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**Supporting Ebola Virus Disease Survivors for Better Health and Well-Being: an Investigation into the Role of the Sierra Leone Association of EVD Survivors in Bombali District.**

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I am aware of the University's policy on plagiarism and I confirm that the work presented in this dissertation is entirely my own.

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## Preface

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A distinguished tenki to all of the Ebola heroes that I met during my studies. I thank you all so much for your time and for welcoming me to the Sierra Leone Association of Ebola Survivors Bombali. Mamo!

Chris, you're a star. Thank you for being so patient with me, let's make up for all the times that we have missed.

Finally, as always, thank you to Michael and my Mumy for being a fantastic pair of lovely human beings, who I can always call on for support...and last minute proof-reading!

## **Abstract**

Ebola Virus Disease (EVD) survivors in Sierra Leone currently face many challenges. This qualitative study investigates the Sierra Leone EVD Survivors Association and its role in enhancing or diminishing the health and well-being of its members through Salzer's concepts of supports. The study critically examines the survivors' perceived problems and satisfaction of the support that is provided to them and explores the interrelationships between direct and indirect support. Additionally, the thesis considers how the provision of support enhances or undermines the members' self-management.

The research was conducted over a six week period in Makeni, based in Bombali District, Sierra Leone. The qualitative approach involved semi-structured interviews with SLAESB members, key informant interviews with the executive team, complementary observation of an association meeting and a reflexive diary.

The results suggest that the support group has mainly enhanced the health and well-being of EVD survivors, especially in terms of psychosocial health. However, the expectations of SLAESB members have potentially created a dependence on indirect instrumental support. The findings provide an insight into how a support network contributes to the health and well-being of disease survivors in a resource-poor setting, after an outbreak and before confirmed programmes of support are implemented. This study contributes to the discussion surrounding the ambiguities of the concept of support and aims to open up further debate as to the importance of peer networks as a method of enhancing health and well-being.

## Abbreviations

|        |  |
|--------|--|
| AIDS   | Acquired Immune Deficiency Syndrome                          |
| CHO    | Community Health Officer                                     |
| CPES   | Comprehensive Package for EVD Survivors                      |
| EVD    | Ebola Virus Disease  |
| GoSL   | Government of Sierra Leone                                   |
| HIV    | Human Immunodeficiency Virus                                 |
| MoHS   | Ministry of Health and Sanitation                            |
| MSWGCA | Ministry of Social Welfare, Gender and Children's Affairs    |
| NGO    | Non-Governmental Organisation                                |
| PHC    | Public Health Centre   |
| SLAES  | Sierra Leone Association of Ebola Survivors                  |
| SLAESB | Sierra Leone Association of Ebola Survivors Bombali (branch) |
| UN     | United Nations   |
| UNDP   | United Nations Development Programme                         |
| WHI    | World Hope International                                     |
| WHO    | World Health Organisation                                    |

## Definitions

**Survivor:** A person who was diagnosed with EVD, survived and was consequently discharged from the treatment centre once they were no longer a transmitter of the disease. They were issued a certificate of survivor status upon discharge. In addition to their certificate, EVD survivors can be identified from the records kept by Sierra Leone Association of EVD Survivors (SLAES).

**Support group:** A network of peers, sharing common experiences and similar interests, who come together to provide each other with support.

## **Chapter 1. Introduction**

### **1.1. Introduction**

The thesis is concerned with the support given to improve the health and well-being of Ebola Virus Disease (EVD) survivors in Bombali District, Sierra Leone. It achieves this by investigating the Sierra Leone Association of EVD Survivors (SLAES), specifically the branch situated in Bombali (SLAESB). In addition to looking at how the association directly provides its members, the study also explores how SLAES influences and works with other organisations, services and the local community to provide support for EVD survivors. More specifically, the study explores the association's members' perceived availability/expectations of support, actual received support and satisfaction of support.

### **1.2. Background**

The unprecedented EVD epidemic reached Sierra Leone in 2014; by the end of the outbreak, the country had 14,124 reported cases, 3,956 deaths and over 4,000 survivors<sup>1</sup> (WHO, 2016; WHO, 2016b; UNDP, 2016). Due to the relatively recent emergence of EVD and the limited scale of previous outbreaks, the latest epidemic has resulted in more survivors than ever before and consequently, new and unexpected social issues have developed. Although the outbreak is now over, the war against Ebola has not yet ended (GoSL, 2015).

Similar to other communicable diseases that cause sequelae, studies on EVD survivors from previous outbreaks have revealed that the disease can have long-lasting effects on health and well-being. For example, numerous post-infection sequelae have presented themselves, such as ophthalmologic issues, secondary infections and psychosocial manifestations (De Roo et al., 1998; Kibadi et al. 1999; Rowe et al., 1999; Wendo, 2001). Since the latest outbreak, further studies on the sequelae have revealed an even larger array of health issues, collectively known as Post-Ebola Syndrome (PES) and Sierra Leone is now faced with the task of treating over 4,000 survivors for these outcomes and

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<sup>1</sup> The exact number of EVD survivors is unclear and numerous sources state varying data. For example, the UNDP and the Ministry of Health and Sanitation for Sierra Leone state that there are over 4,000 survivors, whereas if you calculate the survivors using the data from The Economist and the WHO's Ebola data and statistics summaries, then it can be assumed that there are over 10,000 survivors. These discrepancies could be accounted for by the resource-poor setting, which can make it difficult to track cases and to achieve reliable diagnoses of EVD. Furthermore, to confuse things further, the executive team of SLAES Bombali District, informed me that there are 7,678 survivors registered to the association. The accuracy of this data can impact upon health needs assessments and public health interventions and is therefore, an avenue that could be explored in future research

preventing any further transmission (Bortel, et al. 2016; Deen, et al. 2015; Scott, et al. 2016; Tiffany, et al. 2016).

Sierra Leone's health sector is one of the poorest in the world and consequently, the country failed to achieve the "minimum International Health Regulations core capacities by 2012" (GoSL, 2015: p24). Events, such as the civil war, which lasted for 12 years, as well as infectious disease outbreaks (i.e. the cholera epidemic in 2012), have restricted the development of the health sector. As a consequence, before the EVD outbreak, "only 35% of facilities had the basic equipment required for service delivery" (GoSL, 2015: p24). The health workforce were largely focused in Freetown, where 50% of all health professionals covered 16% of the country's population (GoSL, 2015: p24). Currently, the already insignificant workforce is greatly depleted, especially since the country lost 221 healthcare workers to EVD (GoSL, 2015: p25).

Based on other survivors from sequelae-causing communicable diseases and patients with chronic infections, such as those with Post-Polio Syndrome and HIV/AIDS patients, physical limitations can impact upon a person's quality of life (Crossley, 1998; Davidson, et al. 2009). Such limitations can have detrimental effects on social connectedness, self-management and independence, as well as general health and psychosocial well-being (Crossley, 1998; Harrison & Stuifbergen, 2006). Therefore, meeting the social needs of EVD survivors is an important consideration in order to prevent another major national health issue. One accepted method to improve people's health and well-being is that of peer support groups and networks (Mead, et al. 2001; Rogers, et al. 2009).

Research has been conducted to demonstrate the benefits and detriments of peer networks and, although research is equivocal, it is evident that support groups have played an important role<sup>2</sup> in previous epidemics, such as HIV/AIDS, as well as in the management of non-communicable diseases, such as cancer and stroke (Kalichman, et al. 1996; Kessler, 2014; Ussher, 2006; Wouters, et al. 2009). With specific reference to EVD survivors, the recentness of the unprecedented outbreak and thus the emergence of support groups indicates a novel area of research; to date no research has examined their functioning and effects. This study aims to contribute to this body of work, in order to provide a new perspective on whether or not being part of a support group can enhance the health and well-being of EVD survivors. It accomplishes this by providing a direct

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<sup>2</sup> Be it good or bad

insight into the SLAESB and establishing a base of information for use in policy-making and future research.

### **1.3. The Role of Support**

The notion of 'support' is a broad concept with many connotations and its use in public health and development is widespread. For the Ebola outbreak in Sierra Leone, support came from numerous national and international actors to control the epidemic in a variety of ways, "from sending medical teams and mobile laboratories, to building treatment centres, to donating funds and supplies, to providing training, to deploying specialists in areas such as epidemiology, community engagement and anthropology" (WHO, n.d.).

Now that the outbreak is over, support needs to be redefined to adapt to the current situation. As mentioned previously, Sierra Leone now has over 4,000 EVD survivors who are confronted with many challenges that can affect their health and well-being. GoSL (2015) have identified them as some of the country's "most vulnerable" individuals and international actors, such as WHO, Public Health England and NGOs have also recognised that the survivors are in urgent need of support (PHE, 2015; UNDP; 2016; WHO, n.d.). Additionally, it is argued that Sierra Leone has an obligation to maintain support to those affected by EVD, as a logical continuation of the current global commitment to end epidemics of neglected tropical diseases and other communicable diseases (UN, 2015).

Support is often conceptualised in various ways within the field of health and well-being, making it difficult to devise policies and interventions to offer it. Salzer (2002) has attempted to categorise these concepts into five main types of support prevalent in the literature. These categories have been chosen for this study, because they incorporate many of the different concepts of support devised by other scholars and academics (Gottlieb, 2000; Kelly, Munoz & Snowden, 1979; Weiss, 1974).

- 1) Emotional Support - someone to confide in, who provides esteem, reassurance, attachment and intimacy
- 2) Instrumental Support - services, money, transportation
- 3) Informational Support - advice/guidance, help with problem-solving and evaluation of behaviour and alternative actions
- 4) Companionship Support - belonging, socialising, feeling connected to others
- 5) Validation - feedback, social comparison

Salzer (2002)

The existence of disparities between different health issues makes the process of providing support extremely complex. For example, EVD is an emerging disease and, thus, only limited research has been conducted on best practices for management of the survivors (WHO, 2015). Consequently, WHO (2016c) is currently in the process of developing a framework of care for Ebola survivors; thus far, they have recommended three areas of care: physical, mental and social. In order to assist Sierra Leone in achieving this, the organisation is working with the MoHS and MSWGCA (2015) to set up a package of Comprehensive Package for EVD Survivors (CPES) in Sierra Leone, involving numerous actors as part of a collaborative effort to ensure the achievement of the best possible solutions to support EVD survivors. However, the published literature so far has mainly focused on clinical care (WHO, 2015).

In addition to the different categories of support, its provision can evidently be influenced by additional factors, such as finance, skills and material resources. Unfortunately, Sierra Leone remains a resource-poor country and the outbreak had a devastating impact on its entire infrastructure (GoSL, 2015; UNOCHA, 2015). Consequently, the country has many obligations to fulfil in order to recover from the outbreak and their dependence on international actors for support is significant (GoSL, 2015). As mentioned previously, Sierra Leone's health system is poor and its health workforce limited, which had a major impact on the spread of EVD during the outbreak (GoSL, 2015; WHO, 2015b). In order to address the issue of a lack of government resources, voluntary EVD survivors were organised and mobilised to raise awareness to help prevent further transmission (Epstein, 2014; WHO, 2015).

The use of a peer network to support the health and well-being of Sierra Leone is an interesting idea, though not an entirely new concept in the literature surrounding public health (Salzer, 2002). Therefore, it seems sensible to investigate this existing structure to assess its viability in providing support to EVD survivors. Peer support is based on a shared experience of EVD, rather than academic knowledge learnt from a "book", which offers an alternative aspect to government-provided services (Borkman, 1999).

Significant research has been conducted to link the use of peer networks, such as support groups, to health and well-being outcomes. For example, Kessler's research group (2014) found that stroke victims that joined a support group benefitted from improved community reintegration, enhanced social connectedness and better access to health services. Both

Achieng et al. (2012) and Bateganya et al. (2016) demonstrated that HIV positive patients - who were members of a peer support network - adhered better to treatment and had improved referral and access to healthcare services. In addition, Bateganya's team (2016) recorded improved health outcomes, a reduction in disease morbidity and an enhanced quality of life. Pappin et al. (2012) also noted an improvement in patients' levels of depression.

However, not all literature supports the idea that support groups can enhance health and well-being outcomes. In fact, Crossley (1998) argues that the role of support groups is much more complex and that they can have varying impacts on the empowerment of members. She examines the temporal horizon of the "sick role" and explains that peer support can have both beneficial and detrimental effects on their rights, access to financial benefits, referral/access to healthcare and psychosocial well-being (Crossley, 1998; Parsons, 1951).

Furthermore, it can be seen from the above examples, that support groups can offer varying degrees of support, which can be direct or indirect. For example, associations can be involved in advocacy, human rights and can act as a referral system for external health services (Achieng et al. 2012; Bateganya et al. 2016; Crossley, 1998). Additionally, they can provide direct methods of support, such as social reintegration and psychosocial counselling (Kessler et al. 2014; Pappin et al. 2012). Doubt remains on whether or not either of these methods of support can enhance the health and well-being of its members (CADTH, 2013; Crossley, 1998). In addition, as previously mentioned, the availability of skills, finance and material resources can also influence the impact of support and it is, therefore, important to look at support groups in a wider context.

Nonetheless, the literature referenced above is sufficient evidence to indicate that support groups can be beneficial in certain contexts. In this case, the study group of interest are EVD survivors, many of whom suffer from PES, which is relatively unstudied. Consequently, the future of the condition is uncertain, making support difficult to plan and implement. Furthermore, the current literature mainly focuses on support groups for long-term conditions in other countries, which is a different context to EVD survivor support groups in Sierra Leone. There is a clear gap in research regarding support groups in this context and thus this study is an investigation into the concept of an EVD survivor support group as a method to improve the health and well-being of EVD survivors in Sierra Leone.

#### **1.4. Sierra Leone Association of Ebola Survivors**

The University of Makeni<sup>3</sup> (UNIMAK) provided awareness of SLAES and revealed that all EVD survivors in the country are members<sup>4</sup>. After an extensive investigation using relevant online academic search engines, such as PubMed, Wiley Online Library, Anthrosource and StarPlus Sheffield, a single appropriate result was returned, namely Kuriansky's (2016) book 'The Psychosocial Aspects of a Deadly Epidemic: What Ebola Has Taught Us'. This work contained brief, but useful information on the formation and motives of SLAES. In addition to the book, the search led to one research paper that acknowledged the association as helping them in their own investigation (Deen, 2015).

Excluding academic work, most knowledge regarding SLAES prior to arrival of the research project in Sierra Leone, was based on the association's Facebook page, a few news articles and a WHO meeting report (Acland, 2016; Anon., 2016; SLAES, 2015; WHO, 2015). Furthermore, after using the search engine on the WHO website, the WHO meeting report was the only document or page that mentioned SLAES (WHO, 2015c). Consequently, research in this area is insignificant, yet at the same time SLAES is extremely relevant to Sierra Leone's recovery from the Ebola outbreak.

As an addition to the work just described, this study intends to provide more in-depth information regarding SLAES and in particular, the Bombali District branch of the organisation, in order to deepen our understanding of the processes involved in improving the health and well-being of EVD survivors in Sierra Leone. The findings contribute more accessible and collective data on the organisational structure and the aims/motives of SLAES; it also indicates how the association administers support to its members, both directly and indirectly. More generally, this study demonstrates how to approach research on the subject of support for EVD survivors in Sierra Leone.

Before undertaking this study, by using the research gathered from the internet and from contacts at UNIMAK, it could be determined that in January 2015, a group of EVD survivors took the initiative to form SLAES (2015). The SLAES organisation was principally created to "foster social cohesion, economic reliability and sustainable development

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<sup>3</sup> Host organisation in Makeni, Sierra Leone

<sup>4</sup> Although there are discrepancies, which are explained later in the thesis

among (the survivors)” (Kuriansky, 2016). Additionally, as well as providing support, the association played a role in ending the outbreak by organising voluntary survivors (who were now immune to the disease) to mobilise communities, especially in quarantined areas (Epstein, 2014; WHO, 2015).

After the outbreak, SLAES worked closely with the Ministry of Social Welfare, Gender and Children’s Affairs (MSWGCA) to reduce the stigma attached to EVD survivors and advocated for the adoption of laws that would penalise offenders (Kuriansky, 2016; WHO, 2015). Furthermore, the association organised a national protest in April, 2016, in order to demand the free healthcare that they had been promised by the GoSL which, according to the WHO meeting report (2015), had been a successful campaign (Anon., 2016). Currently, SLAES aims to be involved in post-Ebola development strategies and to ensure effective communication between the government and the survivors, whilst continuing to strive for better social conditions to improve their health and well-being (WHO, 2015).

## **1.5. Field Site Context**

### UNIMAK’s Mission Statement:

To promote human, social, political and economic development in Sierra Leone and Africa as a whole, which at the same time respects the environment so that its resources are used for the benefit of all.

UNIMAK, n.d.

The research period lasted for six weeks and during that time I was based at the host organisation, UNIMAK, which is an educational facility established as a private university in 2009 (UNIMAK, n.d.). The facility was the third university to be formed in Sierra Leone and is based in Makeni, the largest city in Bombali District in the Northern Province (UNIMAK, n.d.; UNOCHA, 2015). During the Ebola outbreak, UNIMAK staff were actively involved in the containment of the disease and worked in collaboration with the University of Cambridge to open a diagnostics laboratory (Wellcome Trust, 2016). Currently, the university continues to research the disease, working closely with EVD survivors and SLAES in both the Bombali and Port Loko Districts (UNIMAK, n.d.).

UNICEF collaborated with MSWGCA to map Ebola survivors across Sierra Leone and, in November 2015, 418 survivors were registered in Bombali District (UNICEF, 2015). A meeting was conducted with the executive team, who confirmed that the latest number of survivors registered to their branch was 436. These survivors are entitled to free

healthcare and have been allocated a facility dedicated to their health and well-being, established at an old government clinic in Makeni<sup>5</sup>. As a result, the location of UNIMAK as a base was ideal for proximity and access to EVD survivors in the Bombali District.

## **1.6. Research Value**

The WHO have listed Ebola virus disease as a top emerging disease requiring “urgent R&D attention”, because they believe it could feasibly cause another major outbreak in the near future (WHO, 2015d). In recent years, there has also been more attention regarding the aftermath of an EVD epidemic (Scott, et al. 2016). Therefore, research surrounding Ebola has rapidly increased, especially since the unprecedented outbreak in West Africa. However, following the last epidemic, the research so far has mainly focused on the clinical outcomes of the outbreak, particularly psychosocial effects and physical symptoms caused by Post-Ebola Syndrome (PES) (Bortel, et al. 2016; Deen, et al. 2015; Scott, et al. 2016). Currently, there is little focus on how different factors and/or interventions can enhance or diminish the health and well-being of EVD survivors. This study substantially contributes towards this area of research, by providing an insight into the effects of being a member of an extensive network of EVD survivors, such as SLAES.

Furthermore, as previously mentioned, limited data can be found regarding SLAES, which is the biggest association of EVD survivors in Sierra Leone<sup>6</sup>. This study contributes a more accessible and extensive awareness of SLAES, which will supply an improved groundwork for future research. Finally, based on the evidence that HIV/AIDS patient associations have contributed to the “scale-up of HIV/AIDS prevention, treatment, care and support”, researchers at the University of Makeni (UNIMAK) believe that the same concept could apply to EVD survivor associations (Wadoum, et al. 2016). Therefore, it is hoped that the findings of the study will support the University of Makeni in their own research and help them continue their positive and valuable collaboration with SLAES.

# **Chapter 2. Conceptual Framework**

## **2.1. Salzer’s Categories of Support**

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<sup>5</sup> Information was identified upon arrival in Makeni, Sierra Leone

<sup>6</sup> Based on the fact that every survivor in Sierra Leone automatically becomes a member, which was identified during a key informant interview

In an attempt to understand the support that is received as a member of SLAES, Salzer's (2002) categories of support will be used as a basic framework, because it incorporates a large variety of concepts found within the literature. This enables comparison between the role of a support group in the context of EVD survivors in Sierra Leone, to literature - with similar conceptualisations of support - on support groups in different contexts. For example, comparisons of care could be made between EVD survivor support groups and patients with long-term conditions or support groups in resource-poor settings (DoH, 2005; Elafros, et al. 2013).

- 1) Emotional Support - someone to confide in, who provides esteem, reassurance, attachment and intimacy
- 2) Instrumental Support - services, money, transportation
- 3) Informational Support - advice/guidance, help with problem-solving and evaluation of behaviour and alternative actions
- 4) Companionship Support - belonging, socialising, feeling connected to others
- 5) Validation - feedback, social comparison

Salzer (2002)

There is a certain degree of overlap between each type of support, but Salzer (2002) provides a useful base for analysis. For example, support interventions such as counselling could be categorised as emotional, instrumental (services), informational, companionship and validation support, depending on the context in which it is delivered. Nevertheless, below are some examples of support group interventions from each category that have either enhanced or diminished the health and well-being of the members.

### **2.1.1. Emotional Support**

Emotional support is relevant to EVD survivors for many reasons. Firstly, the trauma they faced during the outbreak, such as losing their loved ones, or the alienation of an isolation unit, can have repercussions on their psychological state (Rabelo et al. 2016). Secondly, after the outbreak the survivors can be prone to feelings of guilt and can face stigma in their communities (Kuriansky, 2016). An example of a support group that has provided emotional support in a similar context is a peer association in Zambia (a resource-poor setting) for epileptic youths, which helped reduce stigma by sharing "problem-solving advice and...coping techniques" (Elafros, et al. 2013). In addition, Beattie et al. (2010) and Gurnani et al. (2011) found that support groups could reduce stigma by working with policy-makers and mobilising the communities.

### **2.1.2. Instrumental Support**

Many recognise the need for EVD survivors to have access to a variety of services; Berghs (2015) and WHO (2015) both recommend comprehensive support, inclusive of material resources and social, economic and health services. Achieng et al. (2012) and Bateganya et al. (2016) both demonstrated that HIV positive patients who were members of support groups in resource-poor settings had enhanced accessibility to instrumental support. It was found that through open discussions and peer encouragement, patients were better able to inform each other of any health issues they were experiencing, thus setting a referral network in motion.

### **2.1.3. Informational Support**

In contrast to the studies above, Crossley (1998) found that HIV positive patients who were members of a patients' association had increased potential to experience detrimental effects, in addition to the benefits. For example, due to receiving information and advice regarding government benefits available to them, the majority of the members had chosen to quit their jobs (despite feeling physically able to work), thus creating a financial dependence. Therefore, whilst not being too much of a problem in a wealthier state such as Britain, in a resource-poor setting, cash benefits could have a disadvantageous affect.

### **2.1.4. Companionship Support**

Sattoe et al. (2013) conducted a study on young people with end-stage renal disease who attended a peer support camp. Peer buddy-to-attendee support lead to increased socialising within the camp. However, it was found that the camp caused a "diminished sense of inclusion" due to "over-identification" of self by the attendees, which became apparent after support camp had finished. Consequently, this issue of feeling disconnected with others outside of the peer network is an important consideration.

### **2.1.5. Validation**

Kessler et al. (2014) conducted a study on a stroke peer association, which provided peer counselling between a newly discharged stroke patient and a "stroke survivor who is experiencing good community reintegration". The pairs also met for discussions and had telephone follow up calls. These support interventions provided validation and social comparison and benefitted its members by initiating the helper-therapy principle (Reissman, 1965).

## **2.2. Wider Context**

One shortcoming of Salzer's (2002) categories is the adequacy of the framework in the context of SLAES. For example, there is no mention of direct or indirect support, both of which can apply to all categories. The indirect support for EVD survivors in Sierra Leone can be provided by a number of external actors, such as GoSL and NGOs. Therefore, it is important to consider whether or not the support survivors receive as part of SLAES is direct or indirect and, if indirect, how the association influences access to this support. Factors such as funding, priorities and availability of skills can impact on the relationships between SLAES and these organisations. Therefore, this study takes these additional factors into consideration during analysis of the data, in order to determine the EVD survivors' dependence on external actors.

### **2.2.1. External Actor Commitments**

WHO (2015) and GoSL (2015) have committed to restoring health services, psychosocial support services, providing cash transfers business and education and to aid employment and livelihoods. However, access to these services could be difficult in a resource-poor setting. Numerous NGOs and MSWGCA have also promised material resource packages, including food, money, clothing and homeware, which some survivors received immediately after discharge (WHO, 2015). Unfortunately, not all survivors have received their discharge packages and MSWGCA have admitted to complications, such as an incomplete registration database of EVD survivors (VOA, 2016). In the long-term, Sierra Leone are working closely with national and international actors to construct CPES, as mentioned earlier in this thesis. Currently, limited literature can be found regarding the types of support this will offer.

## **2.3. The "Sick Role"**

Parsons (1951) introduced a theory that when an individual is ill they deviate from the norms of society and take on the social role of being sick. He believed that as long as the illness was legitimised, this dependency on the healthcare system was sanctioned behaviour. Parsons also believed that the individual had the responsibility to improve their own health, by pursuing the best treatment.

*“Illness is predominantly a withdrawal into a dependent relation, it is asking ‘to be taken care of’”*

(Parsons, 1951: p285)

However, many academics contested his work and claimed that he did not consider those with long-term conditions or individuals in different contexts. For example, Radley (1994) suggests that when a patient suffers from a condition that has a level of uncertainty regarding the illness, then this can impact on the relationship the individual has with medical professionals. Furthermore, Crossley (1998) states that “practical, everyday problems experienced by the sufferer of chronic illness may be better understood by other people in the same situation”, which therefore, decreases the sick person’s dependency on the state.

As previously mentioned, it is possible to draw comparisons between EVD survivors and patients with long-term conditions. Consequently, whilst exploring the support that the members of SLAESB receive, I took the “sick role” into consideration, in order to investigate their self-management and independence of/dependence on external actors.

## **Chapter 3. Research Design**

### **3.1. Research Aims**

The overall aim of this study was to investigate SLAES, especially in relation to its effects on the support given to improve the health and well-being of EVD survivors in the Bombali District of Sierra Leone. This was conducted by critically exploring the support that had been provided to SLAES from the GoSL and other organisations, and by examining how this was distributed to its members. By drawing from literature and guidelines produced by WHO and GoSL on the recommended care for EVD survivors, the study investigates the role that SLAES plays in its delivery. In addition, the research determined the members’ perceptions of support for EVD survivors, identifying discrepancies between perceived support and received support. Furthermore, participant opinions were gathered on the value of SLAES in terms of enhancing or diminishing their health and well-being.

### **3.2. Research Questions**

1. What is SLAES and how does it operate in Bombali District?

- a) History
  - b) Organisational structure
  - c) Organisational culture
2. What are the members' perceptions of the problems they face as EVD survivors?
  3. Based on Salzer's (2002) categories, which types of support does the association provide to its members?
    - a) How do these fit into the wider context?
    - b) How satisfied are the members with the support that is provided by SLAES?
  4. How does SLAES enhance or undermine survivors' own self-management?

### **3.3. Research Methods and Methodology**

In order to best achieve the research aims, a predominantly qualitative approach was adopted because of its suitability for exploring and interpreting the "opinions and experiences" of the participants (Hay, 2005). Many researchers, including Patton (2001) and Wiersma (2000), recommend triangulation of data collection methods in order to increase the reliability and credibility of findings. Therefore, four methods of data collection were employed: semi-structured interviews, key informant interviews, complementary observation and a reflexive field diary. Additionally, by using the contacts I met once I had arrived in Sierra Leone, I endeavoured to expand my documentary evidence. By doing so, it helped build a better picture of SLAES and the Bombali branch (SLAESB), which was used to refine my research methodology and to put my work in a broader body of evidence.

#### **3.3.1. Semi-Structured Interviews**

It was decided that the use of semi-structured interviews was the best method to investigate the participants' views and opinions, whilst maintaining rapport (Hay, 2005: p80,83). The approach enabled a certain level of control over the direction of the interview, without making any other contributions that would affect the responses of the participant (Sorrell & Redmond, 1995; Melia, 2000). The semi-structured method also facilitated flexibility in the framework of the interview, because it allowed a conversational flow. Whiting (2008) states that this approach is favourable for revealing previously unidentified information and thus leading to additional lines of enquiry.

Hay (2005: p 17) states that qualitative methods are useful to comprehend the "naturalised discourses that exclude and marginalise certain groups", making it suitable to research the

study population of interest. These were members of SLAESB and thus participants were initially approached at one of their regular meetings by my supervisor at UNIMAK, who has vast experience of working with the EVD survivors (both during and after the outbreak) and is known to SLAESB. Having had previous experience conducting research with the Bombali branch of the association, my supervisor was well-placed to deliver information about my arrival and to read out a prepared information sheet<sup>7</sup>. Furthermore, his contact details were already widely known and he was easily contactable in case potential participants wished to discuss matters with him.

The organisation was given details about me and the research I wished to conduct (aims, objectives and the potential impact/outcomes), in addition to my personal reasons for being there as a student studying for my master's degree. Additionally, it was made clear that the participants would be anonymised for their security and were able to opt out of the study at any time. SLAESB members were subsequently invited to ask questions, and given time to contemplate their participation. A meeting with the executive team was organised once I had arrived in Makeni, during which I was able to discuss my situation and my research in more detail. This was subsequently passed on to the extended members in another general meeting<sup>8</sup>. Members that wanted to participate contacted the chairlady of SLAESB and she then helped to organise the interviews.

As a result, due to the nature of my research topic, the sampling technique that was most suitable was convenience sampling. This non-random sampling method was used due to not being able to choose participants, which understandably makes the data less generalisable (Patton, 2001). However, it was the best way to investigate this topic due to the limitations of contacting and accessing EVD survivors. To ensure maximum variety, it was made clear to the chairlady that I required participants that were diverse in factors such as age, gender, livelihood, socioeconomic status etc.

Numerous guidelines for qualitative research, including Bernard (2000: p178) and Morse (1994: p225) advise conducting between 30-50/60 interviews. Therefore, although the sample size for this study was mainly determined by time and weather constraints, there

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<sup>7</sup> See Appendix A

<sup>8</sup> I was unable to attend due to the short notice.

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were 36 participants for the semi-structured interviews, which falls within the recommended amount.

The interviews took place at the survivors' clinic in Makeni; the familiarity of the interview setting enabled the participants to feel at ease, whilst maintaining a professional setting without household distractions (Willis, 2006). Translators were used for the majority of the interviews, translating between English and Krio or Temne<sup>9</sup>.

Preceding the interview, individual participants were read out the consent form<sup>10</sup> in their own language and thumbprint consent was taken if the participant wished to continue. A password-protected dictaphone was used to record all of the semi-structured interviews. These were later transcribed and coded, allowing time for the data to be reviewed and interpreted, whilst enabling the interview itself to flow without interruptions to write down the dialogue (Jackson, 2001). Supporting notes regarding body language and other observations were made in the reflexive diary, providing a strong and well-rounded method of collecting data.

In addition to the semi-structured interviews, informal conversations between myself and NGO workers, local residents and staff members from UNIMAK and the survivors' clinic helped direct me towards further lines of enquiry and relevant survivor support projects (Valentine, 2005). The information that I learnt from these conversations was not directly used for data analysis, but instead contributed towards my overall documentary evidence and helped to form the key informant interviews. Furthermore, as recommended by Hasselkus (1991), I made sure to frequently discuss my findings with my translators and supervisor from UNIMAK, otherwise known as 'peer debriefing'. Their cultural background and research experience ensured that I did not omit any themes that I may not have noticed.

### **3.3.2. Key Informant Interviews**

For the key informant interviews, the initial process of recruiting participants was similar, but at the point of the executive meeting, I asked them directly if they would like to be interviewed. Four of the key informants were from the executive team of SLAESB and the

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<sup>9</sup> Please see 2.3.3. Interpreters in the Ethics and Limitations section

<sup>10</sup> See Appendix B

fifth was a community health officer (CHO) working at the survivors' clinic. All five key informants were literate, so I was able to give them information sheets for further contemplation, before giving them time to decide.

The key informant interviews were more "loosely structured" than the semi-structured interviews and allowed me to gain a wider knowledge of the research context, providing me with more factual information regarding SLAES (USAID, 1996). Furthermore, they were also informed by issues that had arisen from the literature and information I had established from previous interviews with EVD survivors. Similarly to the semi-structured interviews, these interviews were also recorded.

Willis (2006) recommends interviewing key informants twice: at the beginning of the research period in order to gain information that may prove to be useful, and at the end to discuss key findings and ask additional questions that may have emerged from other interviews. However, due to time restrictions and participant schedules, this was only possible for key informant KI02, whereas the additional key informants were interviewed only towards the end of the research period.

### **3.3.3. Complementary Observation**

In order to gain the best possible understanding of how SLAES functions, I asked the executive team of SLAESB if I could sit in on some of their general meetings. As per Kearns (2010: p193), this method of "complementary observation" enabled me to observe EVD survivors in a more natural setting. However, although my intention was to remain as a non-participant, my presence inevitably had an impact on the behaviour I witnessed during the meeting and I acknowledged the fact that I was classed as what Gold (1958) would call an observer-as-participant. Nonetheless, witnessing the activities of SLAESB added value to the data I collected in the semi-structured interviews and, as long as I remain critically reflexive in my analysis, my observations are "self-conscious, effective and ethically sound" (Kearns, 2010: p192).

I chose not to take notes during the meeting or utilise an audio recorder, because I believed that these methods would be disruptive and could have affected the EVD survivors' willingness to participate. Therefore, I made sure to give myself time directly after the meeting to take field notes and record relevant observations. The meeting was mostly conducted in Krio, which made it slightly more difficult to understand the

proceedings. However, as the meeting took place towards the end of my study, I had a better grasp of the language and was able to comprehend the majority of what was discussed<sup>11</sup>. Furthermore, my translator was also present during the meeting, so I was able to ask questions at the end of the event and receive confirmations on what I had already deduced.

### **3.3.4. Reflexive Field Diary**

Before embarking on my placement, I began a reflexive diary to document my experiences and feelings, which enabled me to examine my perceptions, assumptions and motives (Jackson, 2001). In this way I was able to ensure “transparency in the research process” (Ortlipp, 2008). In addition, it enabled me to remain aware of any limitations to my data, such as the issues of power and positionality (Sultana, 2007).

## **3.4. Data Analysis**

Based on the literature surrounding support groups and the conceptual framework, I came up with a list of categories that I would expect to occur in the data. I manually coded both the transcripts and the reflexive diary, highlighting any codes that fit into the categories and creating new categories for any codes that did not fit into the criteria (Jackson, 2001). As per Cope (2003: p446), I started by using a ‘descriptive’ level of coding, to mark *in vivo* codes<sup>12</sup> and, after I had begun my data analysis and reflected upon the literature, I returned to the transcripts for a second level of ‘analytic’ coding. In this way, I was able to link the data more effectively to the wider literature and refine my original research questions and framework based on the strength of the thematic evidence. This thoroughness during the coding stage improves the accuracy of the coding and is also recommended by Jackson (2001) to ensure that no impulsive conclusions are drawn.

After coding, I was able to begin the process of mapping, whereby I drew out associations between themes and categories, and identified cross-cutting themes. In addition, I identified any key words and phrases that I wished to use as quotes.

## **3.5. Ethics and Limitations**

### **3.5.1. Ethics Approval**

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<sup>11</sup> Krio is a language that has a large quantity of English terminology

<sup>12</sup> What was actually stated in the interviews or direct observations made in the reflexive diary.

Ethics approval was granted by both the University of Sheffield and the University of Makeni before any data collection took place<sup>13</sup>.

### **3.5.2. Expectations**

In contrast to what some participants may have believed, that they are being given the “chance to ‘tell their story’” (Hammersley, 2013: p530), I read across and between the individual interviews to generate a more overarching interpretation and understanding. In this way I was able to challenge existing perceptions and look at the data collectively, rather than focusing on individual case studies (Ratner, 2002). Therefore, there is an understandable degree of discordance between the expectations of the participants and the findings of my study (Hammersley, 2013). This was enhanced by the collective plight of the survivors, many of whom vehemently stated that they were glad that I had come and were keen for me to return to England to present my findings to advocate for their cause. Accordingly, it is not surprising that I felt an element of deception and guilt, although I had done my best to explain the reasons for my presence and the purpose of my research, as outlined in the section on semi-structured interviews.

### **3.5.3. Positionality**

Vast amounts of literature have explored the area of positionality in field research and thus, I was aware of my status as an educated, British female. To some extent, a certain degree of power imbalance is inevitable when a researcher is from the Global North (Apentiik & Parpart, 2006). Therefore, I thoroughly thought through my research methods before proceeding with my research and endeavoured to remain critically aware of my appearance and actions throughout my study.

Before I arrived in Sierra Leone, my UNIMAK supervisor informed me that I would have to provide support for the EVD survivors that were to participate in my study, in order to give back for their time. Although Ravitch and Mittenfelner Carl (2016) suggest that paying participants is “not necessarily a good idea or ethically appropriate”, due to the risk of financially motivating people to take part in the study, it was my strong belief that I ought to give back to the EVD survivors for donating their time. Furthermore, due to my host organisation’s recommendation that it was culturally appropriate to give the survivors some support for the ordeal that they have been through, I decided to act in accordance with

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<sup>13</sup> See Appendix A and B for information sheet and consent forms

Schwandt (2014), by giving a “reciprocal social act”. Therefore, it was decided that I would give a standardised amount of money to pay for the participant’s travel costs to and from the interview, as well as donating food and medication to SLAESB as a whole, so that the donation would benefit all of the survivors belonging to that branch. It was hoped that this method of giving back would represent my gratitude for their help without affecting my findings. Nevertheless, I acknowledge the fact that the donations still influenced the participation of the EVD survivors and this is something I have taken into account for my data analysis.

Before I began my research, I discussed with my translator how best to approach the interviews and was subsequently told to introduce myself as a student, rather than a researcher. He advised that in Sierra Leone, the perception of students is that they are usually poor and have to live economically. In this way, I was able to reduce the perception (albeit not prevent it entirely) that I was wealthy, because I was not a member of an NGO or research body. This prevented them from thinking of me as a person with a wage that had access to an organisation’s funds which could have benefitted the association. Twyman et al. (1999) suggest that it is important to consider a “researcher as observed” as well as thinking of the “researcher as observer”. Consequently, I made notes of how I felt I was perceived in a reflexive field diary, recording any feelings or notable occurrences, and I took these into consideration when analysing my data.

#### **3.5.4. Interpreters**

Understandably, there are some limitations surrounding the use of translators in research (Temple & Edwards, 2002). The interpreters that were used for this study were both public health students at the University of Makeni; they are both local Sierra Leoneans and have had experience working during the outbreak and interviewing EVD survivors for their own research. Therefore, both translators were aware of interview ethics and positionality. For the majority of the interviews, I worked with the male interpreter, which for the most part, went smoothly and without issue. However, there were moments during the interviews where I assumed he summarised the answers, because the response he had given was much shorter than the participants’. In order to prevent this, I made sure to speak to him about it after and fortunately, it seemed to improve the way he interpreted the interviews, although it is possible that I lost some of the true responses “in translation” (Bujra, 2006).

#### **3.5.5. Time and Expense Limitations**

The research period lasted for 6 months and consequently, I was only able to attend one general SLAESB meeting due to time limitations and weather conditions<sup>14</sup>. In addition, these same limitations prevented me from attending the more frequent chiefdom meetings, which I identified towards the end of my stay in Sierra Leone. Furthermore, more time would have been needed to establish a favourable relationship in order to be granted access to an executive meeting. Therefore, I am aware that the observational research findings are limited and thus its main purpose is to complement the data obtained from the semi-structured interviews.

Additionally, I realised towards the end of the study that I was only interviewing people from chiefdoms close to Makeni. This was because my supervisor had informed the executive team that I was a student with a budget. Therefore, to prevent me from having to pay a higher fee for participants' travel, the chairlady arranged interviews with EVD survivors from Bombali Shebora, Makarie Gbanti and Safroko Chiefdoms only. Consequently, I am aware that my findings are not generalisable for the whole district and acknowledge that the experiences and perceptions of EVD survivors further away from the survivors' clinic/meeting space may be different from those that I interviewed.

## **Chapter 4. Findings and Discussion**

The research findings have been separated into six sections. The first section answers the first research question, giving an overview of SLAES and how it operates in the Bombali District, including the history of the association, its organisational structure, culture and strategic aims. The second section visualises the problems the participants' perceived they faced as an EVD survivor, answering the second research question. The third and fourth sections answer the first part of research question 3, by presenting Salzer's categories of support as direct from SLAES and indirect from external organisations. It also covers the satisfaction of the participants in regards to the support that is provided. The final section is concerned with research question 4, using Parson's (1951) theory of the "sick role" to explore the survivors' self-management.

### **4.1. Sierra Leone Association of EVD Survivors: an Overview**

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<sup>14</sup> During rainy season, it becomes difficult for the members to reach the clinic for meetings. Consequently, the meetings are restricted to once a month. I was present in Sierra Leone for two of these, although I was unable to attend the first one due to the short notice.

#### 4.1.1. From the Roots Up

The SLAES seems to have many roots, involving multiple smaller survivors' associations from different districts that have all seemingly entwined to create the nationwide network that it is today. Participants who claimed they had been part of the association since its formation gave varying accounts of how they first got involved. However, two things can be deduced; firstly, small unions of survivors began to join together after being discharged from treatment centres in 2014 and secondly, in an effort to control the outbreak of EVD, various actors, such as the former minister of MSWGCA and an NGO, known as Restless Development, encouraged the formation of an association.

Supporting Kuriansky's (2016) testament, all key informants agreed that SLAES reached fruition in January-February 2015, after each district sent 2 survivor representatives to a 3-day meeting in Freetown. Upon their return to their own unions, the representatives informed them that they were to form a national association, with Freetown as the headquarters/"umbrella" branch (key informant KI02<sup>15</sup>). In February 2015, a meeting was held at the regional hospital in Bombali District and the executive team were elected via nominations and mutual consent of the survivors that attended. There was no formal ballot, although it was agreed that the positions were held as an interim authoritative structure (key informant KI02), until the association was ready to hold a proper election<sup>16</sup>.

#### 4.1.2. Organisational Structure

During the key informant interviews for the executive team of SLAESB, they were asked to present the organisational structure of the association in whichever way they felt comfortable. They also provided additional verbal explanations about the responsibilities of some of the roles<sup>17</sup> and their positioning in relation to the chain of reporting. Key informants KI01 and KI03 mapped out the structure using a hierarchical tree and KI02 and KI04 chose to use a numbered list<sup>18</sup>. There were some discrepancies between each of the key informant's structures, in terms of missing roles. However, this was discussed with them at a later meeting (at the survivors' clinic) and it was agreed that there were some

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<sup>15</sup> See Appendix C for list of participant and key informant characteristics.

<sup>16</sup> There has been no further mention of when this will be.

<sup>17</sup> Unfortunately, the executive team never provided the role descriptions due to time constraints. However, they did explain that a "Weep" is the person in charge of keeping order during meetings.

<sup>18</sup> See Appendix D

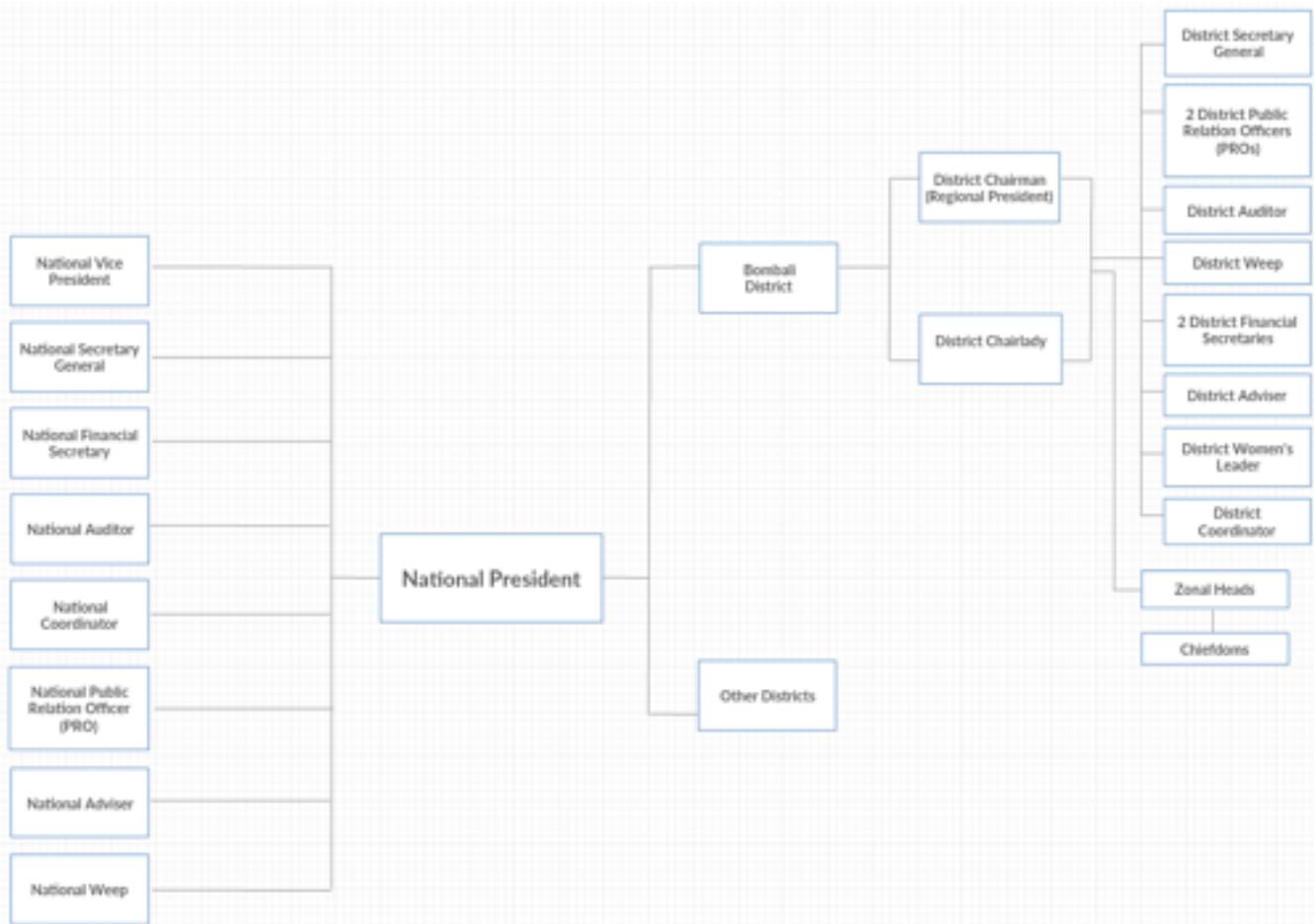


Figure 1. Organisational Structure of Sierra Leone Association of EVD Survivors

mistakes due to human error, which were recorded and taken into account before creating a final organisational structure diagram, as seen in Figure 1. The diagram was sent to the key informants for their comments and was consequently amended before final validation for use in this thesis.

In concurrence with key informant KI02, the information given by all additional key informants and other members of the association portrayed the national executive team as the “umbrella” branch, which the remaining district branches operate under. The national executive team not only operate as the central authority, but are also in charge of the Western Area Districts. The remaining 12 districts each have a branch of SLAES, with their own executive teams. Consequently, SLAES has a highly centralised, mechanistic structure.

Specifically in Bombali District, the executive team also decided to create zonal heads/leaders to represent every chiefdom within the district. This enabled the association to reach all of the EVD survivors, even in the most remote areas. Therefore, when members could not make meetings, or if they could not get in contact due to poor phone signal, then

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the zonal head from that chiefdom would take responsibility. It was their duty, on a weekly basis, to both call the executive team to give updates and to attend meetings at the survivors' clinic. The general meetings were originally held every Sunday, but due to rainy season, poor road conditions and transportation costs, the meetings had been reduced to the last Sunday of every month. However, smaller meetings were held with zonal heads in each chiefdom, usually weekly.

The main method of communication between the members of SLAES is via phone, with regular phone calls between the executives and zonal heads. The chairman and chairlady contact the national president weekly, or whenever they need to discuss anything. Furthermore, there were WhatsApp groups for national and district executives, Bombali district executives and all SLAESB members. A Facebook page is also in use, although access to internet in Sierra Leone is very limited and thus, this is not their main source of communication (CIA, 2016).

In support of the information provided in the WHO (2015) meeting report, participants confirmed that one of the initial aims of the association was to utilise the immunity of the survivors to access quarantined communities; this was to share information on hygiene and ways to avoid transmission. In addition,

#### **4.1.3. “Who feels it, knows it”: Organisational Culture**

From the interviews, it was clear that the survivors shared similar values and beliefs. Their motto “who feels it, knows it” was repeated throughout the six weeks I spent in Sierra Leone and many participants expressed their pride of being united as an association.

*“They form [sic] it so that they would be able to defend us as survivors. Someone will be there to talk for us, to advocate. Everybody will be able to benefit from it. So that we know each other and help each other. If you have any problem [sic], you have somebody to help you.”*

(Participant B8, 43 year old female, teacher)

#### **4.1.4. Organisational Strategic Aims**

After spending six weeks interviewing participants and key informants, observing their interactions and attending a general meeting, it was clear that the main aim of SLAES was



### 4.3. Direct Support from SLAESB

Analysis revealed that the majority of support received directly from SLAESB could be categorised as emotional, companionship and informational, with an element of validation. The semi-structured interviews included a section on why the participants attended SLAESB meetings/activities and many participants mentioned that the association provided unity, the ability to socialise and the opportunity to be together, which directly relates to Salzer's (2002) companionship category of support.

*"Then we unite and come together, sharing our problems [...] every Sunday"*

(Participant B17, 27 year old male, unemployed)

When asked about the proceedings of the general meetings, all participants informed me that they meet to discuss and share their problems and strengths. This was confirmed during my observation of a meeting, where I was able to witness first-hand how the EVD survivors presented their problems and discussed possible solutions. In the interviews, upon asking participants if they found the emotional and companionship support helpful, the majority agreed that it was:

*"For social reasons, when we talk to each other we be [sic] fine. Many people have lost loved ones, so we meet together to share challenges [...] they are very good for me"*

(Participant B3, 35 year old female, petty trader)

A few of the participants also mentioned that they themselves did not experience many, or even any, problems as an EVD survivor. However, they were still happy to be part of the association, because it made them feel valued:

*"I feel so good to work for my survivors and let them be fully reintegrated into their communities"*

(Key informant KI02)

Salzer's category of validation was also evident, as the EVD survivors were able to compare themselves through activities provided by SLAESB - firstly, during the meeting's discussions and secondly, through the counselling that was provided by the executive team:

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*“When you come with your problem [...] I will just give you my testimony. They are looking at me, as long as I am. I lost my husband during this plight. I have my children, I have everybody at home. I’m not frustrated, so why you? Where is the one that is helping you? So we coach them, we talk to them, we counsel.”*

(Key informant KI01)

These findings support a number of studies mentioned previously, such as the research on the anxiety and psychosocial state of HIV positive patients that had joined a peer support group (Pappin et al. 2012) and the study that demonstrated an increase in social connectedness for stroke survivors that were members of a support group (Kessler et al. 2014).

In addition to the validation, companionship and emotional support, the meetings had an informational aspect. For example, a zonal head mentioned some health issues that an EVD survivor from his chiefdom had been experiencing and others at the meeting were able to advise him, based on their own experience and from health information that they had received from the clinic. The advice was to take the survivor to the clinic for a health check-up and thus demonstrated how the support group was used to refer its members to health services.

Further informational support was demonstrated in the semi-structured interviews. For instance, there was an emphasis on stigma being an issue for the participants:

*“Even my husband, the first day I came [...] he was just sitting down looking at me, saying “praise god you have come back”. He was rejoicing, but for you to see your loved one and just embrace him, he was just sitting [...] The children also were scared, sitting down, looking at me.”*

(Participant B8, 43 year old female, teacher)

From the interview data, there was unanimous agreement that the stigma had improved significantly since the formation of SLAES and participants believed that the association had helped provide emotional, companionship and informational support in order to achieve this:

*“The government and survivors worked together to make sure that nobody stigmatised us [...] we talk [sic] to the brothers and sisters who were affected [...] people should not stigmatise the survivors. For anytime that happen [sic], the chairman move [sic] swiftly to consult social welfare, so they will deal with that individual”*

(Participant M3, 36 year old male, unemployed)

As can be seen from the above quote, the emotional support came from confiding in each other, the companionship came from working together and the informational support involved problem-solving to reduce stigma faced by the survivors. Additional support came from MSWGCA, with whom SLAESB approached community leaders to advocate better treatment of EVD survivors<sup>19</sup>. Comparisons can be drawn with Elafros, et al. (2013) and their study on epileptic youths in Zambia. Similar methods of problem-solving were used to reduce stigma and external actors were also involved in providing the support. However, although the participants all agreed that the stigma had reduced, some mentioned that it remained in non-survivor specific healthcare centres.

The EVD survivors were kept informed about a variety of things, such as health advice, Ebola-related research updates, future plans for the association (both nationwide and more specifically, for the Bombali District), NGO projects, government messages and services available to survivors:

*“If NGOs want to help, we will know during the meeting”*

(Participant B20, 18 year old female, unemployed)

Once again, personal observations made during the meeting supported the evidence collected from the interviews. Informational proceedings began with an agenda, read out by a member of the executive team. Once announced, the chairman started with the first subject on the agenda, concerning the closure of the district’s survivors’ clinic in September 2016. This issue led directly onto SLAESB’s quest to find new headquarters, because their rent<sup>20</sup> to use the clinic as an office space would finish at the same time as the clinic closure. Third on the agenda, some of the support services that have just been confirmed - as part of the CPES - were briefly explained. Afterwards, the meeting was

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<sup>19</sup> Explained in more detail in the Indirect Support section

<sup>20</sup> Rent paid via a donation - “Thanks to Dr Sue” (key informant KI04)

opened up for discussion and the EVD survivors were invited to speak and offer their opinions and suggestions.

From both the interviews and the complementary observation, it was clear that, although the survivors were happy to receive updates and announcements, they were mostly dissatisfied with the content of the information given:

*“Sometimes, if I go to meetings, it is just empty talk. I will waste my time. Meetings need to inform us of improvements”*

(Participant B8, 43 year old female, teacher)

This opinion was voiced by many of the participants, who informed me that most of the information regarding external support was meaningless, because often, these would never come to fruition. To explore this further, my analysis led me to look at the indirect support that had been promised to the EVD survivors and also, what they hoped to receive.

#### **4.4. Indirect Support from SLAESB**

My findings suggest that the indirect support that is available through SLAESB can mostly be categorised as instrumental and some informational. Furthermore, the support provided to EVD survivors in relation to the stigma they faced was a mixture of indirect instrumental and informational support from MSWGCA and direct emotional, companionship and informational support from SLAESB. In accordance with Kuriansky (2016) and WHO (2015), the participants confirmed that the association had worked closely with GoSL to talk to community leaders and take legal action against perpetrators.

However, when asked about the support they had received from external actors, many of the participants did not immediately mention this support and instead, spoke of the discharge packet from GoSL. Although the majority of survivors acknowledged the acquirement of this support, some participants assured me that they had never received anything from the government, which supports the statement made by MSWGCA regarding the complications with delivery (VOA, 2016). Furthermore, there was general agreement that the packages<sup>21</sup> were not substantial enough to support them:

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<sup>21</sup> It is unclear exactly what was in these packages, because participants gave varying accounts. However, they probably included food, clothing, bedding, cooking utensils and money

*“I appreciate the government, as they gave me bedding, cooking utensils and food when I was discharged, but it is not enough, because I have to provide clothes for the children.*

*They need education and food.”*

(Participant B4, 35 year old female, petty trader)

In addition to the discharge packages, participants mentioned donations of varying amounts of cash transfers (usually under 250,000 Leones<sup>22</sup>), food and different homeware items:

*“The support we receive, it [sic] not the same. It look [sic] different, what some receive, I don’t receive”*

(Key informant KI04)

The inconsistency of what each survivor had received seemed to be due to their differential experiences with various NGO projects, because each participant mentioned distinct actors when asked about who had provided them with support. Furthermore, the key informants and participant B22 explained that at the beginning of SLAES’ existence, they had to help register the survivors and direct NGOs to their target groups, so that the organisations would include survivors “they were about to ignore” (participant B22, 28 year old male, unemployed).

In addition to the unreliable survivor databases, the inconsistency of support delivery could be explained by budget constraints and different target groups. For example, UNDP (2016) have joined forces with GoSL to target 2,500 survivors for monthly stipends, with a focus on women and children in EVD hotspots. Similarly, other actors, such as Partners in Health (PIH), have only managed to reach a limited number of survivors with their instrumental support and have stated that costs were a “crucial issue” (WHO, 2015).

Money was also an important issue for the SLAESB meetings, because the association needed to pay for members’ transport to and from the survivors’ clinic. Although key informant KI02 explained that this money was provided for them by Medical Research Centre (MRC), funds were low and thus the executive team had to be careful with budgeting for meetings and paying for survivors that lived far away from Makeni. One of

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<sup>22</sup> Roughly £34

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the ways in which they handled this was to decrease the amount of general meetings and to have weekly meetings with the zonal heads instead. As mentioned previously, this enabled survivors to hold meetings in their own chiefdoms and use their zonal heads as representatives to save on transport costs.

Despite this apparent emphasis on financial support, it was interesting to hear that one survivor perceived it as partially detrimental to their health and well-being:

*“They are hearing this rumour or that, that survivors are being given some kind of money incentive or package, so they are taking us as people who have money. So some of them are saying, no [...] so these challenges are faced by us. You want to cry for help, whatever, he or she will just say, ‘my friend, you are somebody that is being helped by [sic] government, so I cannot help you”*

(Participant B16, 24 year old male, trader)

This finding was relatively unexpected, because of the trauma that loss that the EVD survivors have experienced (PHE, 2015; UNDP; 2016; WHO, n.d.). The participant’s exposure to this attitude may have occurred due to the community sensitisation campaigns, which termed EVD survivors as “heroes”. Due to this being the only example of such behaviour, it probably does not have much significance in this study. However, because the “hero” campaign was nationwide, it might be useful to explore this further in other chiefdoms and districts, where perceptions of survivors may be different.

Furthermore, upon interviewing the key informants, it became clear that they also perceived financial support slightly differently. In fact, their main concern was the lack of skills training, livelihood and educational support. For example:

*“Rather than giving them 200,000, little things, let us give them livelihood support. 90% of the organisations don’t provide livelihood support, they just give them this money. Those things don’t last”*

(Key informant KI01)

Although the majority of non-key informant participants expressed money as their biggest need, they all went on to explain how they would use it for things such as livelihoods/business, education and healthcare. Moreover, the support they were requesting was not only for themselves, but for their families and dependents. For example, when asked about her problems as an EVD survivor, one participant immediately focused on her family's problems:

*"I have lots of children at home, I need to be paying their tuition fees. Financially. Even our health is a problem for us. Especially because clinical care is for our survival, not for our independence [...] I need money"*

(Participant M5, 47 year old female, petty trader)

Consequently, in an effort to delve further into the normal participants' requirements of support, it was sometimes necessary to prompt the participants during the interviews to suggest something more long-term/sustainable as well. Even so, most survivors already seemed keen (without prompting) to discuss alternative instrumental support such as skills training and livelihood or educational support. The findings revealed that, although these types of support are being offered by NGOs, there was significant inconsistency in the experiences of different SLAESB members relating to its delivery.

*"Now for example, if this organisation comes say [sic] we cannot target all survivors, maybe this organisation will come and say that they want 30 survivors to do whatever skill training that individual wants"*

(Participant B22, 28 year old male, unemployed)

The way in which SLAESB chooses who participates in the support that is provided is by assessing which survivors are most suited or most in need of the support. Key Informant KI04 stated that they look at a survivor's vulnerability and also the "technicality", because they want to make sure that the skills training reaches those that will benefit from it the most. Many of the survivors agreed that this was correct and that they were happy with the way the association dealt with the indirect support. However, a few indicated mistrust of the executive team and participant B8 (43 year old female, teacher) claimed that the executives "only give to people they know or are connected to". Furthermore, all

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participants acknowledged that most of the livelihood support and skills training had now finished, due to the departure of NGOs from Sierra Leone.

*“It has taken 3 months of no help and they are not helping us again”*

(Participant B18, 40 year old male, unemployed)

Other services which come under Salzer’s instrumental category, include educational support, which only one participant told me they had received:

*“I can remember once or twice we have been given money so we can pay my siblings school charges. This is the biggest help”*

(Participant M2, 22 year old male, petty trader)

These findings suggest that current educational services are insufficient to support the members of SLAESB. In contrast, the majority of the participants were appreciative of the health services that were available to them. Furthermore, there was an awareness that the association had provided them with the opportunity to advocate for their right to free healthcare, as promised by GoSL (Anon., 2016; WHO, 2015). The achievement of acquiring a clinic to specifically target survivors had improved their access to medication and health services:

*“Before the opening of this clinic, we are [sic] having cases where survivors want to deliver [babies], nurses were not in the place, they don’t want to accept them. So I think that’s the main problem why [sic] they opened this clinic. 8% of health workers are survivors, so we know the problems of our survivors.”*

(Key informant K01)

Based on the key informant interviews, it became clear that the majority of health workers at the survivors’ clinic in Bombali District were survivors themselves. These survivor health workers had been relocated from other hospitals, because of the issues surrounding stigma from other health professionals. This was generally perceived as a good thing, although there was still dissatisfaction regarding the medication that the participants were provided. For example:

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*“When the sickness exceeds capacity [of the clinic] they refer us to various health centres. Of which when we go there for us to have proper medication, there’s a big challenge to [sic] them. If you don’t have money, how will you get good medication?”*

(Participant M1, 22 year old female, farmer)

In congruence with this information, the interview with key informant KO5, who works as a CHO at the survivors’ clinic, revealed that the clinic had limited funding for medication. Therefore, some of the participants complained about the lack of medication and articulated their need for improved availability of treatment. Furthermore, as previously mentioned in the survivors’ meeting, all of the key informants divulged that the clinic was due to close in September 2016. The closure will mean that survivors’ will no longer have access to focused services, although CPES aims to address some of these issues<sup>23</sup>. In addition, the closure signifies the end of SLAESB’s rent and consequently, they will lose their office space as well. Nevertheless, recent contact with the executive team has revealed that MSWGCA has rented a new office in Makeni, to be used exclusively by SLAESB.

#### **4.3.1. Comprehensive Package for EVD Survivors**

Limited data was collected on CPES, mainly because there is very little confirmed or published yet, but also because it was difficult to track down the World Hope International (WHI) representative<sup>24</sup> who was leading the project in Bombali District. However, during the observed meeting and the interview with key informant KI04, more information was gathered regarding CPES. Key informant KI04 informed me that the three key aims were to provide physical, psychosocial and social support, which matches the WHO recommendations for EVD survivor support (WHO, 2016c).

In regards to physical health, the government aims to strengthen the health infrastructure, by incorporating free survivor care at all hospitals, including public health centres (PHCs). Therefore, the healthcare should be easier to access. Mobile health clinics have also been promised, in order to reach those survivors that live in rural areas. For psychosocial health, the government aims to train EVD survivors as advocates, to provide peer counselling.

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<sup>23</sup> Explained in the CPES section below

<sup>24</sup> Unfortunately, our schedules never lined up for an interview

Key informant KI04 also implied that these advocates will be employed to collect data for a survivor needs assessment.

For educational support, the government plans to provide the survivors with scholarships. I was informed that there would be 50 educational scholarships for online courses, to be distributed to members chosen by the executive teams of SLAES (nationwide). When this was announced at the general meeting, I noted in my field diary that there was great dissatisfaction and unrest amongst the members that attended. Participants seemed angry and expressed their concern, by stating that it was not enough and unsuitable for EVD survivors' needs.

*“It’s going to be one of our challenges because most of our colleagues here don’t even know how to use a computer. So how can they enrol on such programmes? To me, I think we have to start somewhere else”*

(Key informant KI04)

#### **4.5. A Tangled Web of Support: the Wider Context**

As can be seen from the findings, SLAES is used as a gateway between the EVD survivors of Sierra Leone and external actors, such as GoSL and NGOs. The study also aimed to explore how the association influences these actors to provide support for its members. Firstly, it is important to note the differences in the categories of support provided by SLAES and the external actors. As can be seen from the data<sup>25</sup>, the main interrelationships occur between the informational support provided by the association and the instrumental support provided by the external actors.

For example, informational support such as referral to health services is significantly dependent on the healthcare system. The participants and key informants mentioned the lack of medication available at the survivors' clinic. First of all, this shows their dependency on government funding in order to access treatment, which is in accordance with Parson's (1951) theory of the "sick role". Secondly, if the participants tried to claim their entitlement to free healthcare at other hospitals, they faced stigma and were often charged for the medication or tests. Consequently, this reveals the instability of the indirect support and supports the literature regarding Sierra Leone's insufficient health service delivery (GoSL,

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<sup>25</sup> See Appendix E

2015: p25). Nonetheless, the findings confirmed that SLAESB participants had taken part in the national demonstrations to advocate their right to free healthcare in April, 2016. The data I gathered during the interviews revealed that the participants agreed that their access to healthcare had improved because of those actions.

Another example of where SLAES effectively influenced an external actor was during social sensitisation after the EVD outbreak. The members of the association were able to inform the executive team about any stigma they faced in their communities, which was subsequently referred to MSWGCA. SLAES would meet with representatives of the ministry regularly and worked together to approach community leaders and change legislation. Similar to the studies by Beattie et al. (2010) and Gurnani et al. (2011), the perceived reduction in stigma was due to support group activities, such as working with policy-makers and community mobilisation. Therefore, the mix of direct emotional, companionship and informational support and indirect instrumental and informational support appears to have had a beneficial effect on the EVD survivors' health and well-being.

As for NGO projects, the interviews revealed the participants' perceived need of such instrumental support. Although SLAESB had played a role in registering survivors and directing the organisations to their target groups, the access that participants had to this support was dependent on the NGOs' funding, available skills, research aims and individual characteristics of the EVD survivors (as to whether they were suitable for the project). Moreover, NGO projects seem to have significantly decreased over the last few months and the participants and key informants suggested that this was due to lack of interest. When asked about the actions they could take to encourage further support from NGOs, none of the participants could give me a clear answer.

Similarly, the same concepts of dependence apply for the relationship between SLAESB and the government. However, the association has a more direct way of influencing GoSL, through their contact with MSWGCA. Regular meetings allow the executive team to relay their survivors' needs and their needs as an association to the policy-makers. Although the influence may not be apparent to the participants of my study, there are clear signs that the ministry has beneficially supported SLAESB. For example, the community sensitisation led to a decrease in the participants' perception of stigma and the recent acquisition of a new office space was due to their support.

The national demonstration of EVD survivors' to campaign for free healthcare also had a significant impact on accessing short-term support from the government. As stated in the findings, this short-term support means that private survivor clinics are facing closure in September 2016. However, towards the end of the study, evidence of CPES became more apparent and it was identified that the package aims to provide the same types of support recommended by WHO (2016c). Consequently, it can be seen that SLAESB has had some positive influence on government support, which indirectly benefits the health and well-being of EVD survivors. Nevertheless, there is a strong possibility this could change over time, due to the implementation of CPES.

In contrast, when I asked key informants about whether they had been involved in any of the meetings to plan CPES at the national level, they all stated that they had had no involvement and were not told about meetings and conferences in Freetown or Bo. In fact, there seemed to be some agreement that the national branch of SLAES were the only ones involved in government-led or WHO conferences. Furthermore, upon learning about a conference concerning EVD survivors that had no survivor representatives present, one of the key informants said:

*"It makes me feel that we are still not recognised by government and government is still pushing us at [sic] the extreme corner. But this one, I blame the national executive because if I were them, if my office, my chair, is in Freetown, I'll go all out to know any issue that has to do with survivors; any meeting, any forum, any conference, for my presence to be felt. And that is what I am doing here in Bombali."*

(Key Informant KI04)

Consequently, there seems to be some failures in communication, between the government/external actors and the national branch of SLAES and/or between the national branch of SLAES and SLAESB. Other participants also agreed that their influence in decision-making processes for survivor support was low. This prompted me to ask them for suggestions on how they would enhance their influence and the majority of participants responded by saying that SLAES should be allowed to manage their own affairs and therefore, they would be respected more and included in the decision-making.

*“The organisation should be sending messages to [sic] government and other organisations, saying we want to man our own affairs. The government will involve us more in decision-making and we need our own office.”*

(Participant B9, 27 year old female, petty trader)

Considering the fact that MSWGCA have recently issued SLAESB with their own office, this further demonstrates the role that SLAESB plays in influencing the GoSL. Therefore, further research needs to be conducted to investigate any developments.

#### **4.6. Does SLAESB Enhance or Undermine Self-Management?**

The results demonstrate that the participants receive a variety of support from all five of Salzer’s categories. However, the biggest emphasis was the concept of instrumental support, especially financial. The interviews suggested that the survivors were significantly dependent on external actors in order to receive this and thus their self-management is undermined. Consequently, Parson’s (1951) theory of the “sick role” seems to apply. However, this could be explained by the receipt of money and material resources immediately after discharge from treatment centres, which could have set EVD survivors’ expectations high (UNDP, 2016; WHO, 2015). Furthermore, it is acknowledged that my positionality could have affected the responses given, because the participants may have hoped that I would be able to provide them with further financial support. Even so, the recurrence of the theme and the fact that the perception was shared by individuals with a variety of characteristics supports the significance of this response. As the country recovers from the EVD outbreak and developments in the infrastructure occur, the context will likely change and more research will be needed to explore the temporal horizon of the survivors’ dependency (Crossley, 1998).

The dependence on financial support could also be explained by the lack of reliable skills trainings and livelihood support, which is most likely due to the lack of government funding (GoSL, 2015). However, the findings suggest that CPES is beginning to progress from the planning stage to the initial implementation and one of its key areas aims to cover social support, such as livelihoods and skills training (MoHS & MSWGCA, 2015). The need for further research on CPES is recommended in order to explore the support it will provide to SLAESB.

Findings suggest that their psychosocial well-being is mostly self-managed, using direct emotional, companionship and validation support, which enhances the survivors' self-management. The findings are based on SLAESB activities, the satisfaction levels with the support that was directly provided and the lack of psychosocial problems reported. However, the way in which the participants understood my research project could have affected responses, because their definition of health and well-being may be different to my own. For instance, the issue of mental health is not yet widely recognised in Sierra Leone and thus they might not perceive psychosocial problems as factors contributing to their health (Hann et al. 2015). In retrospective, I could have started the interviews with a definition of health and well-being, which could have made them more aware of the psychosocial aspects as well.

Nevertheless, the participants mostly expressed happiness when asked about their feelings towards SLAES. They all agreed that their network reached out to even the most hard-to-reach survivors and portrays their unity. The instalment of zonal heads solved the problem of paying for all of the SLAESB's members' travel costs to and from the meetings, which demonstrated the association's self-management.

## **5. Conclusion**

As can be seen in this study, SLAES is highly organised and operates nationally in Sierra Leone. The network enables the representation of each district, which extends the reach of the association in order to reach all of the Sierra Leonean EVD survivors.

The Bombali branch demonstrates a proficiency in self-management of emotional, companionship, validation and, to some extent, informational support, which play a role in enhancing the health and well-being of EVD survivors. However, the association lacks funding to provide effective instrumental support and depends heavily on external actors, such as GoSL and NGOs to benefit their members. In order to access this support for its members, SLAES influenced the government through advocacy and close contact with policy-makers. In relation to NGOs, although the association did not appear to have a great influence over the support they provided, numerous projects were delivered immediately after the outbreak, albeit with some gaps of coverage. Currently, the survivors do not perceive the indirect support as being beneficial to their health, although this is mainly due to the cessation of NGO projects.

This study provides an insight into how a support network contributes to the health and well-being of disease survivors in a resource-poor setting, after an outbreak and before confirmed programmes of support are implemented. The results suggest that the support group has mainly enhanced the health and well-being of EVD survivors, especially in terms of psychosocial health. However, the expectations of SLAESB members have potentially created a dependence on instrumental support, provided by GoSL and NGOs. These findings are prone to change over time, because of the dynamic context, such as the implementation of CPES. The ambiguities of the concept of support have been explored in the context of an EVD survivor support group in Sierra Leone and thus the study aims to open up further debate as to the importance of peer networks as a method of enhancing health and well-being.

## **6. Future Recommendations**

1. Caution needs to be taken when investigating the survivors as one association. There are over 4,000 survivors living across Sierra Leone, all with separate identities and needs. As demonstrated by the differences between the participants and the key informants in this study, their perceptions of required support were different and thus they will require projects that are specifically targeted.
2. SLAESB is just one branch of SLAES and is closely situated to the Freetown headquarters of the association. Therefore, the way in which it operates could be different to other branches from different districts. Additionally, the environment and terrain differs across Sierra Leone, so there will be other factors to consider when investigating other branches of SLAES.
3. Education needs to be provided to members of SLAES, due to the levels of illiteracy amongst the EVD survivors. To provide a sustainable means of rebuilding their lives, these levels must be improved.
4. It is recommended that there should be a readjustment to the organisational structure of SLAES, so that the national executive team contains representatives from each district, rather than members from the Western Area districts. This way there will be greater political representation of each branch of SLAES and it should improve the involvement of all EVD survivors, regardless of district, in decision-making processes.
5. SLAESB has been given a new office, but it is recommended that the association also receives a bank account, to ensure transparency of its in- and outgoings.

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## Appendix

### Appendix A - Information Sheet (read out at survivors' meeting)

#### **Supporting Ebola Virus Disease Survivors for Better Health and Well-Being: an Investigation into the Role of the Sierra Leone Association of EVD Survivors in Bombali District.**

You are being invited to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to listen to the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for listening.

The purpose of this research project is to find out about the support that is provided to Ebola survivors in Bombali District in Sierra Leone. It aims to investigate Sierra Leone Association of EVD Survivors (SLAES) and explore how it operates in Bombali. In addition, the study will examine your perceptions on the problems you face as a survivor and the support you receive through the association. Overall, the aim is to identify any gaps in the provision of support or areas of improvement, to aid future development of resources and best practice for support groups. This will be undertaken over the next 6 weeks and the project will be handed in on September 8th 2016.

You were chosen to take part in this research because of your experience with Ebola and your membership to SLAES. The insight that you can provide me with will be invaluable to my project. It is necessary that I hear from people who, from experience, can tell me whether or not the support provided is adequate, has benefits or detriments and generally impacts upon your life. I will be asking 30+ Ebola survivors (above the age of 18) to take part in a semi-structured interview. In addition, I would like to interview the executive team of the Bombali branch of SLAES and, if I am welcome, attend some of the meetings, so that I can observe and experience the support that is provided.

It is up to you to decide whether or not to take part. If you do decide to take part, your consent will be given by providing a finger print and you can still withdraw at any time. You do not have to give a reason and you do not have to answer all of the questions if you do not want to.

If you decide to take part then you will be asked to take part in an interview, which will be conducted by myself and a translator. The interview should take about 20-30 minutes to complete. You will only be required to participate once. When answering the interview questions, please listen carefully and answer any questions to the best of your knowledge. If you believe that you have more to contribute, then please feel free to contact me throughout my stay, via your chairlady.

It is possible that you could feel a certain level of discomfort when providing me with your opinions. It can be quite a personal issue for some and it will not affect you in any way if you decide to pull out of this research.

Whilst there are no immediate benefits to taking part in this research, it is hoped that this work will help future development of resources and best practice for support groups; it could help to show what should be prioritised to aid recovery of survivors and what external help from actors (such as NGOs and the government) is required. A contribution towards travel expenses will be provided and I will be making a donation of food and medical supplies to the Sierra Leone Association of Ebola Survivors, to be distributed equally to the survivors in Bombali District.

If the research study is to stop earlier than expected, then you will be no longer required to take part in the interviews. You will be contacted in the occurrence of such an event. The reason(s) for it stopping prematurely will be explained.

If you have any complaints during the process then you can contact my Project Supervisor, Raoul Emeric Guetiya Wadoum M.Sc, at the University of Makeni.

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All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be identified in any reports or publications.

This study is organised by the University of Sheffield. It is part of the Public Health and International Development Master's degree and is part of my dissertation project. This research project is not funded and has been ethically approved via the Department of Geography and Public Health's ethics review procedure.

Thank you for taking part.

Alice Johnson

**Appendix B - Consent Form**

Title of Research Project:

Supporting Ebola Virus Disease Survivors for Better Health and Well-Being: an Investigation into the Role of the Sierra Leone Association of EVD Survivors in Bombali District.

Name of Researcher:

Alice Johnson

**Participant Identification Number for this project:****Please initial box**

1. I confirm that I have read and understand the information sheet/letter (delete as applicable) dated *[insert date]* explaining the above research project and I have had the opportunity to ask questions about the project.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. *Insert contact number here of lead researcher/member of research team (as appropriate).*
3. I understand that my responses will be kept strictly confidential (only if true). I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
4. I agree for the data collected from me to be used in future research
5. I agree to take part in the above research project.

\_\_\_\_\_  
Name of Participant  
(or legal representative)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent  
(if different from lead researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*To be signed and dated in presence of the participant*

\_\_\_\_\_  
Lead Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*To be signed and dated in presence of the participant*

Copies:

*Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.*

**Appendix C - Participants and Key Informants**Participant Information

| Participant Code | Gender | Age | Employment Before | Employment After                   | Reasons for Change in Employment (if given)      | Chiefdom        |
|------------------|--------|-----|-------------------|------------------------------------|--|-----------------|
| S1               | Male   | 31  | Farmer            | Farmer                             |  | Safroko         |
| B1               | Female | 22  | Petty Trader      | Unemployed                         | Did not work during outbreak, so lost money      | Bombali Shebora |
| B2               | Male   | 23  | Student           | Unemployed                         | Unable to find employment due to stigma          | Bombali Shebora |
| B3               | Female | 35  | Business          | Petty Trader                       | Lost money during illness                        | Bombali Shebora |
| B4               | Female | 35  | Petty Trader      | Petty Trader (but minimised hours) | Health   | Bombali Shebora |
| B5               | Male   | 45  | Driver            | Unemployed                         | Unable to get work as EVD survivor               | Bombali Shebora |
| B6               | Female | 30  | Nurse             | Nurse                              |  | Bombali Shebora |
| B7               | Female | 27  | Nurse             | Student                            | Wants to learn public health due to EVD outbreak | Bombali Shebora |
| B8               | Female | 43  | Teacher           | Teacher                            |  | Bombali Shebora |
| B9               | Female | 27  | Petty Trader      | Petty Trader                       |  | Bombali Shebora |
| B10              | Female | 39  | Business          | Unemployed                         | Lost money during illness                        | Bombali Shebora |
| B11              | Female | 38  | Nursing Aid       | Unemployed                         |  | Bombali Shebora |
| B12              | Male   | 26  | Student           | Unable to complete studies         | Can't afford to complete                         | Bombali Shebora |
| B13              | Male   | 27  | Driver            | Business                           |  | Bombali Shebora |
| B14              | Male   | 37  | Security          | Unemployed                         | No advocate                                      | Bombali Shebora |
| B15              | Male   | 36  | Business          | Unemployed                         | Money was burnt during infection control         | Bombali Shebora |

| Participant Code | Gender | Age | Employment Before        | Employment After                         | Reasons for Change in Employment (if given)  | Chiefdom        |
|------------------|--------|-----|--------------------------|--|--|-----------------|
| B16              | Male   | 24  | Project Worker           | Trader                                   |  | Bombali Shebora |
| B17              | Male   | 27  | Unemployed               | Unemployed                               |  | Bombali Shebora |
| B18              | Male   | 40  | Power-Saw Operator       | Unemployed                               | Health                                       | Bombali Shebora |
| B19              | Male   | 60  | Tailor                   | Still a Tailor but minimised hours       | Health (poor sight)                          | Bombali Shebora |
| B20              | Female | 18  | Business                 | Unemployed                               | Business has collapsed due to illness        | Bombali Shebora |
| B21              | Female | 22  | Business                 | Unemployed                               |  | Bombali Shebora |
| B22              | Male   | 28  | College Student          | Unable to Graduate                       | Needs finance to graduate and no certificate | Bombali Shebora |
| B23              | Male   | 33  | Farmer                   | Farmer + Volunteer at Hospital           |  | Bombali Shebora |
| M1               | Female | 22  | Business                 | Farmer                                   |  | Makarie Gbanti  |
| M2               | Male   | 22  | Petty Trader             | Petty Trader                             |  | Makarie Gbanti  |
| M3               | Male   | 36  | Unemployed               | Unemployed                               |  | Makarie Gbanti  |
| M4               | Male   | 38  | Agriculture and Business | Agriculture and Business (but minimised) | Health                                       | Makarie Gbanti  |
| M5               | Female | 47  | Petty Trader             | Petty Trader                             |  | Makarie Gbanti  |
| M6               | Female | 35  | Farmer and Business      | Family Work + Petty Trader               | Health and loss of money during illness      | Makarie Gbanti  |
| M7               | Female | 28  | Petty Trader             | Petty Trader                             |  | Makarie Gbanti  |
| M8               | Female | 37  | Business                 | Porter                                   |  | Makarie Gbanti  |
| M9               | Female | 35  | Teacher                  | Teacher                                  |  | Makarie Gbanti  |

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| Participant Code | Gender | Age | Employment Before       | Employment After | Reasons for Change in Employment (if given) | Chiefdom       |
|------------------|--------|-----|-------------------------|------------------|---|----------------|
| M10              | Male   | 35  | Porter + Volunteer      | Farmer           |   | Makarie Gbanti |
| M11              | Female | 45  | Petty Trader and Farmer | Petty Trader     | Health                                      | Makarie Gbanti |

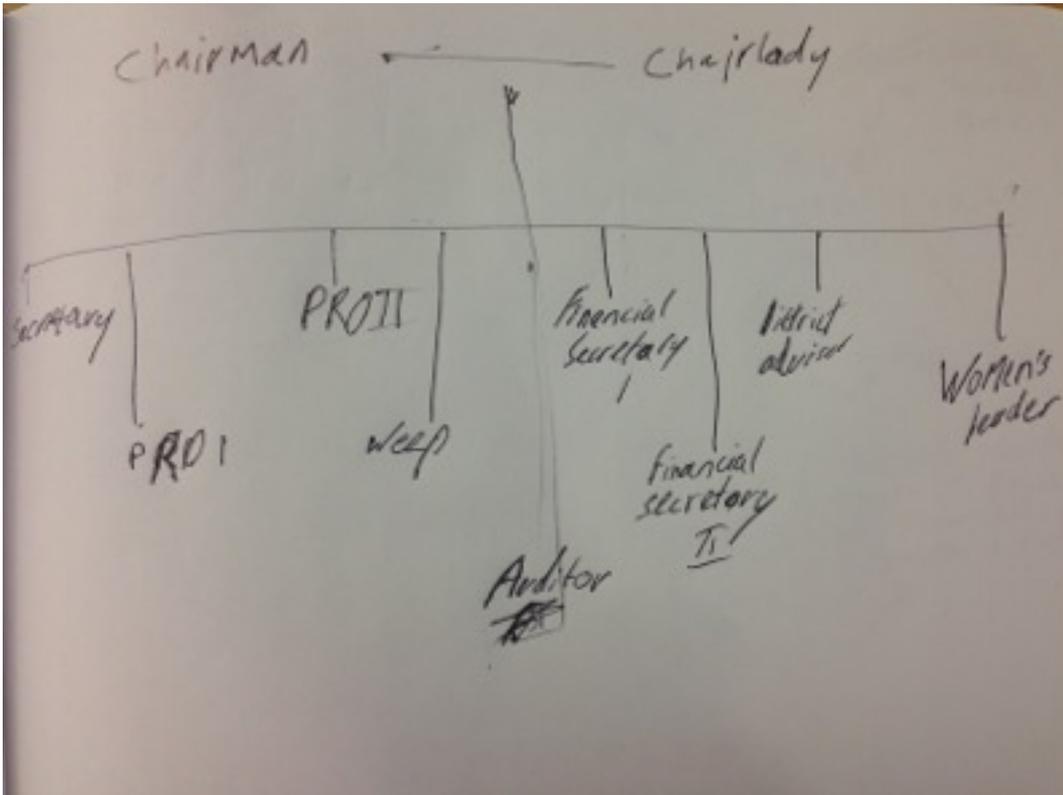
Key informant Information

| Key Informant Code | Relation to SLAESB       | Gender |
|--------------------|--------------------------|--------|
| KI01               | Executive Team           | Female |
| KI02               | Executive Team           | Female |
| KI03               | Executive Team           | Female |
| KI04               | Executive Team           | Male   |
| KI05               | CHO at Survivors' Clinic | Male   |

Additional details on key informant characteristics have been removed in order to protect their anonymity.

## Appendix D - Organisational Structures

### 1. Key Informant KI01

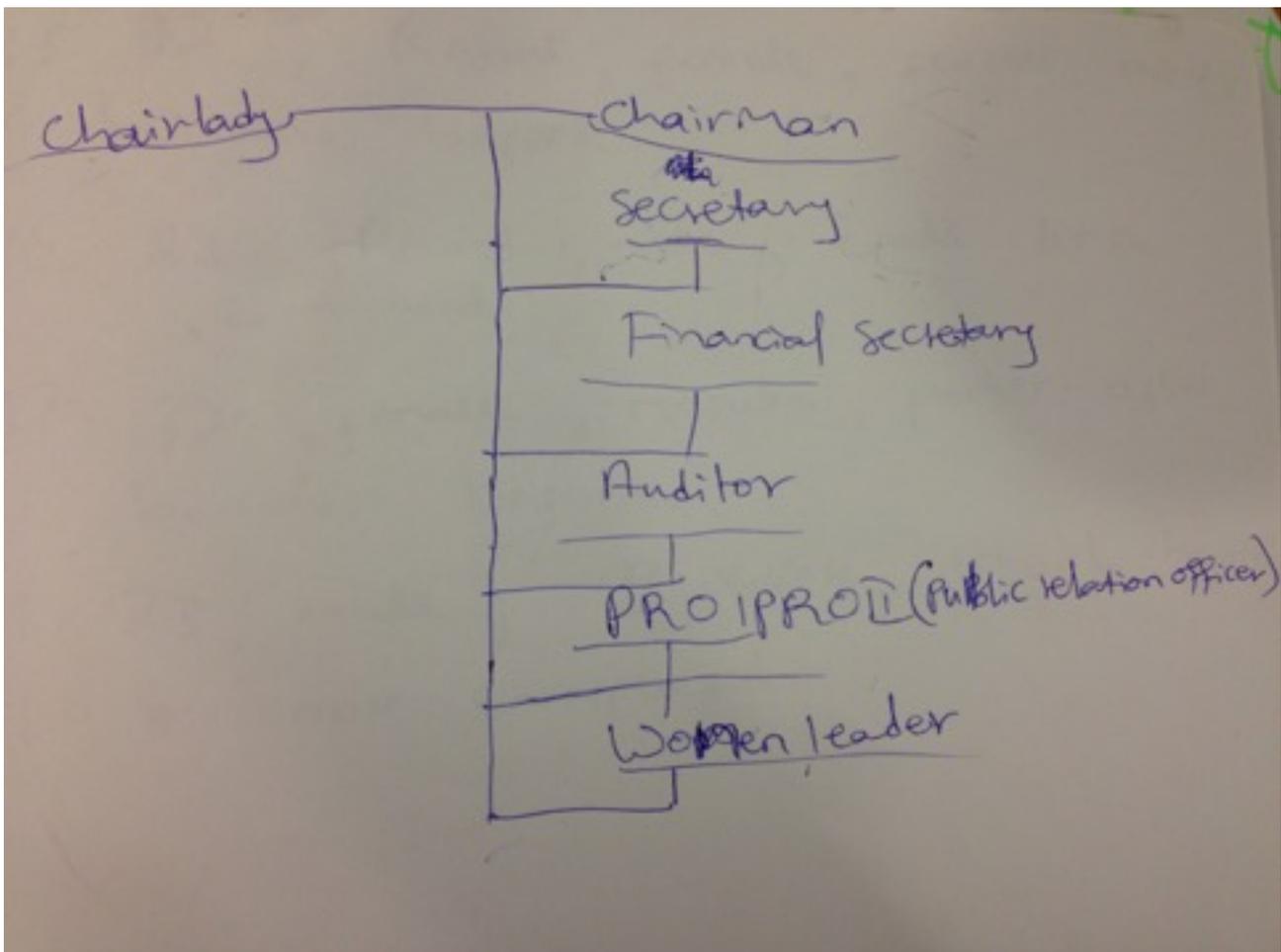


### 2. Key Informant KI02

“(1) National President, (2) National Vice President, (3) National Secretary, (4) National Public Relation Officer (PRO), (5) National Financial Secretary, (6) National Coordinator, (7) National Adviser, (8) National Auditor, (9) National Weep.

The structure of each District, for example Bombali District (1) District Chairman, (2) District Chairlady, (3) Regional Coordinator, (4) District Secretary, (5) Public Relation Officer (PRO 1,2), (6) District Auditor, (7) District weep, (8) District Financial Secretary 1&2, (8) District Adviser, (10) Women's Leader”

3. Key Informant KI03



4. Key Informant KI04

- 1 The national president
- 2 The national coordinator
- 3 secretary general
- 4 The public relation officer
- 5 The financial secretary and
- 6 The treasurer

THE DISTRICTS BRANCHES ARE MADE UP OF:

- 1 The chairman
- 2 The deputy chair
- 3 The secretary
- 4 The public relation officer
- 5 The financial secretary and
- 6 The women leader

### Appendix E - Interrelationships Between Direct and Indirect Support

