDV	14	7	50.0%
2012	DRC	BDBV	52	25	48.1%
2014	Guinea	EBOV	3,811	2,543	66.7%
2014	Liberia	EBOV	10,675	4,809	45%
2014	Sierra Leone	EBOV	14,124	3,956	28%
2014	Mali	EBOV	8	6	75%
2014	Nigeria	EBOV	20	8	40%
2014	Senegal	EBOV	1	0	0%
2014	Italy	EBOV	1	0	0%
2014	Spain	EBOV	1	0	0%
2014	UK	EBOV	1	0	0%
2014	USA	EBOV	4	1	25%

Data source: http://www.cdc.gov/vhf/ebola/outbreaks/history/distribution-map (WHO, 2016a)

In order to ensure effective case management of an EVD outbreak, the following pillars roles need to be defined and activated : active surveillance, adequate laboratory services, contact tracing, safe burials, community engagements and social mobilizations (WHO, 2015). There is no known therapy identified for EVD. Experimental findings may provide therapy for filovirus infection (Peters & LeDuc, 1999).

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2.2 Prevalence of Post-Ebola Syndrome

A study was conducted in Kenema District, Sierra Leone in 2014 using a convenience sampling method. Of the 81 EVD survivors involved, 50% of survivors in the study reported experiencing symptoms after discharged from an Ebola Treatment Unit (Nanyonga et al, 2016; WHO, 2016).

A cross-sectional Study involving 304 survivors in Bombali District, Sierra Leone in 2015 to enquire about health difficulties faced by EVD survivors, health complications they were suffering post EVD, the onset of these complains and co-morbid encounters. One hundred and eighty-nine survivors reported health problems upon discharge from the ETU (Nabena et al., 2016).

Survivors participating in a survey in Guinea in 2015, reported 103 of the 105 survivors experienced symptoms after their discharge from the Ebola Treatment Unit (Qureshi, 2015).

In 2015, 8 Ebola Virus Disease survivors treated in the United States were assessed for symptoms arising and treatment taken after EVD. All EVD survivors reported a symptom experienced during their recovery stage post EVD (Epstein, Wong, Kallen, & Uyeki, 2016).

A cross-sectional study was conducted in 2015 at the Military Hospital, Freetown Sierra Leone involving 44 survivors. The study aimed at recording symptoms experienced by survivors upon initial follow-up visit after 3 weeks from the ETU with negative RT-PCR result. Survivors in the study reported at least one symptom experienced after discharge from the ETU (Scott et al., 2016).

As shown by a cohort study in 1995, in Kikwit Democratic Republic of Congo with 29 EVD survivors and 152 households contacts. Two-third of survivors continued to experience symptoms during 21 months follow-up visits following EVD (Rowe et al., 1999).

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An assessment of 166 EVD survivors was conducted in Freetown, Sierra Leone at the Medicine San Frontier Ebola Survivors Clinic within four months after discharge from the ETU. This was done to describe the long–term complications of EVD and their risk factors. All EVD survivors reported experiencing health problems (Tiffany et al., 2016).

2.3 General symptoms among Ebola Survivors by human systems

2.3.1 Post- Ebola Symptoms of the Musculoskeletal System

A study by Nabena in Bombali district Sierra Leone, in 2015 shows of the 304 survivors, 189 complained of PES. More than half suffered joints pain. Widespread body pain was also reported among survivors (Nabena et al., 2016).

Recently published in 2015 in Nigeria was a paper by an EVD survivor. She stated that, upon discharge from the ETU, joint, chest and muscles pains were experienced. She further narrated that these aches continued for about six months ranging from mild to severe aches (Igonoh, 2016).

In Liberia, the ongoing study by the partnership for research of Ebola virus in Liberia has published preliminary findings after examination of 82 survivors by a team of neurologists from the National Institute of Neurological Disorders and stroke. The average age of Ebola survivors been examined was 35 years. One of the commonest symptoms recorded was muscles pain (American Academy of Neurology, 2016).

Stated from records reviewed at the Medicine San Frontier Clinic in Monrovia, Liberia, arthralgia shows to be the most constantly recorded symptom. It has been experienced by 50-70% of EVD survivors seeking care at the clinic. The commonly affected joints were in the order of occurrences: the knee, back, hips, fingers, wrists, neck, shoulders, ankles and elbows (Vetter et al., 2016).

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In Kenema district, Sierra Leone in 2015, a survey was conducted among 81 EVD survivors. As revealed by the study, all survivors experienced continuous health and social problems. Some of the most prevailing symptoms that have been observed in patient were musculoskeletal and epigastric pain (Nanyonga et al., 2016).

A total of one hundred and three Ebola virus disease survivors out of 105 participants in a study in Guinea suffered common symptoms such as joints pain, muscles pain, abdominal pain and back pain (Qureshi, 2015).

During the assessment of eight Ebola virus disease survivors treated in the United States of America, survivors were asked questions pertaining to diagnostic testing, symptoms experienced and treatment taken during the recovery stage. Symptoms reported were both mild and intense health problems that needed treatment or re-hospitalization. One of the frequently occurring symptoms were arthralgia. Among all eight survivors, only one patient had all symptoms resolved in totality (Epstein et al, 2015).

A cross-sectional study of early clinical sequelae of Ebola virus disease in Sierra Leone was done involving 603 survivors. The study describes the nature, prevalence and predictor of ocular, auditory and articular EVD sequelae among survivors. Arthralgia was reported by 74% of EVD survivors that participated in the Study. Concluding he stated, during EVD convalescence, clinical sequelae are common (Mattia et al., 2016).

A cohort study published in Uganda after the 2007 Bundibugyo EVD outbreak revealed, long-term symptoms among EVD survivors. Joints pain was one of the symptoms experienced 29 months after discharge from the ETU (Clark et al., 2015).

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A Cross-sectional study involving 44 survivors was conducted at the 34TH Military Hospital, Freetown, Sierra Leone; 27% of EVD survivors had joints pain, 34% experienced muscles pain and 9% suffered both muscles and joints pain. On the overall musculoskeletal pain was experienced by 70% of EVD survivors in the study during convalescence (Scott et al., 2016).

2.3.2 Post- Ebola Symptoms of the Neurological System

Preliminary findings have been published by the partnership for research of Ebola virus in Liberia. The findings were released after an examination of 82 EVD survivors by a team of neurologists from the National Institute of Neurological Disorders and stroke. It states that majority of survivors reported neurological irregularities. The commonest ongoing health problems were memory loss, headache, weakness and depression (NIH, 2015).

Qureshi and others in Guinea in 2015 assessing more than a hundred survivors stated EVD survivors suffered common symptoms such as insomnia, dizziness, decreased exercise intolerance and headaches. Survivors also reported psychological effects such as post-traumatic stress and depression (Qureshi et al., 2015).

An assessment of EVD survivors in the United States has shown 75% of the 8 survivors complained of psychological symptoms; to include anxiety, short-term memory loss, lethargy and insomnia. Three of the survivors complained of paresthesia while one was treated for peripheral neuropathy (Epstein et al., 2016).

While describing the nature, prevalence and predictor of ocular, auditory and articular EVD sequelae among survivors in Sierra Leone, new ocular symptoms were recorded accounting for 60% and uveitis 18%. New ocular symptoms and uveitis were jointly reported clinical manifestation. These symptoms were independently associated with higher Ebola viral load during the acute stage of EVD (Mattia et al., 2016).

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Vackey and others have discussed a patient 43 years of age who was evacuated to the United States from Kenema, Sierra Leone during the 2014 West African Ebola outbreak. The patient was discharged after forty days of treatment with a combination of experimental antiviral agent and other therapies. Three weeks after discharged, a general ocular complaint developed in a patient. By 9 weeks after patient discharge, "he developed acute hypertensive anterior uveitis in his left eye. The patient received topical and oral hypertensive agents initially but the complaint progress. The patient aqueous fluid was tested positive for Ebola virus by quantitative reverse transcriptase polymerase chain reaction (qRT-PCR)". Patient's vision improved with a combination of tropical injectable and "twenty-one-day course of experimental antiviral agent". Ocular complications have been observed in the patients especially uveitis. Persistence of EVD in aqueous humor has been identified in one patient with progressive acute hypertensive anterior uveitis (Varkey et al., 2016).

In Bombali district Sierra Leone, in 2015 a study involving 304 EVD survivors reports 189 survivors had suffered health problems of which more than half complain of eyes problem during post-discharge from an ETU (Nabena et al., 2016).

By EVD survivors participating in a cross-sectional study in Freetown, Sierra Leone, ocular problems have been suffered by 14%. Ocular symptoms were described as a pain of the eyes, blurred vision, clear discharge, and red eyes (Scott et al., 2016).

Five of the eight survivors participating in an assessment of their health status post-Ebola in the United States had complained of ocular pain, discomfort, and blurriness of the eyes (Epstein et al., 2016). Eyes problem was one of the commonest symptoms complained of among 103 Ebola virus disease survivors in Guinea in 2015. A total of one hundred and five Ebola virus disease survivors participated in the study (Qureshi, 2015).

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Ocular problems also reported from the record reviewed by Vetter at the Medicine San Frontier Clinic in Monrovia, Liberia was eyes pain, conjunctivitis, hyper-lacrimation, uveitis, and loss of visual acuity seem to be common among survivors (Vetter et al., 2016).

Eye problems have been reported by 50% of 81 EVD survivors in Kenema District, Sierra Leone in 2015 (Nanyonga et al., 2016; WHO, 2016b).

A study to ascertain long-term health problems of EVD survivors in Uganda was carried out with 49 survivors and seronegative controls. The result shows that survivors of Bundibugyo Ebola virus outbreak were at greater risk than controls for long-term health problems. One of which were ocular problems such as ocular pain and blurred vision (Clark et al., 2015).

Other studies have published reports of neurological symptoms experienced by EVD survivors after discharged from the treatment center. Studies (Nanyonga et al., 2016) report include headache, excessive fatigue, insomnia, and anxiety. Also, fatigue as stated by (Igonoh, 2016), headache and psychological problems as reported by (Nabena et al., 2016), and sleep difficulty, memory problems, loss hearing and confusion among EVD survivors after 29 months post discharge (Clark et al., 2015). Headache accounting for 48% was also reported by Scott in Sierra Leone, after conducting a cross-sectional study to determine symptoms post EVD (Scott et al., 2016).

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2.3.3 Post-Ebola Symptoms of the Integumentary System

Stated by Ada in Nigeria, along her recovery path, she experienced common desquamation of skin and hair loss. She went further to say, despite some survivors experiencing symptoms, others do not experience any. These symptoms tend to vary by patient based on the patient's immune system. (Igonoh, 2016).

Skin abnormalities were reported among 189 EVD survivors in Bombali district Sierra Leone, during a cross-sectional study following discharge from the ETU in 2015. Skin disease accounted for 13% while hair loss was reported by 4% of EVD survivors been studied (Nabena et al., 2016). A survey was done between 4-7 weeks after discharge, among 8 EVD patients who had survived EVD in the United States. Alopecia was reported by 75% of the respondents during the interviewed (Epstein et al., 2016).

As published in findings from a record reviewed at the Medicine San Frontier Clinic in Liberia, survivors have reported skin diseases such as desquamation of the skin, dryness of skin and pruritus. Sites that were affected by these symptoms were the hands and the feet. Also, alopecia has been experienced by some EVD survivors reporting at the clinic (Vetter et al., 2016).

2.3.4 Post- Ebola Symptoms of the Reproductive System

A cross-sectional study was conducted in Bombali district, Sierra Leone involving 304 participants. In the study, females constituted over half of participants in the study, 189 of the survivors interviewed had experienced a symptom after ETU discharge. Some complaints reported were menstrual irregularity and erectile dysfunction. The onset of complaints varies and was often irregular (Nabena et al., 2016).

Survey conducted among 105 Ebola virus disease survivors in Guinea stated 103 had suffered common symptoms one of which were sexual dysfunction (Qureshi et al., 2015).

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Another survey in Kenema district, Sierra Leone in 2015 reported amenorrhea as one of the symptoms experienced by EVD survivors upon discharge from the ETU (Nanyonga et al., 2016; WHO, 2016b).

2.4 Onset of Post-Ebola Syndrome

A paper has been published by an EVD survivor in Nigeria in 2015. Stated by the survivor, symptoms continued after discharge ranging from mild to severe aches. These symptoms tend to vary by the patient based on the patient's immune system. The survivor went further to say that there is no two survivor which display the same symptom (Igonoh, 2016) .

Ongoing five years study by the partnership for research of Ebola virus in Liberia has published preliminary findings after examination of 82 survivors. It has stated that the onset of health problems started at least six months after being certified disease free (NIH, 2015).

Symptoms onset among Ebola virus disease survivors treated in the United States of America were believed to have occurred between 2-4 weeks following discharge from the ETU. This was stated during interviews with survivors between 16-28 weeks after discharge (Epstein et al., 2016)

A record reviewed done in Liberia shows that PES begins often in the first few weeks after discharge and probably last for more than a year, despite the severity of symptoms which might decrease with time (Vetter et al., 2016).

During the 2014 West African Ebola Virus Disease outbreak, a doctor working in Sierra Leone became infected and was flown to the United States for treatment. The patient survived. During recovery, he was examined for PES. Symptoms developed in the patient by 10 weeks following discharge (Varkey et al., 2016).

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A cross-sectional study in Bombali district, Sierra Leone involving 304 EVD survivors also published its findings. It shows that majority of Ebola Virus Disease survivors start to experienced health problems between 1-4 weeks post-discharge from an ETU (Nabena et al., 2016).

2.5 Duration of Post-Ebola Syndrome

Forty-nine survivors were contacted 29 months after the EVD outbreak in Uganda. The study also included seronegative controls. These survivors provided information about their health status and capability to function, also blood samples were obtained for further study. The result shows that survivors of Bundibugyo Ebola virus infection outbreak were at greater risk than controls for long-term health problems (Clark et al., 2015).

The Ebola virus Disease can display systemic infections that tend to persist long in the survivor after patient have been diagnosed negative. Evident were other viral infections, 10% joints pain recorded between 3-5 years following chikungunya and 29% hearing loss following Lassa fever outbreak (Racaniello, 2016).

Reported of long-term symptoms by a cohort study involving 29 EVD survivors and 152 contacts. They were followed up to determine whether their body fluid contains a positive strain of EVD and secondary transmission do occur during post-discharge symptoms. It shows survivors experienced symptoms up to 6 and 21 months of follow-up visits (Rowe et al., 1999).

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2.6 Economic Challenges

The Liberia Institute for Statistics and Geo-Information Services has published the report from it 2014 Households Income and Expenditure Survey. The paper revealed the unemployment rates nationally to be 3%. Also, 77% of the head count were involved in agriculture activities while 41% were wage employees and 38% were self-employed (LISGIS, 2016).

Stated by a World Bank Group in a report tittled Ebola Virus Disease, from Crisis to More Résilient Heath System, the economic cost of the Country had dropped from 5% prior to the EVD outbreak to 2% in 2014 (Marquez, 2016).

2.7 Social Challenges

In 1998 a survey of Ebola survivor's feelings and experiences in Kikwit, Democratic Republic of Congo was conducted. A total of 34 survivors were interviewed. Women survivors who participated in the survey constituted 76%. Twelve participating survivors were hospital staff. Sixteen of the survivors were married. The onset of EVD was immediately suspected by 32% of survivors. Initial feelings were fear of falling seriously ill (50%), denial (47%), shame (15%), and fear of being accused by neighbors (21%). Survivors participating in the survey that received support from the medical staff were 85%. After Ebola, during the recovery period about 35% of survivors felt rejected by either a friend, family member or neighbor. Eighteen of survivors reported having no money during sickness. No psychological effect from EVD was reported among 39% of survivors, but intensify grief was experienced by family members who relatives did not survive the epidemic (De Roo et al., 1998).

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A study was done in Northern Uganda in 2003, It aim was to look at the cultural context of Ebola. Survivors reported being stigmatized more than 1 month after discharged from the hospital. This was because survivors were still experiencing other health problems such as fatigue, leg pains and vision problems. The majority of survivors reported intense stigmatization. Survivors were banned from returning home, while some were abandoned by their spouses. Women experienced (82%) higher level of stigma compare to men (Barry & Amola, 2003).

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CHAPTER THREE

3.0 METHODS

3.1 Study design

The research was a cross-sectional study that employed both quantitative and qualitative research methods. A quantitative method was used to collect data on the types of PES, and to calculate the estimated prevalence, onset, and duration of Post-Ebola Syndrome. Also, the qualitative method was used to collect data on the socio-economic challenges survivors of PES faced.

3.2 Study area

The study was done in Montserrado County. Montserrado County is one of the fifteen counties in Libera. It hosts the County's capital Monrovia. Montserrado County is made up of urban Monrovia, greater Monrovia, and rural Montserrado. It has seven health districts namely: Careysburg, Bushrod Island, Somalia Drive, St. Paul, Central Monrovia, Todee and Common wealth districts. (Figure 2)

Map of the Study Area

Figure 2: Map of the Health district in Montserrado County, Liberia 2016

Source: WHO, 2016

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3.3 Variables

3.3.1 Dependent Variable:

Post-Ebola Syndrome – The kind of health problems EVD survivor remembered suffering from the first week of discharge to interview date.

3.3.2 Independent Variables:

1. Age- any EVD survivor selected as a participant who is ≥18years.
2. Sex- Female & Male
3. Employment status- any EVD survivor who is earning ≥$100.00 Liberian dollars daily, weekly, or monthly during post-EVD recovery
4. Duration of symptoms- the number of months PES lasted in EVD survivor after discharge from an ETU.
5. The length of stay in the ETU- the total days, weeks, or months an EVD survivor spend in the ETU from the date of admission to date of discharge.
6. Marital status- An EVD survivor who is either single, married, divorced, widow/ widower
7. Residence- An EVD survivor who lives in one of the seven health districts in Montserrado County (Somalia Drive, Commonwealth, Central Monrovia, Bushrod Island, St. Paul, Careysburg and Todee Districts)
8. Social challenges- An EVD survivor who was stigmatized by husband, wife, family members, employer, or community. Also, an EVD survivors experiencing gender-specific health problems during post-ebola recovery.
9. Economic challenges- an EVD survivor who is not able to work due to PES or stigmatization by an employer, friends or community.
10. The number of symptoms- a total number of symptoms reported by an EVD survivor from the first week of discharge to interview date.

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11. The onset of PES- The start month of symptoms EVD survivor experienced upon discharge from an ETU.

3.4 Study population

The study population was Ebola Virus Disease Survivors recorded in Montserrado County from the beginning of the outbreak May 2014- March 2015. The population of EVD survivors in Montserrado County accounts for 58% of EVD survivors in Liberia.

3.5 Sampling

3.5.1. Sample Size Determination

The sample size (n) was 250 survivors. To get the sample size for the study, stat calculator in Epi info was used with a population of 712 survivors line-listed by MOH, at a 50% prevalence, a significance level of 5% and a 10% rate for non-responses. However, during pretest of the study tool, one in every five survivors could not provide accurate answers to all the questions been asked. We further increased the non-response rate to 20%. Thereby giving us a sample size of 300. The estimated 50% prevalence used in this study was reported in Sequele of Ebola Virus Disease, Kenema Sierra Leone in 2015 by Nanyonga.

3.5.2 Inclusion criteria :

1. All Ebola survivors ≥18years of age
2. EVD survivor should be a resident of one of the seven health districts in Montserrado County
3. All EVD survivors providing a photocopy or original discharge certificate
4. All EVD survivors with a membership card of the Survivors network, Liberia.
5. An EVD survivor that consented to be a part of the study

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3.5.3 Exclusion criteria :

1. All Ebola survivor <18 years of age
2. EVD survivor who is not a resident of one of the seven health districts in Montserrado County
3. Any EVD survivor who did not have an original or photocopy of the discharge certificate.
4. Any EVD survivor that could not provide an identification card of the survivor network
5. EVD survivors that refuse to be a part of the study by not signing the consent form

3.6 Sampling Method

3.6.1 Quantitative Sampling Method

A stratified sampling method was used. Survivors in Montserrado County who met the inclusion criteria for the study was stratified by the seven health districts. To get a true representation of EVD survivors ≥18 years in each health districts needed for the interview, the population of survivors proportionate to size for each health district was calculated as follow. (Table 2)

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Table 2: Distribution of Ebola Survivors proportionate to the size of Health Districts in Montserrado County

Health Districts in Montserrado	Number of Survivors ≥18 yrs. in each health district	Percentage of survivors in each health district	Number of survivors ≥18 yrs. in each health district needed for the interview
Bushrod Island	216	30.34%	81
Central Monrovia	78	10.96%	29
Commonwealth	164	23.03%	62
Somalia drive	164	23.03%	62
St. Paul	71	9.97%	27
Careysburg	16	2.25%	6
Todee	3	0.42%	1
Total	**712**	**100%**	**268**

After which,

1) We listed all survivors in Montserrado County according to the 7 health districts in the County placing each survivor under their specific health district of residence.
2) Seven separate lists of EVD survivors were developed
3) Each list recorded the total survivors in each of the 7 health districts in Montserrado County.
4) We further used a simple random techniques with a random number table to randomly pick our study participants.
5) Each numeral on the random number table had five digits of which the last two digits of each picked number was taken.
6) We looked for the picked number obtained from the random number table on the list of survivors for a particular health district.

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7) The name, address and telephone number been represented by the picked number from the random number table were written on a separate sheet as a participant for the study from the particular health district.
8) Continuously performing this method one at a time, we did for each health district until our sample size for the study was achieved.
9) A number was replaced in a situation where the random two digits picked was above the listed survivors in a particular health district.

3.6.2. Qualitative Sampling Method

Participants were selected for the qualitative survey from the five health districts with the highest number of survivors. We used a purposive sampling technique in which, we attended two weekly meetings of each of the five health districts during which time we randomly selected participants for the discussion. Age categories for the discussion were, adolescent females and males age 18-35 years and adult males and females 36 years and above. Also after the selection of participants, we held meetings with survivors at which time we discuss a convenient place, date and time for each discussion. Each focus group discussions consisted of eight participants. Four participants of Central Monrovia merged with 4 participants of St. Paul district for the discussion. The focus group discussions in Bushrod Island consisted of females 18-35 years of age while, the merged St. Paul and Central Monrovia districts FGD consisted of females 36 years and above. Male 18-35 years of age FGD was conducted in Somalia Drive District and males 36 years and above FGD was carry out in Commonwealth district. (Figure 3)

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Table 3 Distribution of Focus group participants by health Districts, Montserrado County, Liberia 2015-2016

Health Districts in Montserrado	EVD Survivors ≥18 yrs. needed for the FGD
Bushrod Island	8
Central Monrovia	4
Commonwealth	8
Somalia Drive	8
St. Paul	4
Total	32

3.7 Data collection techniques

Prior to the selection of participants to partake in the study, the principal researcher met with the national coordinator, president, sector heads and sector supervisors of Ebola Survivors Network in Liberia. This meeting was organized to explain the study, its importance, and the process through which participants were to be selected to take part in the study. After which, the recruitment process of participants for the study was conducted from November- December 2015. Data collection began in January 2016 and continued until April 2015. During which time participants of the study were visited at their homes, clinics and market places in communities around Montserrado County. Data were collected through interviews with Ebola survivors using a semi- structured questionnaire to determine the prevalence of Post-Ebola syndrome among Ebola virus disease survivors in Montserrado County. The questionnaire was used to record survivors demographic information, individual Ebola history, and pre and post-Ebola medical history.

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A total of four focus group discussions were conducted to determine the socio-economic challenges of Post-Ebola syndrome on survivors. The focus group discussions were done at a convenient location in four of the health districts. Firstly, the study team went through a formal introduction with participants. After which, ground rules for the focus group discussion were read to the participants. Prior to commencing discussions, survivors were informed that discussions were going to be recorded, notes were written and pictures were taken. All survivors participating in the discussion were asked to sign a consent form. After which a unique identification number was given to each discussant. A psycho-social counselor briefly talked to survivors, encouraging them to fully participate and minimize the wave of trauma, sadness, and emotions it caused them by participating in the discussion. Survivors were asked to think through a recall period of 12 months beginning March 2014-March 2015.

3.7.1 Quantitative data Collection

Upon completion of the meeting with Ebola survivors, the interview with participants began. Using the selected names, address and telephone number bearing the picked last two digits from the specific sampling frame, participants were called via mobile phone prior to the team visit. This was done to maximize time and cost. Three teams consisting of two members each, a research assistant, psycho-social counselor and a social mobilizer from the survivors network located survivors at their homes in communities around Montserrado County. Those not seen at their homes were visited at the clinic or market places. Before the commencement of interviews, Informed consent was signed by each participant and principal investigator or research assistant. Each interview lasted a maximum of 20-25 minutes.

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3.7.2 Qualitative data collection

The principal researcher conducted focus group discussion with Ebola survivors in Montserrado County using an interview guide. A total of four (4) focus group discussions were conducted. Each discussion consisted of 8 participants. Eight adolescents male between the ages 18-35 years and 8 adolescents female between the ages 18-35 years. Also 8 adult females of ages >35 years and 8 adults males of ages >35 years. Each focus group discussion lasted a maximum of 2 hours 30 minutes. A team of three members comprising of a moderator, note taker, and psycho-social counselor were used to collect data during the focus group discussions. Survivors were asked one at a time to call their unique identification numbers and explain their experienced from the onset of EVD which entails contacting infection, seeking treatment, admission to the ETU , how did their community, employers and family received them following discharge from an ETU, and whether there were health problems experienced by post-Ebola recovery. Also, they were asked about their past and present jobs, if survivors were not earning anything how were they coping, whether they have access health care upon discharge, if yes how and where have they accessed health care. These were to evaluate the socio-economic challenges of post-Ebola syndrome on survivors.

3.8 Ethical consideration

The study protocol and instruments were approved by the University of Liberia Pacific Institute of Research & Evaluation International Review Board Monrovia, Liberia 00004982. A total of five meetings were conducted with Ebola Survivor Network. The first meeting was with officials and the national coordinator of Ebola Survivors Network. The other four meetings were done in four sectors of Montserrado County. This was done to explain the objectives and method of the study before participation of survivors. A written informed consent by each participant was signed to ensure willingness, privacy, and confidentiality of information.

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In a situation where there were an illiterate/incapacitated survivors an ink pad was provided in order to gain consent.

3.9 Training of Research Assistants

The collection of data was done within a three-month period, January-April 2016. Prior to the beginning of the study, five research assistants who met the criteria during recruitment of research assistants were hired and trained. Of the five research assistants hired, two assisted the principal researcher during the focus group discussion by performing the following roles as a note taker and a psycho-social counselor.

3.10 Pretesting

Pre-testing of the data collection instrument was carried out in two randomly selected communities involving 30 participants. Communities were in Margibi County, specifically Boys Town and Dolo's Town communities. In Dolo's Town, an interpreter of the Town helped some participants to understand questions been asked. The maximum time reached to complete a questionnaire was 45 minutes. While in Boys Town community, the maximum time it took to complete a questionnaire was 35 minutes. After the pretest, questions number two, five, seven and fifteen were refined.

3.11 Data Quality Control

3.11.1 Quantitative Data Quality Control

The research assistants were trained to administer the questionnaires. Education was also provided for research assistants on how to probe further for open-ended questions during interviews. The principal researcher checked all questionnaire at the close of the day to counter-check completeness of questionnaire.The researcher also conducted review meetings three times a week with research assistants. This was to discuss difficulties experienced in the day and issues raised by participants.

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3.11.2 Qualitative Data Quality Control

After the interviews, field notes were inserted into the relevant sections of the transcription and further linked to the relevant respondent(s), where applicable. We reviewed the transcribed data for accuracy and/or completeness.

3.12 Data Entry Processing

3.12.1 Quantitative Data Entry Processing

A new file was open in SPSS version 23 field. A form was created where questions from the questionnaire were typed, variables were sorted and coded, and value labels were given to variables with multiple responses. Data was entered, saved and analyzed in SPSS version 23 field.

3.12.2 Qualitative Data Entry & Processing

The focus group discussion recordings done were played continuously and transcribed. Transcriptions were compared with notes taken. Transcripts were grouped into themes and responses based on the category of questions. Thematic codes were developed based on focus group topic guide. Responses to questions under each theme were further grouped into options of range 2-6. From the narratives, recurrent statements and responses were typed and analyzed by percentages using excel 3.0 software.

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3.13 Data Analysis

3.13.1 Quantitative Data Analysis

The characteristics of study participants were explained through descriptive statistics.

Demographic variables that were continuous, were measured using the median and mode.

Prevalence of PES by demographic variables was presented in composite tables by proportions.

Graph depicting the prevalence of PES among EVD survivors by residence (health districts)

Composite table showing types, frequency and percentages distribution of individual symptoms participants experienced to include: chest pain, muscles pain, eyes problems, abdominal pain, joints pain, unusual tiredness, headache etc.

Graphs depicting the onset and duration of PES from 1-3, 4-6, 9-10 and 10-12 months by systems of the human body.

Bar charts showing the number of PES experienced among EVD survivors

Multiple logistic regression model presented to show risk factors of PES by independent variables (sex, age, employment status, the length of stay, and educational level) at a 95% confidence interval and a p-value of <0.05.

3.13.2 Qualitative Data Analysis

A total of 6 themes were generated to include; Experienced of EVD, Socio-challenges faced by EVD survivors, coping mechanisms adapted by EVD survivors, sex-related challenges of PES among EVD survivors, economic challenges of PES among EVD survivors, Accessibility of health care provided to EVD survivors post discharge. Also, direct quotes were written with references made to their specific speakers.

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CHAPTER FOUR

4.0 RESULTS

4.1 Characteristics of Respondents

Sixty- three percent (190/300) of the study participants were females. For the 262 respondents who could recall their ages during the interview, their ages ranged from 18-70 years with a median of 30 years and a modal age of 34 years. While during the focus group discussion, the ages range was 18-53 years with a median age of 36 years and the modal age was 28 years. Most of the participating EVD survivors in the study were single accounting for 61% (182/300), followed by married survivors accounting for 27% (81/300). Of the total participating survivors, 56% (168/300) were not employed, 44% (132/300) were employed. Also of all respondents who stated their occupations, business people accounted for 28% (84/300), followed by students with 18% (54/300). (Figure 4)

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Table 4: Distribution of socio-demographic characteristics of all participating EVD survivors in the study in Montserrado County, Liberia, 2015-2016

Variables	Frequency N=300	Proportion (%)
Age Categories (years)		
18-24	52	17.3
25-34	101	33.7
35-44	97	32.3
45-54	38	12.7
55-64	5	1.7
>65	1	0.3
Unknown*	6	2
Sex		
Male	110	36.6
Female	190	63.3
Marital status		
Single	182	61
Married	81	27
Divorced	4	1
Widower & Widow	33	11
Employment status		
Employed	132	44
Unemployed	168	56

(*) Unknown depict survivors who could not recall their ages during the interview.

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4.2 Prevalence of PES among EVD survivors in Montserrado County, Liberia, 2015-2016

Of all respondents, 8.7% (26/300) had never experienced PES. The remaining 91.3% (274/300) complained of at least having experienced a health problem.

a. Overall, the prevalence of PES was higher among divorced and widowed respondents than among single and married participants. The prevalence of PES among survivors was 1.5% (4/274) and 12% (32/274) respectively for divorced and widowed whilst it was 60% (167/274) and 26% (71/81) among single and married respondents respectively. Also, the prevalence of PES among EVD survivors that were unemployed was high accounting for 53% (145/274). Females experienced PES more indicating 65% (178/274) compare to their male counterparts. It was observed that PES occurred mainly in the adult population between ages 25-34 years 34% (93/274) and 35-44 years 33% (90/274). (Figure 5).

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Table 5: Prevalence of PES among EVD survivors by age, sex, marital and employment status in Montserrado County, Liberia 2015-2016

Variables	Post-Ebola Syndrome			
	Yes (N=274)		No (N=26)	
	(n)	(%)	(n)	(%)
Age Categories (years)				
18-24	45	16	7	27
25-34	93	34	8	31
35-44	90	33	7	27
45-54	35	13	3	12
≥55	5	1.8	1	3.8
Unknown ages	6	2.2		
Sex				
Male	96	35	14	54
Female	178	65	12	46
Marital status				
Single	167	60	15	58
Married	71	26	10	38
Divorced	4	1.5		
Widower/Widow	32	12	1	3.8
Employment status				
Employed	129	47	6	23
Unemployed	145	53	20	77

*yes (EVD survivors having PES)*no (EVD survivors who did not report having PES), n= number of people

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4.2.2. Prevalence of PES by health districts in Montserrado County, Liberia 2015-2016

Prevalence of PES among EVD survivors by health districts in Montserrado County ranged from 0.4% (1/274) in Todee District, St. Paul 3.6% (10/274), Central Monrovia 12.4% (34/274), Commonwealth 24.1% (66/274), Somalia 26.6% (73/274) and 32.8% (90/274) in Bushrod District. (Figure 3)

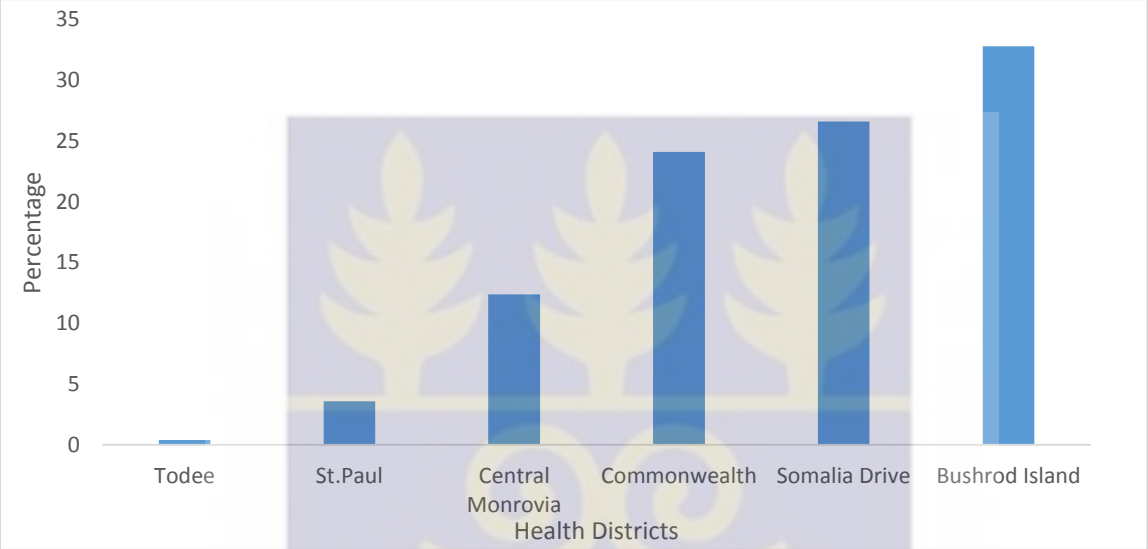

Figure 3: Prevalence of PES among EVD survivors in Health district in Montserrado County, Liberia 2015-2016

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4.3 The Types of PES among EVD survivors in Montserrado County in 2015-2016

The commonest symptoms observed among respondents with PES were joint pains (59%), headache (51%), eyes problem (44 %), muscles pain (32.8%) and unusual tiredness (25.7%).The least symptoms observed were depression (14.9%) and anxiety (17.2%) (Table 6)

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Table 6: Types of PES reported among respondents in Montserrado County, Liberia 2015-2016

PES	Frequency	Proportion
Chest pain	58	**21.6**
	203	75.7
Muscles Pain	88	**32.8**
	177	66
Eyes Problems	118	**44.0**
	146	54.5
Abdominal Pain	61	**22.8**
	201	75
Testis Pain	13	16.2*
	67	83.7
Joints Pain	158	**59**
	107	39.9
Menstrual Problems	32	19.7*
	130	80
Unusual Tiredness	69	**25.7**
	196	73
Itching of Skin	40	14.9
	224	83.6
Peeling of the Skin	47	17.5
	215	80.2
Anxiety	46	17.2
	215	80.2
Depression	40	14.9
	221	82.5
Sleep Disorder	57	**21.3**
	205	76.5
Headache	136	**50.7**
	130	48.5
Others	186	68

"Others" represent symptoms other than the 14 listed above while includes Absentmindedness, hair loss, generalized body pain, back aches, swollen feet, diabetes, hemorrhoids, ear pain, hearing loss, erectile dysfunction, heart palpitation, frequent fever, numbness of feet, liver and heart problems. (*) Percentage calculated using only denominator of relevant sex. Symptoms not averaging up to 268 survivors interviewed accounts for survivors with no PES.

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4.3.1. Types of other symptoms EVD survivors experienced in Montserrado County, Liberia 2015-2016

At total of 68% (186/274) EVD survivors with PES reported experiencing symptoms other than the 14 commonest symptoms identified. These other symptoms included hair loss 11.3 % (21/186), absent-mindedness 5.4% (10/186), and loss of appetite 2% (4/186) while others were recorded below 1%. (Figure 4)

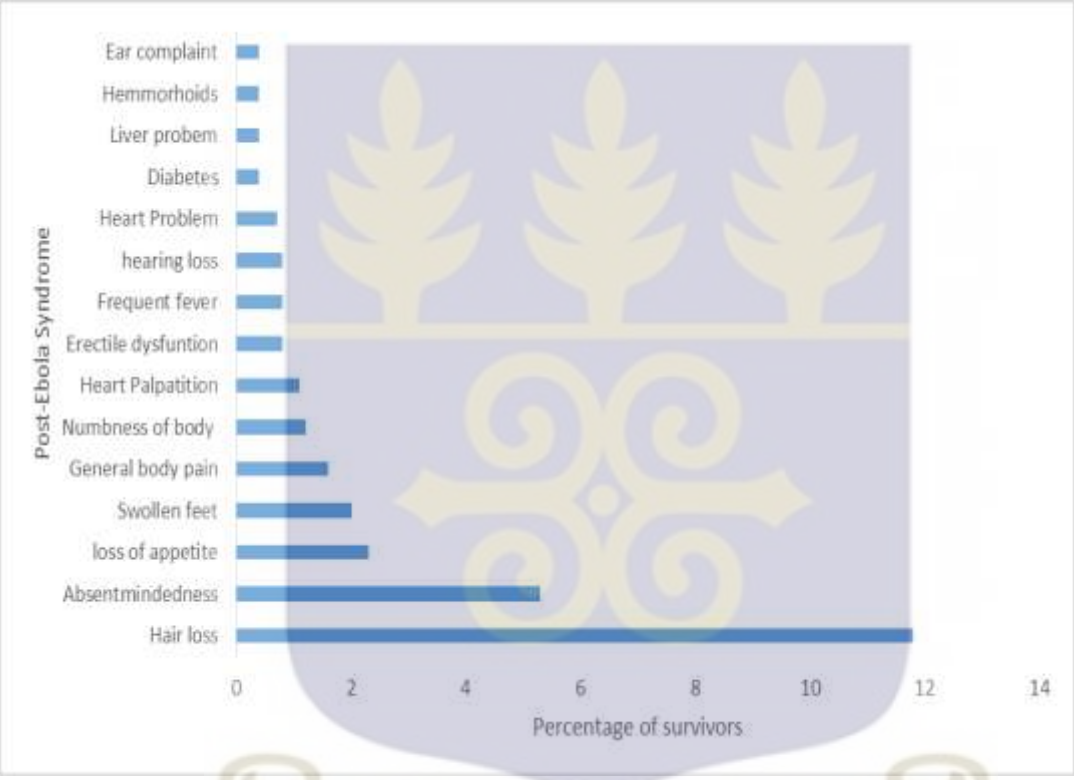

Figure 4: Distribution of other symptoms EVD survivors experienced in Montserrado County, Liberia 2015-2016.

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4.3.2. The number of symptoms experienced by EVD survivors in Montserrado County, Liberia 2015-2016.

Among the 274 EVD survivors who had experienced symptoms, 18% (49/274), had experienced a single symptom, 64% (175/274) had experienced between 2-6 symptoms, while 18% (50/274) reported having experienced more than six symptoms. (Figure 5)

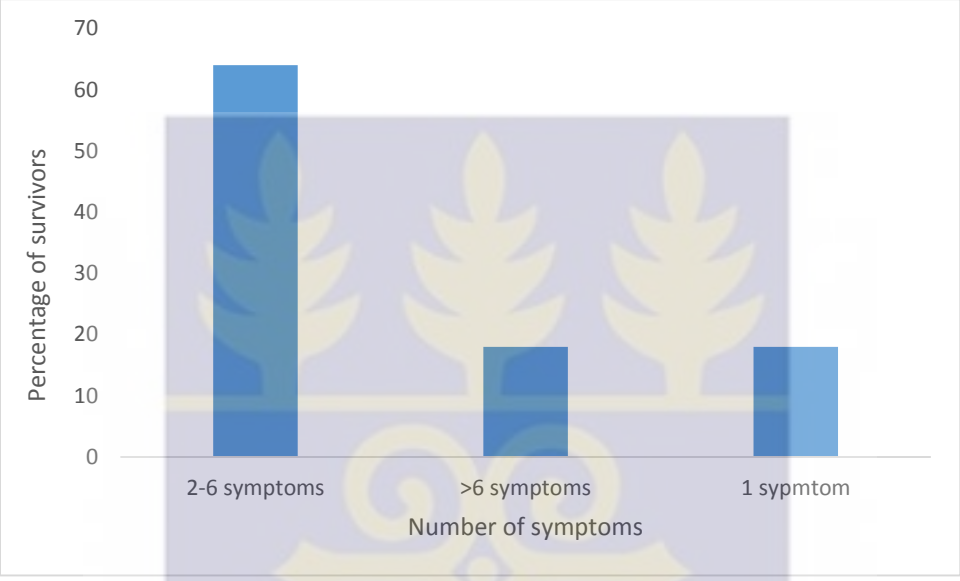

Figure 5: Number of symptoms experienced by EVD survivors in Montserrado County, Liberia 2015-2016

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4.4.1 The Onset of PES of the Musculoskeletal System among EVD survivors in Montserrado County, Liberia 2015-2016

Within the first 3 months of recovery from EVD, the majority of survivors started experiencing musculoskeletal symptoms such as joint pain 76%, abdominal pain 73%, muscles pain 72%, and chest pain 69%. In the second quarter of the year 4-6 months, joints pain were reported by 6% of survivors, abdominal pain 5%, and muscles pain 4%. During the third quarter of the year 7-9 months, abdominal pain accounted for 10%, chest pain 9%, joints pain 8% and muscles pain 7%. As reported in the last quarter of the year 10-12 months less than 5% of cases were reported for each symptom. (Figure 6)

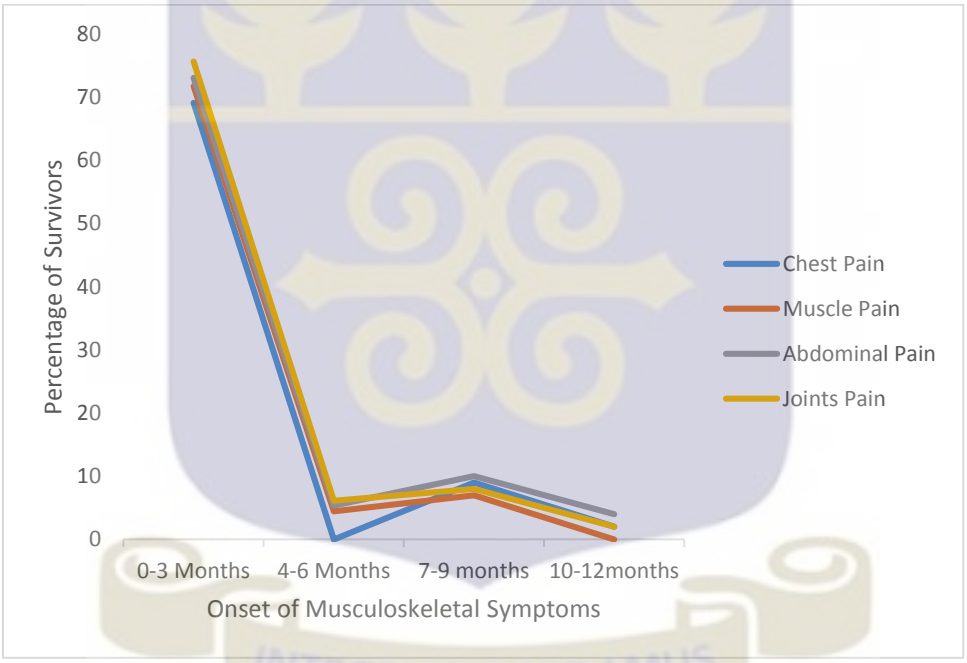

Figure 6: Onset of PES of the Musculoskeletal System among EVD Survivors in Montserrado County, Liberia, 2015-2016

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4.4.2 The Onset of PES of the Neurological System among EVD survivors in Montserrado County, Liberia 2015-2016

During the first 3 months of recovery from EVD, majority of EVD survivors had reported experiencing a wide range of neurological problems consisting of sleep disorder 88%, headache 82%, unusual tiredness 80%, anxiety 78%, eyes problems 76% and depression 74%. By the second quarter 4-6 months less number of survivors reported neurological symptoms sleep disorder 16%, headache 14%, unusual tiredness 12%, anxiety 11%, and depression accounting for 5% of survivors. Between the 7-12 months, less than 10% of survivors complained of neurological symptoms. (Figure 7)

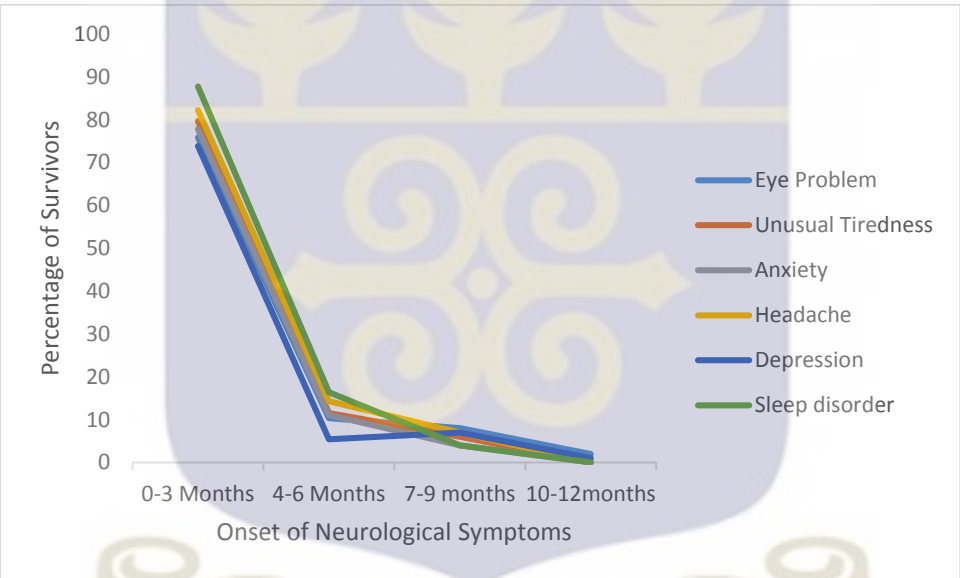

Figure 7: Onset of PES of the Neurological System among EVD Survivors in Montserrado County, Liberia, 2015-2016

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4.4.3 The Onset of PES of the Reproductive System among EVD survivors in Montserrado County, Liberia 2015-2016

Testes pain was reported by 78% of survivors during the first 3 months post discharge, 11% of male survivors complained of testes pain between 4-6 and 7-9 months each and by 10-12 months 6% reported experiencing testes pain. While females survivors accounting for 91% reported menstrual problems during 1-3 months, 18% reported problems by 4-6 months, 9% by 7-9 months and less than 5% by 10-12 months. These menstrual problems include menstrual irregularities and cessation. (Figure 8)

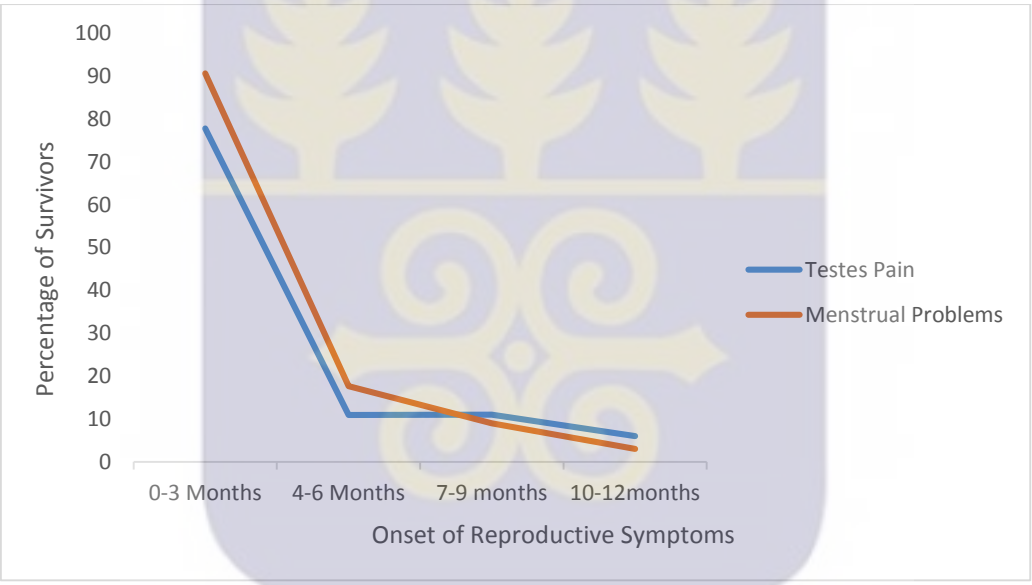

Figure 8 : Onset of PES of the Reproductive System among EVD survivors in Montserrado County, Liberia, 2015-2016

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4.4.4. The Onset of PES of the Integumentary System among EVD survivors in Montserrado County, Liberia 2015-2016

Itching of the skin and peeling of the skin were reported by 84% and 91% of survivors between 1-3 months respectively, 16% and 19% by 4-6 months, 11% and 2% 7-9 months while 5% of survivors complained of itching of skin by 10-12 months. (Figure 9)

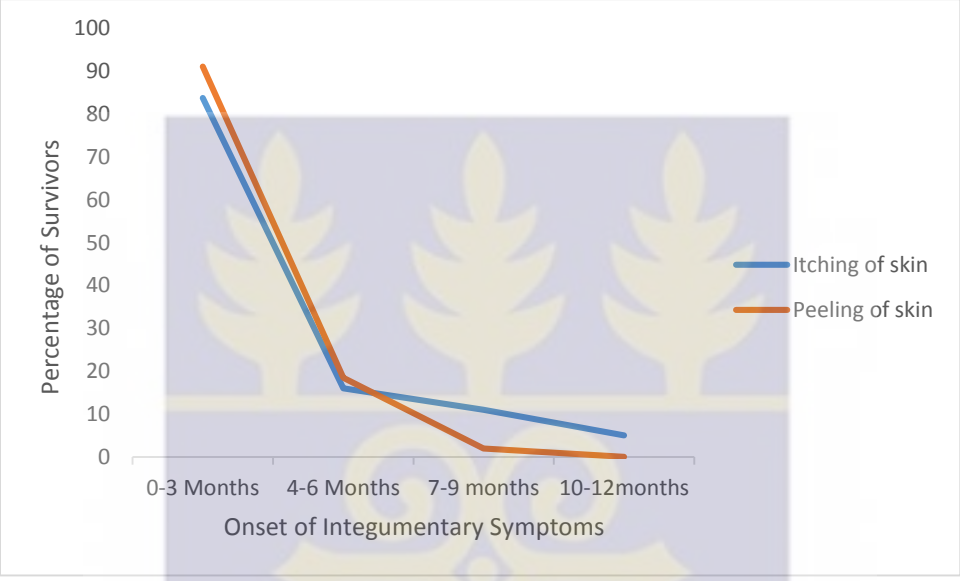

Figure 9: Onset of PES of the Integumentary System among EVD survivors in Montserrado County, Liberia, 2015-2016

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4.5.1 Duration of PES of the Musculoskeletal System among EVD survivors in Montserrado County 2015-2016

EVD survivors experienced symptoms of the musculoskeletal system with duration of 12 months. EVD survivors 54% reported chest pain to have lasted for 3 months periods. Less than 15% of survivors chest pain ended between 4-9 months while 23 % of survivors said chest pain persisted 12 months. Abdominal pain was reported by 40% of survivors to have lasted for a 3 month period followed by less than 15% of survivors who stated abdominal pain ended by the 9 month and 32% with duration up to 12 months. Muscle pain was reported by 40% of survivors to have ended by 3 months while 33% reported symptom persist up to 12 months. Joint pain 19% was reported to have ended by 3 months and 39% complained of joints pain up to 12 months. (Figure10)

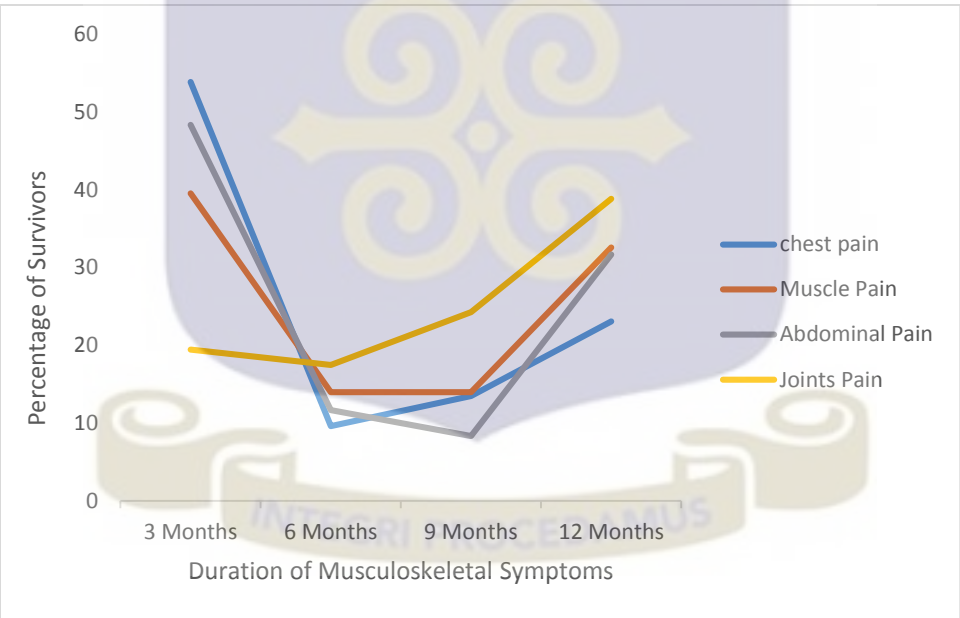

Figure 10: Duration of PES of the Musculoskeletal System among EVD survivors in Montserrado County, Liberia 2015-2016

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4.5.2. The Duration of PES of the Neurological system among EVD survivors in Montserrado County 2015-2016

Number of Survivors with symptoms of the neurological system reported to have ended by 3 months is as follow; anxiety 41%, depression 39%, eyes problem 34%, headache 28%, unusual tiredness 24% and sleep disorder 21%. While less than 35 % reported symptoms to have ended between 4-9 months and majority accounting for unusual tiredness 61%, headache 57%, sleep disorder 47%, eyes problem 46 %, depression 39% and anxiety 13% to have persisted up to 12 months. (Figure 11)

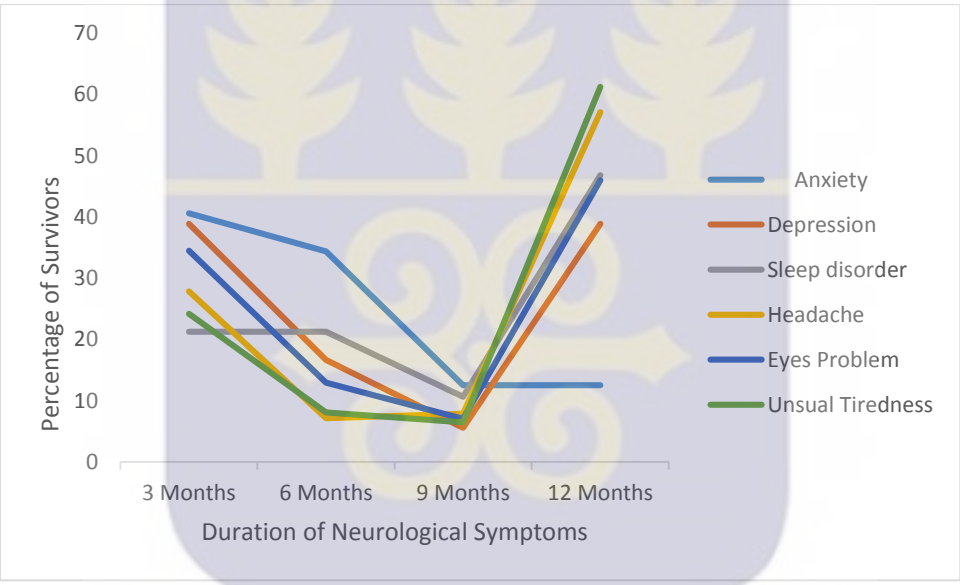

Figure 11: Duration of PES of the Neurological System among EVD survivors in Montserrado County, Liberia 2015-2016

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4.5.3. The Duration of PES of the Reproductive system among EVD survivors in Montserrado County 2015-2016

Symptoms of the reproductive system reported by survivors, recorded few cases that ended within 3 months and this accounted for testes pain 19%, and menstrual problems 25%. By 6 months during recovery 29% of testes pain cases and menstrual problems, 13% was reported to have ended. While a higher number of survivors, testes pain 34% and menstrual problems 53% were stated to have ended by the 9 months post discharge. For each symptom testes pain and menstrual problems, less than 20% of survivors stated experiencing symptoms up to the 12 months post discharge. (Figure 12)

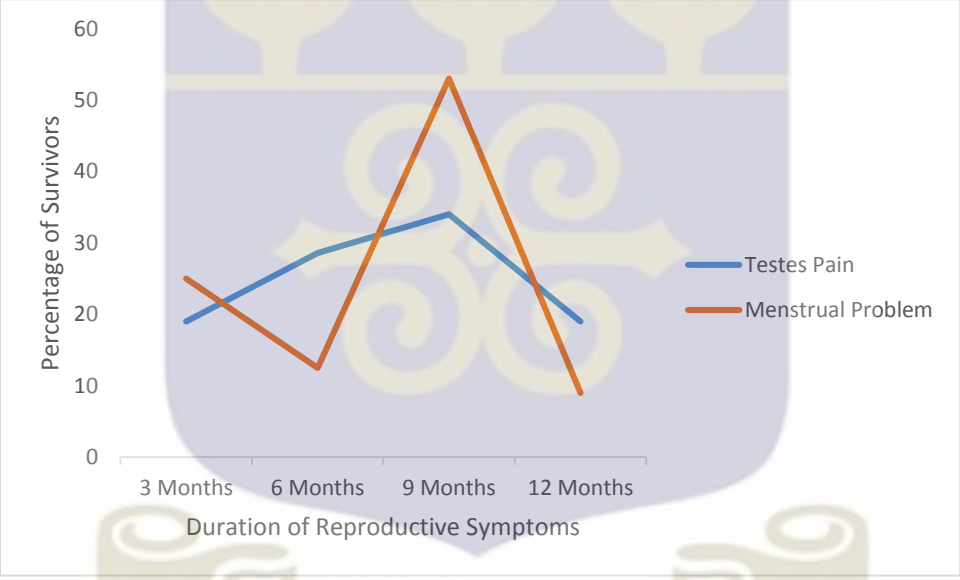

Figure 12: Duration of PES of the Reproductive System among EVD survivors in Montserrado County, Liberia 2015-2016

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4.5.4. The Duration of PES of the Integumentary system among EVD survivors in Montserrado County 2015-2016

Skin problems reported such as itching of the skin (56%), and peeling of the skin (84%) were seen to have ended by the 3rd month among EVD survivors after discharge. Less than 15% of survivors reported skin problems between 4-6 months. And persisted up to 12 months accounting for 22% itching skin and peeling skin (2%). (Figure 12)

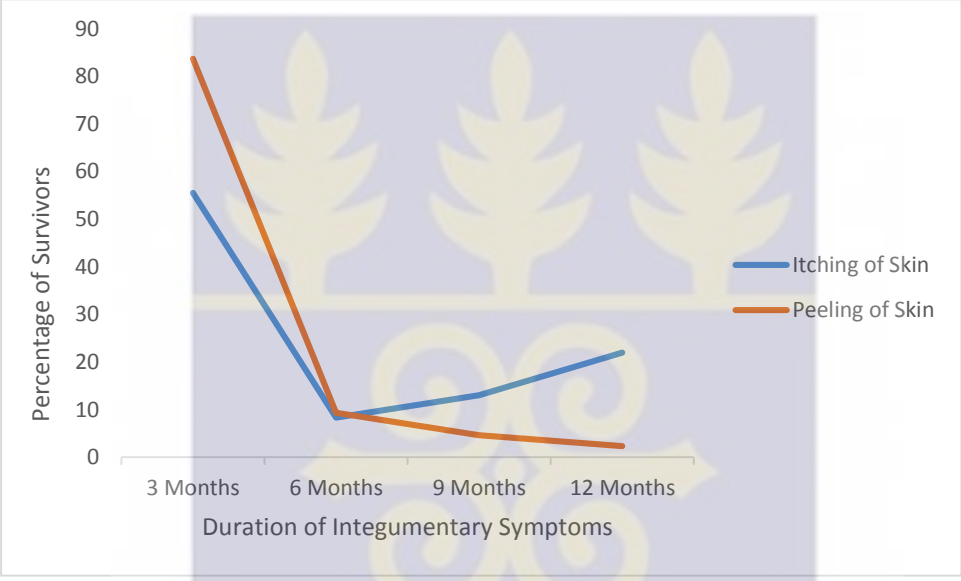

Figure 13: Duration of PES of the Integumentary System among EVD survivors in Montserrado County, Liberia 2015-2016

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4.6 Risk factors of Post-Ebola Syndrome among EVD survivors in Montserrado County, Liberia 2015-2016

We also determined the risk factors associated with PES. Using the adjusted odd ratio as the reference we observed there was no variable that was significantly associated with PES. Notwithstanding, among respondents interviewed of who stated been educated, they were 1.74 times more likely to report PES than uneducated respondents (AOR=1.74, [CI=0.58-5.15], p-value >0.05). Respondents with age between 35-70 years were 0.52 times less likely to experienced PES compare to respondents 18-34 years (AOR=0.52, [CI=0.20-1.34], p-value >0.05). Survivors interviewed having a short length of stay in an ETU (<2 weeks) were 0.62 times less likely to complained of PES than survivors who stay for a long time in an ETU (AOR=0.62, [CI=0.25 – 1.51], p-value > 0.05). Male respondents were 0.09 times less likely to experienced PES compare to female counter parts (AOR=0.45, [CI=0.18 -1.12], p-value >0.05). Participants interviewed who stated been employed were 2.42 times more likely to report PES than those unemployed participants (AOR=2.42, [CI=0.88-6.65], p-value >0.05). (Figure 7)

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Table 7: Binary Logistic Regression model depicting risk factors of PES among survivors

Independent Variables	N	Unadjusted OR	95% CI	P-value (0.05)	Adjusted OR	95% CI	P-value (0.05)
Employment Status							
No	268	1.000			1.000		
Yes		1.911	0.770-4.743	0.155	2.415	0.877-6.650	0.090
Age (years)							
18-34	262	1.000			1.000		
35-70		0.800	0.350-1.828	0.595	0.516	0.199 – 1.337	0.173
Length of stay in ETU							
Long	250	1.000			1.000		
Short		0.637	0.264-1.537	0.312	0.613	0.250 – 1.505	0.286
Sex							
Female	268	1.000			1.000		
Male		0.423	0.186-0.966	0.035	0.447	0.178 – 1.124	0.090
Education							
No	266	1.000			1.000		
Yes		1.334	0.506-3.531	0.557	1.735	0.584 -5.153	0.321

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4.7 Socio-Economic challenges of PES among EVD survivors

Theme 1: Experience of EVD

Contracting EVD

Fifty-six percent (18/32) of discussants had contracted the virus from a family member (mother, father, sister, brother, wife, husband, cousin, daughter, aunt, in-laws, and uncle).While, 31.3% (10/32) of survivors got infected from a neighbor or friend and 12.5% (4/32) didn't remember how they got infected. (Table 8)

Table 8: Distribution of responses from EVD survivors of their EVD experiences in Montserrado County, Liberia, 2015

Categories	Recurrent statements	Total Respondents (n=32)	Percentage (%)
Seeking care during illness	Self-Reporting	13	40.6
	Community or household member reporting	19	59.9
Total		32	100

Theme 2: Social challenges among EVD survivors upon discharge from the ETU

Reception from Family upon return from the ETU

Upon return from the ETU, sixty-two percent (20/32) of respondents said a majority of family members happily welcome them, nine percent (3/32) said they received distant love, they were confined to a room with all necessary things and no visitations from others except telephone calls. Other survivors complained of being abandoned by their partners 15.6% (5/32) upon return in which females constituted eighty percent (4/5).The remaining thirteen percent (4/32) respondents said they came home to meet only family members who were either little sisters, brothers or children since others had died as a result of the outbreak.

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Reception from community upon discharge from the ETU

Of the 32 participants, less than forty percent (10/32) reported being stigmatized by the community for about 6 months. Twenty-eight percent (9/32) suffered stigma that caused them to relocate to another community, six percent (2/32) of the respondents stated that their community members never knew they had the virus, six percent (2/32) participants said community members stood far away and spoke to survivors. A total of twenty-eight percent (9/32) of the respondents were accompanied by a psycho-social team members to their community leadership upon discharge from the ETU.

> **Speaker 1 of the 1st female FGD involving respondents between ages (18-35yrs)** "*I used to speak to my neighbors they never used to answer me, but once there is life there is hope".*
>
> **Speaker 4 of the 2nd female FGD involving respondents of ages (>35yrs)***"We were prevented from accessing market, creek and my children banned from going to their yard. I had to move to a new community.*

Reception from employer toward EVD survivors Post-Ebola

During the group discussion, of the total respondents responding to reception received by their employer upon discharge from the ETU, three percent (1/32) of survivors were warmly received by their employer, thirteen percent (4/32) of survivors were replaced by someone on the job and told not to return to work, thirteen percent (4/32) of survivors were afraid of being stigmatized and therefore never return to work. Almost thirteen percent thirteen percent (4/32) of the employers never knew their employees had come down with the Ebola Virus Disease and had survived while forty-four percent (14/32) of the total respondents were self-employed and unemployed respondents accounted for sixteen percent (5/32).

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Speaker 2 of the 2nd Male FGD involving respondents of ages >35 years *"My first visit to my place of work upon return from the ETU was not welcoming so, I made up my mind never to go back there''.*

Theme 3:

Coping mechanism adapted for stigmatization upon return from the ETU

As stated during the group discussion, fifty-three percent (17/32) of survivors said they adapted avoidance as a method of addressing stigmatization by community, friends and family members twenty-five percent (8/32) were aided by the health team visit to their community leaders. Whilst twenty-two percent (7/32) of survivors reported moving to a different community because of being provoked continuously.

Speaker 4 of the 1st Male FGD involving respondents between ages 18-35 years "*Perfection, I am an electrician whatever work I am asked to do I will do it good that they will come back needing my service and not stigmatized me"*

Theme 4:

Sex-related challenges of PES among EVD survivors following EVD outbreak

Also captured by the interview, nine percent (21/242) of respondents said family and friends were not coming around them, five percent (13/242) of survivors reported never having sexual feeling any longer, and five percent (11/242) of survivors stated their partners had walked out of the home from fear of contracting the virus. About eighty-one percent (197/242) of survivors experienced no gender specific problem. As part of the focus group discussion, nine percent (3/32) survivors complained of not maintaining an erection throughout sex. While six percent (2/32) of discussants were worried about having kids now that they were not seeing their menses post infection. Of the total 32 respondents, eighty-four percent (27/32) never complained of sex-related challenges.

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Speaker 8 of the 1st female FGD involving respondents between ages 18-30 years

"I lost my husband and both of my kids during the Ebola outbreak in Liberia since I left the ETU in June 2014 I have never seen my menses. I don't know if I will have children again".

Theme 5: Economic challenges of PES among EVD survivors post EVD outbreak

During the interview with survivors, thirty-one percent (76/242) said PES was affecting them they cannot work, forty-four percent (107/242) stated PES was affecting them but they can still work, while twenty-five percent (59/242) said PES has not affected them and they could still work. While during the discussion survivors thirty-four percent (11/32) said they were self-employed, forty-four percent (14/32) said they were employed by an entity and twenty-two percent (7/32) said they were unemployed. Survivors accounting for thirty-one percent (10/32) quit previous job post-Ebola. The reason for quitting was because, their goods and shops were destroyed during the outbreak, and nine percent (3/32) said they were afraid of being stigmatized so they never return to their jobs. Survivors who said they were unemployed nine percent (3/32) said they depended on their parents for financial support. (Table 9)

Speaker 4 of the 2nd male FGD involving respondents of ages >35 years *"I contracted the virus from the pharmacy, going there always reminds me of how I got infected, so I quit going there and I am working for PREVAIL now despite the small amount they give me''.*

Speaker 4 of the 2ndmale FGD involving respondents of ages >35 years "*The harder I try to hustle with my motorbike for my family the body pain increases''.*

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Table 9: Distribution of income dependents by respondents during the FGD

Categories	Recurrent statements	Total Respondents (n=32)	Percentage (%)
Prior EVD employment Status	Self-Employed	19	59
	Wage Employee	6	18.75
	Unemployed	7	21.9
Total		32	99.6
Post EVD Employment Status	Self-Employed	11	34.4
	Wage Employee	14	43.8
	Unemployed	7	21.9
Total		32	100
Reason for Quitting	Fear of been stigmatized	3	9.38
	Contract ended	1	3.13
	Goods or shop destroyed, no money for continuity	10	31.25
Total		14	43.76
Income of unemployed	Parents and relatives	3	9.38
	Spouse	3	9.38
	Depend on God	1	3.13
Total		7	21.9

Income generation for unemployed respondents

Speaker 1 of the 2nd female FGD involving respondents of ages >35 years *"I usually get help from PUAN-PUAN"*, (Puan-puan is someone who is not your husband or serious spouse but you both share some level of sexual relationship).

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Theme 6: Access to Health care among EVD survivors Post-Ebola

Of the 242 survivors during the interview that reported having symptoms post-Ebola, twenty-four percent (58/242) had never accessed care while seventy-six percent (184/242) had received care either at the research institute (PREVAIL), government health center or private facility. Of the total accessing health care, fifty percent (92/184) had never improved from the treatment they received, thirty-eight percent (70/184) had recovered with treatment while twelfth percent (22/184) of the survivors had somehow improved. Whilst during the focus group discussion all survivors experienced symptoms following discharge and had sought health care. Fifty percent (16/32) of participants had accessed health care at the research clinic, while twenty-two percent (7/32) had accessed health care at government health center and twenty-eight percent (9/32) had accessed care at a private health center.

Of the 50% accessing health care at the research clinic, sixty-nine percent (11/16) had not received treatment while thirty-one percent (5/16) had received treatment. Survivors accessing care at government health center were twenty-two percent (7/32).Of the seven survivors who had accessed care at a government facility seventy-one percent (5/7) reported never receiving satisfactory treatment needed for complains they explained. While twenty-nine percent (2/7) reported being treated well for their illness. All survivors constituting twenty-eight percent (9/32) accessing private health center reported to have received satisfactory treatment.

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Speaker 8 of the 2nd female FGD involving participants >35 years "*PREVAIL inform us they were doing research and not to treat our symptoms the government was responsible to provide treatment for us*".

Speaker 5 of the 1st female FGD involving participants between 18-35 years "*We sit at the government hospital all day to be seen by only a physician assistant that had survived and they say is our Doctor after which, they will give you two tablets after explaining plenty problems to them".*

Speaker 4 of the 2nd female FGD involving participants >35 years" *At the government facilities sometimes if they were to give you ten different drugs they will give you one and write prescription for the rest of the drugs and tell you to buy the others elsewhere with your money"*

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CHAPTER FIVE

5.0 DISCUSSION

The study was conducted among Ebola Virus Disease survivors in Montserrado County, Liberia to document evidence of symptoms experienced among survivors. Findings from the study revealed the prevalence of Post-Ebola Syndrome among survivors in Montserrado County, Liberia was about 91.3%. Similar to other studies, females account for the majority of study participants (Nabena et al, 2016; Scott et al, 2016). In Liberia, the higher number of females participants could be attributed to the fact that, females constitutes more than half of survivors in the Country, a phenomenon which must be further investigated. Almost all survivors complained of having PES after discharged from the ETU and this conforms with Qureshi 2015 study which reported that, 103 of 105 survivors reported symptoms in Guinea (Qureshi, 2015). Nevertheless varying from this finding were other studies which stated all survivors experienced PES Post-EVD outbreak (Nabena et al., 2016; Scott et al., 2016; Vetter et al., 2016). Our findings conforms, to other studies which indicated that, the majority of survivors had reported more than one symptom (Nabena et al., 2016; Scott et al., 2016). Multiple symptoms have been reported by survivors could be attributed to the fact that, due to the prevalence of malaria and other infections that resemble EVD in Liberia, prior symptoms could not be differentiated by survivors (Boggild et al., 2015; Nabena et al., 2016) .The frequently reported symptoms recorded in this study were eye complaint, arthralgia, peeling of skin and headaches. Other symptoms include psychological problem, chest and muscles pain, testes pain, skin diseases, hair loss, abdominal pain, ear complaint, menstrual problem and unusual tiredness, some of which are symptoms that appear during the onset of EVD infection in patients.

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Similar to this study were problems that have been reported in Sierra Leone, Bombali District of which common findings were joints pain, body pain, headache, eyes complaint, psychological problems, skin disease, hearing loss, erectile dysfunction, menstrual irregularity, and hair loss (Nabena et al., 2016).

As reported by EVD survivors in the United States, frequently occurring symptoms were fatigue, joint pain, alopecia, ocular symptoms, and psychological problems (Epstein et al., 2016). Also, preliminary findings of survivors in Liberia by PREVAIL recorded frequently experienced symptoms such as weakness, headache, memory loss, depressed mood, and muscles pain (American Academy of Neurology, 2016). While common sequelae reported in Port Loko, Sierra Leone were arthralgia, ocular problems and auditory symptoms (Mattia et al, 2016). However, findings of the latter three reports (Epstein et al, American Academy of Neurology and Mattia et al) differed a bit from findings of this study with regards to common symptoms experienced. This could probably be due to the fact that host immune response differed per individual due to pre and post-Ebola health history.

In this study, respondents that mostly experienced symptoms were single, married and widowed survivors. It is contrary to results of a study which stated, many widower survivors had experienced PES (Nabena et al., 2016).

EVD survivors mostly experiencing PES among the various age categories in our study population were adults between ages 25-34 and 35-44 years. Reasons for these could be attributed to the fact that, these age categories are mostly people who work to earn their living whether through skilled or unskilled jobs in Liberia. Consistent with our study, was a study in Sierra Leone which stated many adult survivors reported health problems and their justification was that adults mostly perform work that demanded energy (Nabena et al., 2016), and also due to the fact that with increased age, structural and biological alterations occurred making the individual vulnerable to infection one of which is PES (Gavazzi & Krause, 2002).

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Also our study reports, over half of the survivors unemployed during the study reported experiencing PES.

The fact that female survivors participated more in the study compare to their male counterparts can be attributed to the fact that female survivors in Liberia account for more than half of the survivors population. It conforms to study done in Sierra Leone, Bombali District in which it stated that female survivors constituted over half of its study participants (Nabena et al., 2016; Scott et al., 2016).

As observed in the field, joints and muscles pain could best be differentiated by a physician examining a patient, therefore this study has decided to combine both pains during the discussion. Joint pain was experienced by over half of the total survivors complaining of PES while muscles pain were reported by a little over thirty percent of survivors. Survivors describe joints pain as pain experienced in the knee, back, neck, shoulder, and ankles whereas muscle pain were experienced in all muscles parts of their body also, a few of survivors experience general body pain.

In some survivors pain intensifies when trying to carry out normal lives for example selling, walking distances and doing house chores while in other regardless of resuming normal lives these pain existed. This pain was often intermittent with some subsiding by pain relief.

Conforming to this study, was the preliminary finding of a five-year clinical trial been conducted in Liberia which recorded that, joint pain was reported among approximately fifty percent of survivors visiting the Medicine San Frontier Clinic. Joints pain was described as pain in the elbows, wrist, fingers, hips, ankles, neck, back and Knee (Vetter et al., 2016).

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Contrary to the findings from our study, a literature in Sierra Leone has reported that less than thirty percent of survivors had joints pain, seventy-three percent of survivors experienced unspecified joints pain, which was termed as pain in unspecified joints, whilst less than twenty percent suffered muscles pain. Muscles pain was termed as pain in either back, thighs or knees and a little over forty percent had generalized body pain (Scott et al., 2016).

Also stated by a lady in Nigeria, upon discharged from the ETU, she had endured joints and muscles pain. Her pain ranged from, mild to serious, traveling from one joint to another joint. She said these pains were self-controlled by the taking of analgesics (Igonoh, 2016). The previous study conducted on EVD survivors in Kikwit, Democratic Republic of Congo also stated that survivors complained of irregular and seasonal joints pains in large joints (Rowe et al., 1999). Also, other literatures have shown that almost eighty percent of survivors experienced joints pain after discharged from an ETU (Epstein et al., 2016; Mattia et al., 2016). A study in Guinea shows that the majority of survivors suffered joints pain with less than thirty percent experiencing muscles pain and close to half of survivors suffering from back pain. Joints pain was directly associated [R^2=0.09, P=0.008] with lower recovery in terms of EVD survivors been able to resume the performance of normal life (Qureshi, 2015).

Stated by Nabena et al, though survivors are proven cleared by negative results of RT-PCR prior to discharge from the ETU, widespread distribution of the virus during the severe stage might result in viral particles lingering in partitions of the body such as the synovial fluid of the joints (Nabena et al., 2016; Vetter et al., 2016).

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Chest pain was reported by twenty-two percent of respondents in this study while nine percent of EVD survivors in Sierra Leone were reported to have experienced chest pain, and almost twelfth percent having a cough (Scott et al., 2016). Whether the chest pain experienced in Scott population was felt when coughing it is unclear. In Liberia the chest pain reported, was felt when lifting up a heavy substance doing work.

The stomach pain was observed in twenty-three percent of EVD survivors in our study compare with survivors enrolled in the clinical research in Liberia which recorded, a little more than thirty percent (WHO, 2016d).Whilst Scott et al from Sierra Leone reported nine percent of EVD survivors experiencing stomach pain (Scott et al., 2016).

The ocular problems as reported by this paper recorded a little less than fifty percent by EVD survivors. The ocular problem as experienced by respondents in this study were blurred vision, redness, pain and itching of eyes. Recorded by survivors enrolled in a study in Sierra Leone, two weeks post discharged, fourteen percent of survivors reported ocular problems which ranged from eye pain, clear discharge, red eyes and blurred vision (Scott et al., 2016). Reported also by survivors in the United States, sixty-three percent reported eye pain, blurred eyes site between two to eight weeks after discharged from an ETU. These findings are consistent with findings of this study in which survivors complained of similar ocular problems.

Also reported by three studies in sierra Leone, ocular complications were reported by thirty-four, fifty-seven and sixty percent of EVD survivors respectively (Nabena et al., 2016; Tiffany et al., 2016; Mattia et al., 2016).

The three studies findings were consistent with preliminary results published by the clinical research group in Liberia, PREVAIL and stated that fifty-three percent of survivors enrolling in the study experienced vision problems between the first four months post discharged (WHO, 2016d).

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Also, survivors receiving care at the Medicine San Frontier clinic in Liberia had suffered ocular complications ranging from eye pain, inflammation of the uvea, photophobia, loss of visual acuity and hyper-lacrimation (Vetter et al., 2016).

Tiffany further stated that patients with redness of the eyes during acute phase were 10 times more likely to suffer inflammation of the eyes post discharged. Also, the adjusted odds of uveitis in his population of survivors was 3.3 (Tiffany et al., 2016). Whether it was the severity of the virus during the chronic stage of the infection of which strains are now resulting in ocular complaints it is unclear. Another previous study reported an ocular problem to be independently associated with increased viral load during severe stage of EVD infection in Sierra Leone (Mattia et al., 2016).

This study has reported a range of neurological disorders including; Headache which accounts for fifty-one percent. A headache is one of the most commonly reported symptoms recorded by this study. It is also known as one of the commonest reported symptoms among EVD survivors (Javier & Artal, 2016). A headache was also reported by more than forty percent of survivors enrolling in the clinical research by PREVAIL. This was initial findings within six months after discharged from an ETU (WHO, 2016d). Also reported by EVD survivors attending care at the Medicine San Frontier clinic in Liberia, a number of neurological symptoms have been recorded. The study did not establish as to whether these neurological symptoms was associated with severe EVD infection (Vetter et al., 2016).

A headache was experienced by forty-eight percent of EVD survivors in a study in Sierra Leone which was termed as pain affecting the full head (Scott et al., 2016). Another study in Sierra Leone shows more than seventy percent of EVD survivors reported a headache (Nabena et al., 2016). Other neurological symptoms reported by EVD survivors in this study were unusual tiredness, anxiety, depression, sleep disorder, numbness of hands and feet, and absentmindedness.

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Of the total EVD survivors participating in this study, twenty-six percent suffered unusual tiredness. Unusual tiredness was termed in this study as weakness in the body parts. Thirty-two percent of EVD survivors enrolled in the clinical research had experienced unusual tiredness while almost eighty percent of EVD survivors in the United States experienced unusual tiredness (Epstein et al., 2016). A study in Nigeria involving an EVD survivors also shows that EVD patients report unusual tiredness upon discharge from the ETU (Igonoh, 2016).

Respondents complaining of depression in this paper was consistent with other studies that reported fifteen percent of EVD survivors had suffered depression. Also, a study in the United States shows that about half of EVD survivors experienced depression (Epstein et al., 2016).

Sleep disorder was experienced by twenty percent of survivors in this study, whilst more than half of EVD survivors in the United States suffered same (Epstein et al., 2016) and less than twenty-five percent poor sleep cases were reported by two studies in Sierra Leone (Scott et al., 2016; Tiffany et al., 2016).

Six percent of EVD survivors in our study were absentminded while, a higher number accounting for thirteen percent were recorded among survivors enrolled in the clinical research by PREVAIL (WHO, 2016d). Ear problem was reported in a small number of less than two percent of EVD survivors in this study. Ear problems as described by this study include hearing loss and ear pain. Consistent with these findings was a literature in Sierra Leone which stated a little more than five percent of EVD survivors experienced ear problems (Nabena et al., 2016). Contrary to these current findings, was a study in Sierra Leone that stated almost twenty-five percent of EVD survivors suffered ear problems (Mattia et al, 2016) whilst, ear problems was reported among 12% of EVD survivors in the United States (Epstein et al., 2016).

Skin diseases as describe by this paper means itching of skin, which was reported by fifteen percent of survivors and desquamation of the palm and feet were been reported by eighteen percent of EVD survivors.

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The findings in this study conform with reports by the Medicine San Frontier clinic in Liberia which states EVD survivors reported experiencing desquamation and dryness of skin which commonly affected the palm and soles of the feet (Vetter et al., 2016). Also stated by two previous studies in Sierra Leone, itching of the skin was reported by nine percent of EVD survivors (Scott et al., 2016) and skin diseases were reported by thirteen percent of EVD survivors (Nabena et al., 2016).

A study in Nigeria also revealed by an EVD survivors confirms the similar finding of this study stating she experienced dryness and peeling of her elbows, abdomen, hands and feet (Igonoh, 2016). The current study reveals that the odds of peeling of skin was significantly associated with PES. The question here still lingered, was pruritus and desquamation resulting from the concentration of disinfectant used during the stay in the ETU or some other abnormality in the integumentary system.

Hair loss was experienced by eight percent of the respondents involved in our study. This confirms to literature in the United States with more than seventy percent EVD survivors experiencing alopecia (Epstein et al., 2016). Sierra Leone with less than five percent of EVD survivors reporting hair loss (Nabena et al., 2016), in Nigeria by an EVD survivor (Igonoh, 2016) and in Liberia at the Medicine San Frontier clinic (Vetter et al., 2016).

Less than ten percent EVD survivors in this study have reported reproductive system complications that include erectile dysfunction, and testes pain. Female survivors also experienced menstrual problems which include menstrual cessation and irregularities accounting for eleven percent of female survivors. Consistent with these finding is Nabena et al., from Sierra Leone study which reports erectile dysfunction and menstrual problems account for less than five percent each in the population of EVD survivors been studied (Nabena et al., 2016).

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Other symptoms less reported were numbness of body, fever, heart problem, swollen feet heart palpitation.

Finding from this study reveals the onset of symptoms was between the first 1- 12 weeks after discharge from an ETU. Our finding is consistent with other studies which state that symptoms onset began immediately the first few weeks post discharged (Scott et al., 2016; Vetter et al., 2016). Stated also by a study in Sierra Leone that EVD survivors started to complained of PES within one to four weeks after discharge (Nabena et al., 2016).

Also, literature in the United States reports the onset of new symptoms in an EVD survivors 10 weeks after discharge (Varkey et al., 2016). Literature in Sierra Leone also stated, a majority of PES begin right after discharge from the ETU (Tiffany et al, 2016). It was also indirectly stated by a study in Sierra Leone that PES are usually common during the early convalescence stage of EVD (Mattia et al., 2016). The literature on an EVD survivors in Nigeria reported, she left the ETU with some symptoms that persisted after discharge (Igonoh, 2016) .

In this study, the duration of symptoms such as anxiety and peeling of skin recorded less than five percent each by the sixth month. While testis pain and itching of the skin reported being low among EVD survivors by the ninth month with less than three and ten cases recorded respectively. Other symptoms reported by fewer EVD survivors by the >10 month were menstrual problem, chest pain, abdominal pain and depression with 17, 12, 19 and 14 percent respectively.

While symptoms that were most likely to have persisted above >10 months were eyes problems (53%), joints pain (40%), muscles pain (28%), unusual tiredness (38%) and headache (80%). This is consistent with literature published in the Democratic Republic of Congo which states joint pains, muscles pain, abdominal pain, fatigue were the commonest reported during a six months followed up visit. While muscles and joints pain remains high among EVD survivors up to the twenty-one months after EVD (Rowe et al., 1999).

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A cohort study in Uganda has revealed long-term symptoms that might continue for greater than two years. Commonest symptoms reported by this cohort were blurred vision, hearing loss, difficulty swallowing, joint pains, and sleep disorders (Clark et al., 2015). Commonest symptoms recorded, that tend to persist in this cohort is a bit different from findings of this study.

Finding of the focus group discussion part of the study revealed, most survivors were self-employed prior to EVD similar to report published by the Liberia Institute for Statistics and Geo-information Services which states in 2014, 38% of the population in Liberia were self-employed of which seventy-seven percent were involved in agriculture (LISGIS, 2016).

Results of the focus group discussion show 50% of survivors admitted to an ETU contracted the virus from relatives of their households or after visiting and caring for a sick relative. This was similar to findings in Kikwit which stated 82% of survivors that got infected with EVD had interacted with an affected relative (De Roo et al., 1998).

Nineteen percent of EVD survivors got infected from a neighbor in their surrounding or friend in a social club. While other who couldn't remember probably got infected while transacting business or interacted with an infected person unknowingly either riding on a motorbike or in a taxi. Forty percent of focus group discussants who reported themselves were advice to do so by a relative, fear of falling severely sick in the community and be stigmatized.

Similar to this finding was De Roo et al who stated 21% of survivors sought care out of fear of been accused while 15% sought care to avoid shame (De Roo et al., 1998). A large number of self-reported cases in this study could be attributed to the constant hearing of sensitization messages which stated that the earlier you seek care the most likely you were to survive. Community fear of the large spread of the virus and fear of being quarantined led to most community leaders reporting patients to the health team.

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Also patient fear of been stigmatize cause them to stay at home till acute phase, belief that bad treatment was given at the ETU and denial that it was EVD. Kikwit study also said 47% of EVD patients were in a state of denial prior to seeking care (De Roo et al., 1998).

Results of the focus group indicate that with the coming of the Clinical Research group to Liberia, a good number of survivors have been employed. Survivors competent of performing varieties of jobs had been hired despite the aches in their bodies. Which has further, reduced financial burden among survivors. Somehow similar to our study, are findings published in Guinea which stated a high number of survivors participating in the study return to their prior jobs regardless of not being fully recovered but as a result of financial constraints (Qureshi et al, 2015).

The focus group discussion of this study, also shows a number of survivors who could not work probably due to joints pain and muscles pain. This was because most of them were involved in businesses in which they had to walk from one destination to another, farming or standing on their feet in market halls. Also, some of the survivors who were not working but was affected by PES were older people that had been retired or were not physically fit to work again.

Reasons for not maintaining previous jobs were due to the fact that upon return to work, employer and friends would have stigmatized them, while others said they avoided the trauma caused by being reminded of where and how they got infected.

And others stated their job contract ended. The ending of a contract was probably influence by the President of Liberia pronouncement to reduce the over crowdedness of government offices by making non-essential staff stay at home during the peak of the outbreak. A pronouncement that probably was also adopted by some private entities. Survivors said they had no money to continue previous work which can be tied to the fact that goods were damaged, and shops were vandalized by robbers while patients were in the ETU.

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As stated by survivors majority of them have received money packages from a few International Organizations ranging from $60- 100.00 USD for about four months. Despite this assistance, some survivors have not been able to restart businesses.

Upon asking survivors during the FGD why they haven't resume businesses with money given them, a few said now they were alone with no help from any family or friend so they had to pay school fees of children and buy food. Family dependents were high ranging from 1-8 dependents. Less than ten percent of participants had no child.

With regards to accessing care discussants said they have been asked to access care at government health provision sites around Liberia and a clinic ran by the Medicine San Frontier Liberia for two years. Less than ten percent of survivors have received improvement from health care access to government facility. Results from the discussion indicated, seventeen percent had not received improvement due to the fact that there were no drugs given them at the clinic except for PCM, some said they were given a prescription to buy drugs elsewhere which they had no money to buy.

Conforming to our finding is a report by the Research Clinic PREVAIL in which it states, survivors in Liberia are faced with the challenge of accessing health care. Which is due to the unavailability of an adequate number of health centers with free of charge care and required medicine (WHO, 2016d).

Twenty-two percent of survivors had not accessed care for reasons such as limited finance to get better care, fear of being stigmatized, some stated PES was not a burden, while others said they had taken herbal treatments. Survivors who responded saying they had improved somehow complained that once they left the drugs, symptoms return. The American Academy of Neurology through PREVAIL conducted an examination of the eyes of eighty- two survivors after which, some patients were treated with eye drops, ointment, and glasses (American Academy of Neurology, 2016).

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Thirty-four percent discussants enrolled in the clinical research were not treated because their health problems required specialist and some specialized procedures and equipment which were not available like rheumatologist and ophthalmologists. This is in line with findings from the research clinic reporting gaps such as advanced testing and specialist referral in clinical care for survivors (WHO, 2016d).

On the overall 58% study participants have been stigmatized since their return from the ETU whether by only family, friends (neighbors), employers or all three groups. Survivors participating in the FGD complained of being provoke continuously to the extent they had to relocate. With a few of participants reported been abandoned in their homes by husbands and wives as a result of fear of contracting the virus. Consistent with findings of a study in Northern Uganda, majority of survivors reported intense stigmatization. Survivors also were banned from returning home, while some were abandoned by their spouses (Barry & Amola, 2003).

5.1 Limitations of the study

Viral load of EVD survivors in Montserrado County could not be obtained. Due to the incapability of the reference laboratory to perform testing of samples in a safe and timely manner which brought to the picture the CDC laboratory team. Therefore data on viral load are stored with the CDC laboratory team and could not be assessed.

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CHAPTER SIX

6.0 CONCLUSION & RECOMMENDATIONS

6.1 CONCLUSION

This study has indicated that the prevalence of Post-Ebola Syndrome among EVD survivors in Montserrado County, Liberia is high (91.3%). The onset of symptoms was reported between the first1- 12 weeks after discharged from the ETU. Commonest symptoms reported were chest pain, muscle pain, eyes problem, abdominal pain, joint pain, unusual tiredness, sleep disorder, and headache. Symptoms among survivors were often intermittent and peaked by, the sixth month. By the ninth month, most symptoms start to record a lower percentage.

Notwithstanding, a few number of symptoms were shown to have persisted among survivors above ten months but with reduced severity which includes; eyes problem, joints pain, unusual tiredness, and headache. Approximately 58% of survivors reported been stigmatized by either family, friends, or employer. Also, Post-Ebola symptoms differed by a survivor. Clinical care for survivors in Montserrado County remains the biggest gap, less than 10% of survivors have received appropriate treatment for complaints suffered.

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6.2 RECOMMENDATIONS

Based on the findings of this study, the following recommendations are being made;

Ministry of Health

The Ministry of Health, Liberia to negotiate with partners (World Health Organization, Center for Disease and Control, and Medicine San Frontiers) to improve and maintain the care being offered to survivors by increasing the number of health care centers for survivors, providing adequate drugs for appropriate conditions, hiring of specialist for the commonest reported conditions and the building of laboratory capability for advanced testing and screening.

Incident Management System of the Emergency Operation Center

The Incident Management System of the Ministry of Health to develop policies from the recently developed World Health Organization clinical guide of 2016. And ensure the implementation of developed policies by care givers at the ETU to schedule preliminary follow- up visits at clinics for survivors upon leaving the ETU before the country is declared free of EVD. This needs to be done to adequately monitor survivors recovery status and immediately detect any deviation in health Post-EVD to avoid long-term disabilities.

Long-term Recommendations

Government of Liberia

The Government of Liberia through the Ministry of Health should prioritize health care of survivors by lobbying for funding from International donors for the establishment of a modernized and equip hospital for survivors and the management of future outbreaks. Also, the Ministry of Health needs to engage partners (John Hopkins University and Center for Disease Control) to conduct further research to understand and establish factors resulting in Post-Ebola Syndrome.

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REFERENCES

ACAPS. (2015). Ebola in West African Impact on Health Systems. Retrieved June 23, 2016, from http://www.acaps.org

American Academy of Neurology. (2016). Most Ebola survivors examined in study experienced brain symptoms six months after infection. Retrieved May 19, 2016, from https://www.sciencedaily.com

Barry, H. & Amola, R. P. (2003). Cultural contexts of Ebola in northern Uganda. *Emerging Infectious Diseases*, *9*(10), 1242–1248.

Boggild, A. K., Esposito, D. H., Kozarsky, P. E., Andell, V., Beeching, N. J., Campion, D., … Hamer, D. H. (2015). Differential diagnosis of illness in travelers arriving from Sierra Leone, Liberia, or Guinea: a cross-sectional study from the GeoSentinel Surveillance Network. *Annals of Internal Medicine*, *162*(11), 757–764. http://doi.org

BPAC. (2016). Strategies to improve nutrition in elderly people - Prescription foods. Retrieved June 24, 2016, from http://www.bpac.org.nz

CDC. (2016). Elimination of Ebola Virus Transmission in Liberia — September 3, 2015. Retrieved May 20, 2016, from http://www.cdc.gov

Clark, D. V., Kibuuka, H., Millard, M., Wakabi, S., Lukwago, L., Taylor, A., … Robb, M. L. (2015). Long-term sequelae after Ebola virus disease in Bundibugyo, Uganda: a retrospective cohort study. *The Lancet Infectious Diseases*, *15*(8), 905–912. http://doi.org/10.1016/S1473-3099(15)70152-0

De Roo, A., Ado, B., Berthe, R., Yves, G., Karolien, F. & Robert, C. (1998). Survey among survivors of the 1995 Ebola epidemic in Kikwit, Democratic Republic of Congo: their feelings and experiences. *Tropical Medicine & International Health*, *3*(11), 883–885. http://doi.org/10.1046/j.1365-3156.1998.00322.x

University of Ghana http://ugspace.ug.edu.gh

Epstein, L., Wong, K. K., Kallen, A. J., & Uyeki, T. M. (2016). Post-Ebola Signs and Symptoms in U.S. Survivors - NEJMc1506576. Retrieved May 20, 2016, from http://www.nejm.org/doi/pdf/10.1056/NEJMc1506576

Gavazzi, G., & Krause, K.-H. (2002). Ageing and infection. *The Lancet Infectious Diseases*, *2*(11), 659–666. http://doi.org/10.1016/S1473-3099(02)00437-1

Igonoh, A. (2016). Post-Ebola Syndrome. *Pacific Journal Of Medical Sciences*, 3.

Javier, F., & Artal, C. (2016). Post-Ebolavirus disease syndrome: what do we know? - 14787210.2015.1079128. Retrieved May 20, 2016, from http://www.tandfonline.com

LISGIS. (2016). 2014 Household Income and Expenditure Survey. Retrieved June 16, 2016, from http://www.lisgis.net/others

Marquez, P. (2016). Resilient Health Systems. Retrieved June 24, 2016, from http://www.worldbank.org

Mattia, J. G., Vandy, M. J., Chang, J. C., Platt, D. E., Dierberg, K., Bausch, D. G., … Mishra, S. (2016). Early clinical sequelae of Ebola virus disease in Sierra Leone: a cross-sectional study. *The Lancet Infectious Diseases*, *16*(3), 331–338. http://doi.org/10.1016/S1473-3099(15)00489-2

Nabena, E. P., Bakare, W. A., Ilesanmi, O. S., Anyanwu, R., Akuechiama, Inyang, S. E. J., & Famuyide, T. (2016). Health Problems of Ebola Virus Disease Survivors in Sierra Leone, 2015. Retrieved May 20, 2016, from http://benthamopen.com

Nanyonga, M., Saidu, J., Ramsay, A., Shindo, N., & Bausch, D. G. (2016). Sequelae of Ebola Virus Disease, Kenema District, Sierra Leone. *Clinical Infectious Diseases*, *62*(1), 125–126. http://doi.org/10.1093/cid/civ795

NIH. (2015). Study of Ebola survivors opens in Liberia. Retrieved May 20, 2016, from https://www.nih.gov

NIH. (2016). Chlorine poisoning: Retrieved June 24, 2016, from https://www.nlm.nih.gov

University of Ghana http://ugspace.ug.edu.gh

Peters, C. J., & LeDuc, J. W. (1999). An Introduction to Ebola: The Virus and the Disease. Journal of Infectious Diseases, 179(Supplement 1),ix–xvi. http://doi.org/10.1086/514322

Portela, C. F. (1998). Epidemiology of the Ebola Virus: Facts and Hypotheses. *The Brazilian Journal of Infectious Diseases: An Official Publication of the Brazilian Society of Infectious Diseases*, *2*(6), 265–268.

Qureshi, A. I. (2015). Ebola Virus Disease Survivors Study in Guinea. *Clinical Infectious Diseases*, civ453. http://doi.org/10.1093/cid/civ453

Qureshi, A. I., Chughtai, M., Loua, T. O., Kolie, J. P., Camara, H. F. S., Ishfaq, M. F., … Beavogui, K. (2015). Study of Ebola Virus Disease Survivors in Guinea. *Clinical Infectious Diseases*, *61*(7), 1035–1042. http://doi.org/10.1093/cid/civ453

Racaniello, V. (2016). Long-term effects of Ebolavirus infection. Retrieved May 20, 2016, from http://www.virology.ws/2015/06/18/long-term-effects-of-ebolavirus-infection/

Rowe, A. K., Bertolli, J., Khan, A. S., Mukunu, R., Tamfum, J. J. M., Bressler, D., … Ksiazek, T. G. (1999). Clinical, Virologic, and Immunologic Follow-Up of Convalescent Ebola Hemorrhagic Fever Patients and Their Household Contacts, Kikwit, Democratic Republic of the Congo. *Journal of Infectious Diseases*, *179*(Supplement 1), S28–S35. http://doi.org/10.1086/514318

Schaffner William. (2016). "Post ebola syndrome" Persist After Virus Is Cured, Doctor Says. Retrieved June 24,2016, from http://iacfsme.org

Scott, J. T., Sesay, F. R., Massaquoi, T. A., Idriss, B. R., Sahr, F., & Semple, M. G. (2016). Post-Ebola Syndrome, Sierra Leone. *Emerging Infectious Diseases*, *22*(4), 641–646. http://doi.org/10.3201/eid2204.151302

University of Ghana http://ugspace.ug.edu.gh

Tamfum, J. J. M., Mulangu, S., Masumu, J., Kayembe, J. M., Kemp, A., & Paweska, J. T. (2016). Ebola virus outbreaks in Africa: Past and present. Retrieved May 20, 2016, from http://www.ojvr.org

Tiffany, A., Vetter, P., Mattia, J., Dayer, J.-A., Bartsch, M., Kasztura, M., … Ciglenecki, I. (2016). Ebola Virus Disease Complications as Experienced by Survivors in Sierra Leone. *Clinical Infectious Diseases*, *62*(11), 1360–1366. http://doi.org

Varkey, J., Shantha, J. G., Crozier, I., Kraft, C. ., Lyon, M. G., Mehta, A. K., … Yeh, S. (2016). Persistence of Ebola Virus in Ocular Fluid during Convalescence - NEJMoa1500306. Retrieved May 20, 2016, from http://www.nejm.org

Vetter, P., Kaiser, L., Schibler, M., Ciglenecki, I., & Baush, D. B. (2016). Sequelae of Ebola virus disease: the emergency within the emergency. *The Lancet Infectious Diseases*. http://doi.org/10.1016/S1473-3099(16)00077-3

WHO. (2014). Ebola Factsheet Retrieved July 16, 2016, from http://www.who.int

WHO. (2015). Ebola Factsheet Retrieved June 24, 2016, from http://www.who.int

WHO. (2016a). Ebola Situation Reports. Retrieved June 22, 2016, from http://apps.who.int

WHO. (2016b). Helping the Ebola survivors turn the page. Retrieved May 20, 2016, from http://www.who.int

WHO.(2016c). WHO ebolasitrep_10Jun2016. Retrieved June 22, 2016, from http://apps.who.int

WHO. (2016d). WHO meeting on survivors of Ebola virus disease. Retrieved June 18, 2016, from http://reliefweb.int

WHO (2015). Ebola virus disease. Retrieved May 20, 2016, from http://www.who.int

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APPENDICES

Appendix 1

Average Onset of Post-Ebola Syndrome by the Human Systems (Figure 14)

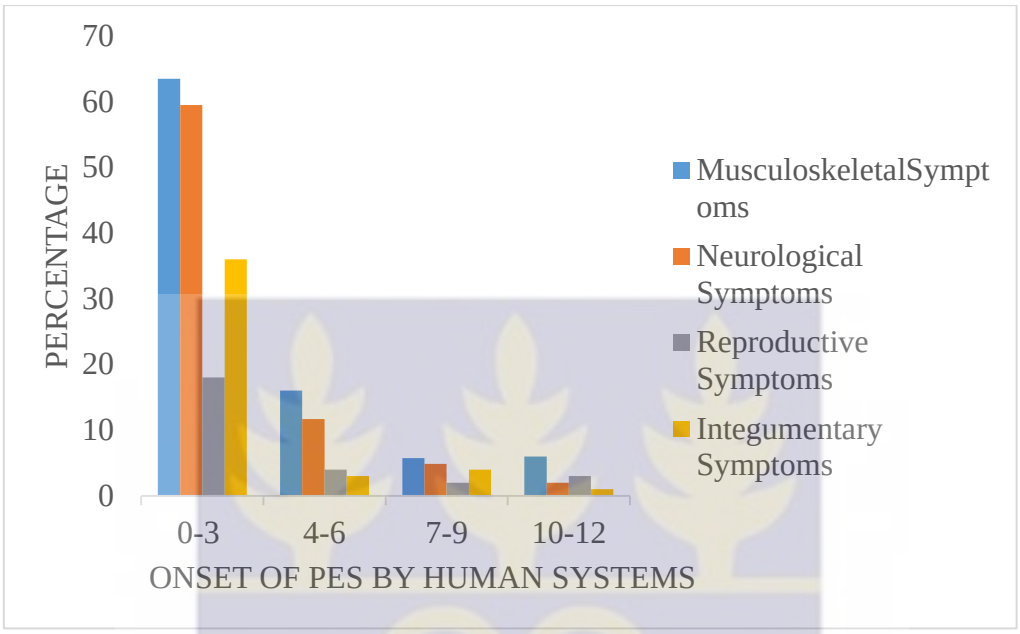

Figure 14: Average Onset of PES by Human Systems among EVD survivors in Montserrado County, Liberia 2015-2016

Average Duration of Post-Ebola Syndrome of the Human Systems (Figure 15)

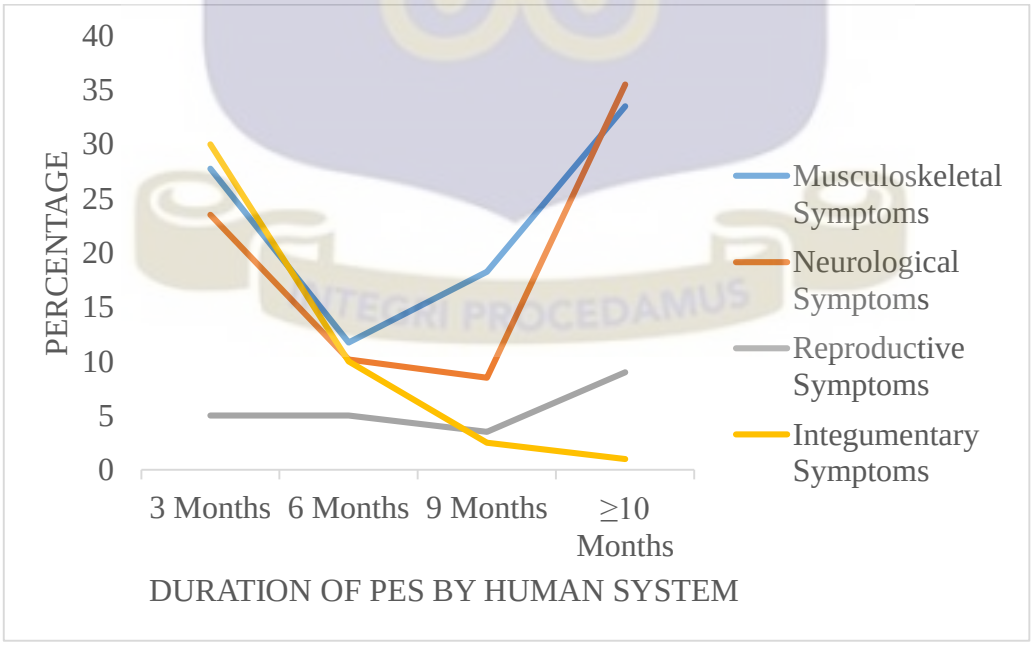

Figure 15: Average Duration of PES by the Human Systems among EVD survivors in Montserrado County, Liberia 2015-2016

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Appendix 2:

Informed Consent

The West African Ebola epidemic that occurred in Guinea, Sierra Leone, Nigeria, Mali and Liberia in 2014 resulted in the highest number of cases and survivors. Ebola survivors account for 10,000-15,000 of 28,637 cases. Most survivors thought leaving the Ebola Treatment Center (ETU) brought the virus episode in their life to an end, but it is not. Many survivors are complaining of health problems ranging from mild to severe complications. These problem as documented in previous study are termed Post Ebola Syndrome (PES/PEVDS). The research is conducted to assessed survivors in Montserrado County which constitute 59% of survivors in Liberia. The assessment is done using a semi-structured questionnaire. The objectives of the study are to determine the types of symptoms, Prevalence of symptoms, the onset of symptoms, duration of symptoms and social economic challenges of PES on survivors. Participation in the research is voluntary and all information of participants involved in the study will be kept confidential. Benefit of the study is that, an evidence of the approximated number of Ebola Survivors with health problems are documented like what has been done in other neighboring Countries (Guinea and Sierra Leone). Also Government and International Partners can use this documented evidence to develop livelihood programs and maintain health care of survivors. There is no risk involved in being a part of the research. The research is individual sponsored and at such only transportation of usd $5.00 will be provided for Participants.

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The above document describing the benefits, risks and procedures for the research title ***(Post-Ebola Syndrome among EVD Survivors in Montserrado County, Liberia)*** has been read and explained to me.

I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

_____ _____

Date Name and signature or mark of volunteer

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

I was present while the benefits, risks and procedures were read to the volunteer.

All questions were answered and the volunteer has agreed to take part in the research.

_____ _____

Date Name and signature of witness

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

_____ _____

Date Name Signature of Person Who Obtained Consent

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Assessing Post-Ebola Syndrome in Survivors

Questionnaire Number _____

Interview Date ____/____/_____ (dd-mm-yyyy)

Background Information

1.	Sex of Respondent	[ ] 1). Male [ ] 2).Female

2.	How old are you as of your last birthday	_____/_____ Years Month/Days

3.	Marital status	[ ] 1). Single [ ] 2). Married [ ] 3).Divorced [ ] 4).Widow/Widower

4.	Where do you live?	

5.	Education level	[ ] 1). Primary [ ] 2). Secondary [ ]3).Tertiary [ ] 4). Others(specify)

6.	Are you employed? If no skip question 7	[ ] 1).Yes [ ] 2).No

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7.	Occupation	[ ] 1). Nurse [ ] 2). Farmer [ ] 3). Teacher [ ] 4). Businessman/Woman [ ] 5).Carpenter [ ] 6). Others (specify)

Table 2: Ebola History

Now we would like to get some brief information regarding when you became sick and the dates that you were in the hospital. If you do not know the exact day, you can guess. If you only know the month, that is fine also. For all dates please use the dd/month format using a 3 LETTER abbreviation for month e.g. 02/SEP/2009)

8.	What date/month you started feeling sick?	_____ /_____/_____ Day Month Year

9.	Which date did you reach a hospital?	_____/_____/_____ Day Month Year

10.	Which Ebola treatment center were you admitted to?	[ ] 1). ELWA 2 [ ] 2). ELWA 3 [ ] 3).MOD 1 [ ] 4). MMU [ ] 5).JFK

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		[ ] 6). UCC [ ] 7). CHINA [ ] 8).ISLAND clinic [ ] 9).BONG

11.	Which date were you discharged?	_____/_____/_____ Day Month Year

12.	How long did you stay in the ETU?	_____/_____ Week(s) Month(s)

13.	During your stay in the ETU, do you remember the drugs given you?	[ ] 1).Yes [ ] 2).No

14.	What were the drugs? Please specify.	[ ] 1).Paracetamol (pain Killer) [ ] 2).ORS [ ] 3).Antibiotics [ ] 4).Antimalarial Pills [ ] 5).Others

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15. Table 3: Pre and Post Ebola Medical History

(Now we would like you to tell us what medical conditions you had BEFORE and AFTER Ebola to see how it compares). In the above question, you told us you got sick with Ebola on XX (look at Date #7). BEFORE this date, can you please tell us what medical problems you had?

	Symptom	**Before**	**After** (Can you please tell us what problems you are facing now?).
a)	Chest pain		
b)	Muscle pain		
c)	Eyes problem		
d)	Stomach pain		
e)	Pain in the testis		
f)	Joint pain		
g)	Menstrual problem		
h)	Unusual tiredness		
i)	Itching of skin		
j)	Peeling of skin		
k)	Worried/frightened		
l)	Depression		
m)	Failure to sleep		
n)	Headache		
o)	Others? Specify		

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16) Can you please indicate which month after your discharge you started experiencing symptom?

	Symptom	Onset of PES			
		Months 0-3	**Months 4- 6**	**Months 6- 9**	**Months 10-12**
a)	Chest pain				
b)	Muscle pain				
c)	Eyes problem				
d)	stomach pain				
e)	Pain in the testis				
f)	Joint pain				
g)	Menstrual problem				
h)	Unusual tiredness				
i)	Itching of skin				
j)	Peeling of the skin				
l)	Worried/frightened				
m)	Depression				
n)	Failure to sleep				
o)	Headache				
p)	Others(specify)				

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17. (Now we would like to know the duration of the symptoms you have mentioned in (ques 16) in the **after** column above. You will be assessed on a quarterly basis for 12 months).

	Symptom	**Duration of PES**			
		Months 0-3	**Months 4- 6**	**Months 6- 9**	**Months 10-12**
a)	Chest pain				
b)	Muscle pain				
c)	Eyes problem				
d)	stomach pain				
e)	Pain in the testis				
f)	Joint pain				
g)	Menstrual problem				
h)	Unusual tiredness				
i)	Itching of skin				
j)	Peeling of the skin				
l)	Worried/frightened				
m)	Depression				
n)	Failure to sleep				
o)	Headache				
p)	Others(specify)				

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18.	Have you received any treatment for any of the conditions above?	[ ] 1). Yes [ ] 2). No

19.	If yes, can you list the drugs given you?	

20.	Did you received any improvement from the drugs given you?	[ ] 1).Yes [ ] 2). No

21.	If no to question 16, why you didn't received any treatment?	[ ] 1). No money [ ] 2). Fear of stigmatization [ ] 3).Distance to Hospital [ ] 4). Others (specify)

22.	Please explain to what extend is the problem affecting your normal life? Can you still work?	

23.	Are these symptoms affecting your personal relationship? Please explain how?	

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24.	Upon discharged from ETU back to your community, how were you received? (Here we address issue of stigmatization).	

25.	Is there anything you would like me to know that I have not ask you? If yes please explain?	

Thanks for your Cooperation

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Appendix 3

Focus Group Discussion Guide

Assessing socio-economic challenges face by Ebola Virus Disease Survivors

Welcome Message

Welcome and thanks for volunteering to take part in this focus group discussion. You have been ask to participate as your point of view is important.

Introduction

This focus group discussion is design to determine the socio-economic challenges Ebola Virus Disease survivors faced by post-Ebola syndrome. Findings from this discussion will inform the Ministry of Health along with other International Organizations and Partners in planning intervention programs for survivors. The focus group discussion will take no more than (2) two hours. This discussion is going to be taped, this is to facilitate adequate recollection of responses.

Anonymity

Although been taped, I would like to assure you that all responses of the discussion will be unidentified. The tapes will be kept safely in a locked facility until they are transcribed. After which they will be destroy. The transcribe notes of the focus group will contain no information that would allow individual subjects to be linked to specific statements. Please try to answer and comment as accurately and truthfully as possible. We will appreciate if you will refrain from discussing the comments of other group members outside the group. We anticipate the participation of everyone, please try to answer and be involved in the discussion as possible.

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Ground rules

- The primary rule is that only one person speaks at a time. Please no interruption when someone is speaking. Please wait until they have finished.
- Raise your hand if you want to talk
- There is no right or wrong answers
- No talking to the person beside you
- There is no order in which participants speaks
- When you do have something to say, please do so. There are many of you in the group and it is important that I obtain the views of each of you.
- You do not have to agree with the views of other people in the group.
- No cellphone
- Does anyone have question/questions?

Please we will like everyone to introduce themselves.

Socio challenges:

Please you have a couple of minutes to think about your experience of how you got infected, to admission into ETU, describing your stay and upon discharge.

- How did you get infected with EVD?
- How did you seek treatment (e.g. self-reporting or bed ridden)?
- Could you kindly tell me your experience during your stay in the ETU (treatment, interaction with health workers, and other patients)?
- How long did you stay in the ETU?
- How were you received by family, community and employer?
- Have you experienced any symptoms since you were discharged from the ETU?
- If yes, what are those symptoms?

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- How are these symptoms affecting your personal relationship?
- With your experience are there any gender- specific challenges that Ebola survivors are faced with?
- Have you experience any form of stigmatization since you were discharged?(e.g. families, community, work mate, church mates or school/class mates)
- What are you coping mechanisms with regards to stigmatization?

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Economic challenges

- Prior to EVD infection, what was your source of income?
- Are you performing same job since Ebola virus disease outbreak (if no, probe for new job and reasons for leaving old job?
- If you are unable to work, what are your coping mechanisms?
- How has EVD affected your monthly income and expenditure? (Explain pre & post)
- How do you access basic health services?
- How has EVD affected you diet?
    - What types of food do you eat? (E.g.
    - What is the frequency of diet?
    - Is it the same as prior EVD outbreak?

Others

- How is EVD affecting your normal life? Socio-cultural (E.g. handshaking, bush meat eating, attendance at social gathering etc)
- Do you think there are future consequences as a result of been infected with EVD?
- Are there any groups providing healthcare, livelihood programs and food security?
- If yes, what group/groups are assisting?