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Analysis of the Liberian Ebola Survivors Support System (ESSS)

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Analysis of the Liberian Ebola Survivors Support System (ESSS)

Jessi Hanson¹,
Patrick Seeco Faley² and
Megan Quinn³

Abstract

A systems theoretical analysis to capture the evolution and transition of the network systems supporting Ebola survivors and their affected communities, during the 2014-15 Ebola outbreak and recovery phases. The qualitative analysis includes a literature review, archival review, and interviews with representatives of key actors operating in strategic action fields. This paper uses a series of Diagrams that visually illustrate the various complex phases and their network changes that occurred and were established during the outbreak. This case analysis provides crucial phase information that both captures the historical events that informed the systems changes, including the development of the Ebola Survivors' Support System (ESSS). Secondly, this analysis acts as, a model of understanding how disease support networks first emerge and can be better supported in other outbreaks.

Keywords: Ebola; Evolution; ESSS; Health

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Introduction

This research applies a systems theoretical analysis to capture the evolution and transition of the network systems supporting Ebola survivors and their affected communities, during the 2014-15 Ebola outbreak and recovery phases. The qualitative analysis uses a series of Diagrams that visually illustrate the various complex phases and their network changes that occurred and were established during the outbreak. This case analysis provides crucial phase information that both captures the historical events that informed the systems changes, including the development of the Ebola Survivors' Support System (ESSS), and secondly, a model of understanding how disease support networks first emerge and can be better supported in other outbreaks.

With the increase of modern disease outbreaks like Ebola, public systems are burdened to assist new afflicted populations never-before documented. These new affected populations provide an often-unforeseen policy issue- tracking not only those who become infected but disease survivor clusters to methodically respond to their unique support needs after their discharge. Systems theory literature offers solutions to this problem by analyzing already-existing networks that developed to respond to outbreak-affected populations. This literature further demonstrates the importance of mapping the process by which a network first develops and changes in the Complex Adaptive System (CAS) of a crisis for future knowledge application. The

2014/15 Ebola Virus Disease (EVD) outbreak in Liberia acts as a vital case study in this endeavour.

Amid the West African Ebola response CAS, the Liberian Ebola survivors' support system (ESSS) eventually grew from an emergent field of action into a legitimate network with improved signals and boundaries over the course of the emergency. However, this learning process was hindered by lack of previous knowledge to inform its formation. There were previous Ebola outbreaks but with little knowledge retention or guidance for key actors about providing care for persons directly impacted by a hemorrhagic disease. The Ebola response was ill-prepared for the extent of survivors whose lives were left in pieces. The early stages of the ESSS may be characterized as delayed, encumbered, and at times inefficient at the expense of helping those most affected by the outbreak. The state would later advocate for a mainstreamed approach placing the ESSS as a leading facilitator in partnership collaboration among fields.

This paper attempts to document for one of the first times a disease survivors support system (DSSS) through a systems theory approach. This analysis tracks the evolution of the Liberian ESSS as a means of: 1) capturing its transition during different phases of the response, 2) key issues, and 3) system structure changes,

to serve as a guide for a more effective policy process during future communicable disease outbreaks.

Methods

This qualitative research includes: 1) an initial literature review of reports and articles covering the Liberian Ebola response including World Health Organization (WHO) and Center for Disease Control (CDC) situation reports and summary reports; 2) an archival review of disaster response documentation collected during Phase 2-3 of the outbreak, including Information Management (IMS) meeting notes and reports; 3) firsthand experiences of two of the authors who participated in relief efforts and led programming for Ebola survivors and their families, including direct work with the ESSS; and 4), interviews with various key representatives of strategic action fields active in the outbreak. This work is in coordination with Government of Liberia (GoL), with appreciation for the Ministry of Gender Development and the Ministry of Health. These two ministries have had multiple official titles, but for this report they will be reference by simplified titles. Lastly, ministry officials and external lead crisis responders later cross-verified the draft of this analysis, providing feedback on the accuracy of its information, findings, and conclusions. All feedback was included in the modification of the final version.

Historical Documentation of Disease Survivors Support Systems

The 2014/15 Ebola pandemic resulted in 28,616 cases, of which approximately one-third were in Liberia [1]. Population data collected during the outbreak was often inaccurate. Yet, it is estimated that there are over 5,000 Liberians who were infected with EVD and survived, later termed by the international health community as Ebola survivors.

Since 1976, there had been over 35 known EVD outbreaks in the world, mostly affecting sub-Saharan Africa with a survival rate ranging from about 20-100%. While no previous outbreaks had such a devastating toll as the 2014/15 crisis, numerous incidences involved victims numbering in the hundreds [2]. A 2014 study published in the *Journal of the Royal Society Interface*, "Global Rise in Human Infectious Disease Outbreaks," shows that since 1980, the number and frequency of global disease outbreaks and their variety have continued to increase. An estimated 65% of these contagions are zoonosis in nature like Ebola. Yet global public health systems continue to lag in preparedness [3].

Most Ebola literature and response programming has mainly focused on disease contract tracing, isolation, as well as treatment and prevention efforts. Much less exists on mapping the network support for surviving victims of the virus. Other deadly diseases that are hemorrhagic or transmitted through bodily-fluids, such as Lassa fever and HIV/AIDS, have better research informing how to systematically respond to the needs of survivors or their households, in what may be considered a disease survivor support system (DSSS). However, this research developed slowly over decades after the viruses appeared. It is well known that persons living with an infectious, life-threatening disease frequently are affected beyond the physical effects of their condition [4,5]. During an emergency, these needs can be life altering.

Phase Transitions - Fields and Interactions

Solé [6] demonstrates that phase transitions happen overtime often through interactions among units that drive dynamic change. The process of change of a network can advance within a transforming complex adaptive system [7-9]. The Liberian EVD response CAS demonstrated a substantial level of adaption and learning during the first three phases of the crisis, which resulted in the emergence and development of the ESSS. This change was often activated through key governmental policy adoptions. The system size depends on the number of different actors and how they adapt to work better together as a continual learning process [6]. This paper will explore the change of the ESSS throughout these phases.

Phase 1: Initial outbreak

The theory of systems by Fligstein and McAdam [7] provides insight into the social order that develops particularly in an emergent system. Furthermore, Fligstein and McAdam present a functional taxonomy for the different actors and fields in operation in analyzing the ESSS, which will be applied frequently within this analysis, including in the phase Diagrams. Throughout the Liberian EVD crisis, a meso-level social order slowly was constructed to support survivors, flocculating in size dependent on the proximate fields operating within the response environment at different times in the crisis. The initial outbreak phase of the response (March to early August 2014) was obstructed by a large diversity of agents attempting to respond to the growing crisis with little knowledge or experience to guide them, often operating independently with little collective action and weak information sharing, as shown in **Diagrams 1 and 1.1**.

Actors

The Ministry of Health and Social Welfare (MOH), under the mandate of the Government of Liberia (GoL), played a crucial mediation and governance role which better stabilized the collective action of multiple survivor organizations, donors and response agencies operating in Liberia around the peak phase. Acting as internal governing unit (IGU) of multiple fields overseeing compliance for entities operating in country on tracking and prevention, treatment, and reintegration of affected persons, the MoH along with lead partner agencies of the Incidence Management System (IMS) enacted policies that promoted the ESSS to become the strategic action field under which all coordination efforts were to occur to aid survivors. However, two exogenous shocks had to occur before this final settlement could be reached in late 2014. The first shock was the identification of patient zero within country, in March 2014, while the second would be the August spike in disease incidences.

Early in the first phase, regional coordination response first arose across the border of Guinea and Sierra Leone from Liberia involving key international health agencies with similar niches in disease response, including: the Center for Disease Control (CDC), World Health Organization (WHO), and Médecins sans Frontières MSF/Doctors without Borders, and the Red Cross [1,2,10]. These international health agencies worked with Liberian agents located on the ground; but mostly they operated in a consultative

Diagram 1: Initial Outbreak Phase (March-July 2014)

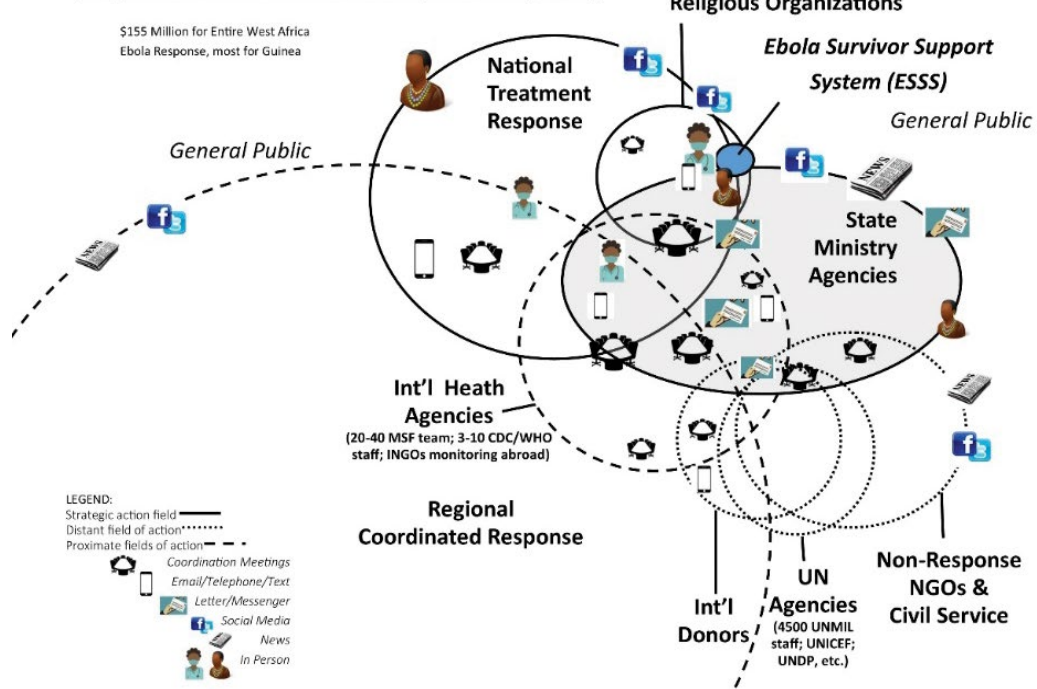


Diagram 1 Initial Outbreak Phase (March-July 2014).

Diagram 1.1: Main Field Information Flow & Survivors

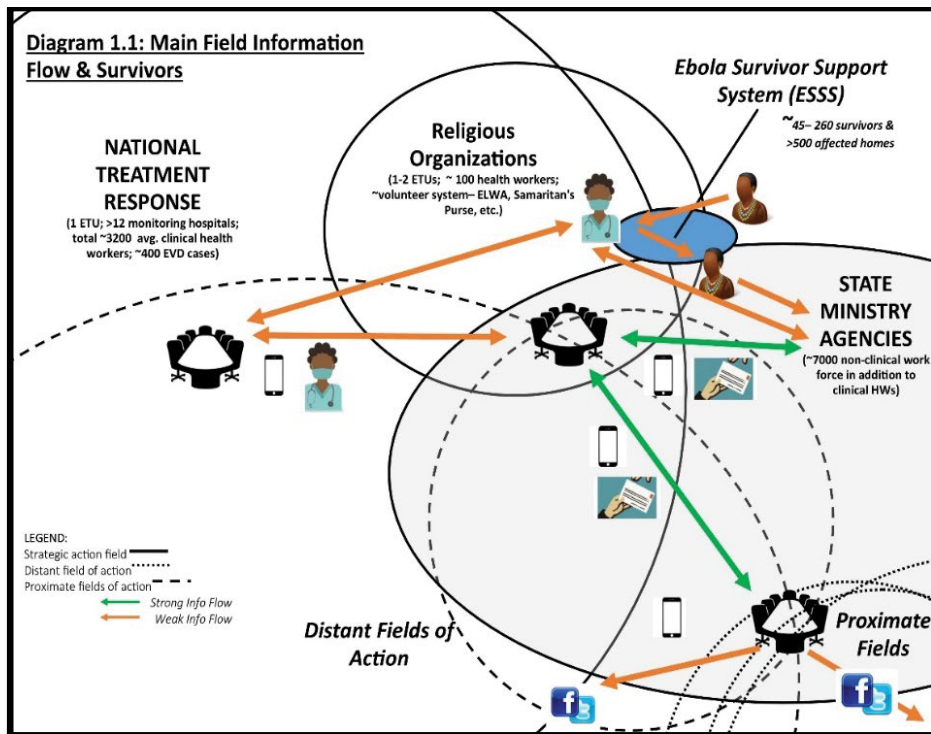


Diagram 1.1 Main Field Information Flow and Survivors.

role as a distant field of action (**Diagram 1**). International health agencies like CDC began sending material and human resources to Liberia, but communication systems were weak. While the UN met with CDC/WHO, their coordination was minimal. The United Nations Office for the Coordination of Humanitarian Affairs

(OCHA) was not activated which may have more quickly ramped up emergency response coordination.

Additionally, many key international donors, United Nations (UN) agencies like UNICEF and the UN Missions in Liberia (UNMIL), and

national and international NGOs, and civil service organizations operating in country to support post-war reconstruction and peace-keeping efforts for over ten years found themselves suddenly incapable to effectively aid the rapidly growing Ebola response crisis. In a CAS, agents on the ground must ongoingly adapt to changes in the environment to remain relevant [8,11]. Yet most of the development and peace-keeping agencies on the ground instead acted as proximate fields resistant to adaption from non-response programming to emergency response action. They tended to view the outbreak as beyond their scope of work or expertise. They instead quickly downsized operations and restricted coordination efforts of their teams beyond the shared boundaries of logistical coordination and resource support to the state ministry agencies. Some would make the change.

Piketty [12] depicts how political and economic system influence one another often represented in power dynamics between actors and control of financial resourcing. Early in the crisis, the state agencies frequently requested funding to expand response services and administration. But, the low number of disease incidents and redistribution of annual ministerial budgets to public health coffers temporarily allowed the state to act more autonomously in combating Ebola. For a time, the state agencies were not reliant on extensive external funding by international donors (now estimated at \$155 million USD) as the cost of the initial phase nationally was relatively low.

Key Issues

In these first chaotic months, persons who survived the disease mostly went unnoticed, bleeding into the general emergency landscape. The first interactions with survivors infrequently occurred informally in person among key stakeholders: state ministry agencies (MOH Ministry of Gender (MOG)), national treatment response actors, and religious organizations, when discharged survivors would return to Ebola Treatment Units (ETUs) and government buildings pleading for support.

By August, the size of the public health sector was heavily depleted of hundreds of frontline workers exposed to extremely high rates of EVD infection, and both health workers and public servants abandoning their posts to flee the crisis. There were not enough volunteers and private health professionals to supplement the growing number of open positions [13]. This decrease in human resourcing weakened information tracking and system flows, as knowledge management systems stalled. Liberian organizational culture traditionally was hierarchical with command structured centralized in ministry departments, which as Innes Booher [14] show involve bureaucratic styling that could hamper normal learning processes. Liberian state ministry agency communication systems, often too outdated for timely communication required, were increasingly stretched thin. Ministerial agencies relied on past methods of communication sharing through scheduled coordination meetings and formal printed letters/reports delivered via messenger after rigorous administrative approval, including multiple signoffs from departmental heads in the central ministry and County Health Team (CHT) requiring hours if not days. Agents within the National Treatment Response shared a similar culture of communication as they comprised of

mainly nationals including MOH staff. Yet foreign entities used electronic methods (phone, internet) that were more familiar and frequently circumvented ministry collaboration.

Information flows involving survivors occurred between fields later in the first phase when professional actors more frequently interacted with survivors (**Diagram 1.1**). Survivors were mainly seeking funding support at first, due to their possessions being destroyed during decontamination or stolen while in treatment, as well as job loss due to stigma of their infection-status and the crisis halting the economy [15]. They were also suffering extreme psychological stress [16]. But there was no better-structured way to communicate these needs (than by standing) outside of ETU and ministry gates (flagging the attention of professionals walking into the compounds and talking with them directly. Few survivors had any other means of communicating with officials who could help them). The growing number of survivors (from a few dozen to 260 by late July) seeking personal meetings with profession health and ministry workers led to the emergence of the ESSS, and provided signals to common needs.

Transition of System Structure

The policy solution for the MOH was to authorize response organizations to hire survivors as temporary paid volunteers, working mostly in Ebola Treatments Units (ETUs) and quarantine centers (ICCs/CCCs). The drivers for this transition were: 1) unique human resource of persons who theoretically were immune to supplement care for contagious patients; 2) motivation of affecting positive change in the face of tragedy [17,18]. The survivors represented a symbol of hope for despondent health teams, particularly as the victim death rate lowered with improved treatment, reenergizing the drive to collaborate on priorities.

Throughout the initial phase, communications between fields in the response CAS remained weak. However, once the survivors' plight was recognized and championed by key agencies, the ESSS would act as one of the lynchpins that connected different field agents under a shared common goal in the peak phase of emergency. Yet, the ESSS remained an emergent field with the only strong information flows occurring through standard ministry response channels to proximate and distant fields of action focused on tracking, treatment, and prevention; survivor support information was carried secondarily (**Diagram 1.1**).

Ongoing Needs

Complicating matters, identifying and tracking survivors became difficult as the number of victims rose towards the peak phase; an untold number of infected persons likely did not seek formal care throughout the first phases of the crisis, and paper-based ETU registries were filled with incomplete or false personal identifiable information [19,20]. Survivors learned mostly through word of mouth through small pockets of survivor support networks and associates from ETU discharge about which officials to contact by phone or visit in person to seek help [17]. Additionally, public fear of survivors was amassing, as much of the population was both ill-informed that survivors were still contagious as well as

held traditional voodoo beliefs of diseases being a spiritual curse, which heightened stigma and discriminatory acts against this vulnerable population [16].

Phase 2: Peak

The second exogenous shock in the crisis was the August 2014 rapid spike in Ebola rates, led to strict border closures and media attention, an increase in international response efforts, as well as an eventual destabilization of the economy and infrastructure capabilities of both the country and region. This exogeneous shock shifted the political and financial dynamics of the response, which as Piketty [12] shows, often fuels relational change between lead actors. Dialogue facilitates negotiating access to need funding and resources, yet there arise new issues of competition. Whereas the Liberian state and national response team had been the primary leaders with support from regional coordination response in the early phase, the peak drove increased international support as the crisis became a pandemic.

This shift drove a larger diversity of new response actors and spurred many older agents in proximate and distant fields of action to adapt their operations to join the response growing from a handful of active NGOs to at one time 37 response NGOs. Coordination between the national treatment response and regional coordinated response overlapped tighter through regional policies designed by international agencies and donors in partnership with the West Africa contingency. However, the influx of new international health actors and transitioning nonprofits (NGOs) changed the power dynamic in terms of human and financial resourcing of the distant and proximate fields (Diagram 2). Feedback loops were poorly constructed, an already inefficient information system was further constrained, and most collaborative decisions and policies were rendered ineffective [18]. As Page [9] demonstrates, too much diversity in a system with limited common knowledge and agreement can unbalance the systematic scales.

Key Issues

Solé [6] explains that fluctuations in one system may lead to the formation of a new system or revisions within it. Additionally, the system size depends on the number of different actors and how they adapt to work better together as a continual learning process. Slowly, the size and scope of the response CAS grew yet individual fields increasingly overlapped in effort, unified by improved signals and boundaries, with the ESSS at the center of this new wave of energy serving as a policy tool for improved collaborative action. However, conflict and competition amongst the different response fields injected divergence in the ESSS as the crisis grew.

In August as the disease climbed to over 1,300 cases, the IMS Committee Deputy Minister proposed to the MoH/IMS the formation of the NESNL, which would be internally overseen and maintained by MoH/IMS representatives and managed by network team of Liberian health officials and survivor leaders. The NESNL was one of multiple clusters which would later develop as incumbents within the ESSS, yielding as Fligstein McAdam [7] refer to as a disproportionate influence within the boundaries of the strategic action fields.

For this project, the term cluster will represent the small groups that developed first as pockets of survivors often who knew each other from ETU treatment or within their communities, banding together for solidarity and support, and eventually gained some financial funding from different agencies such as religious organizations, individual sponsors, civil society organizations, and even larger donor or implementing agencies. Numerous bands developed into or joined clusters as their contingency of informal survivor membership grew. These clusters were often recognized as representative bodies and allowed to speak on their behalf at key response coordination meetings.

By November 2014, the MOH was recognizing the difficulty in tracking and managing not only the enormous input of funding

Diagram 2: Peak Phase (August-December 2014)

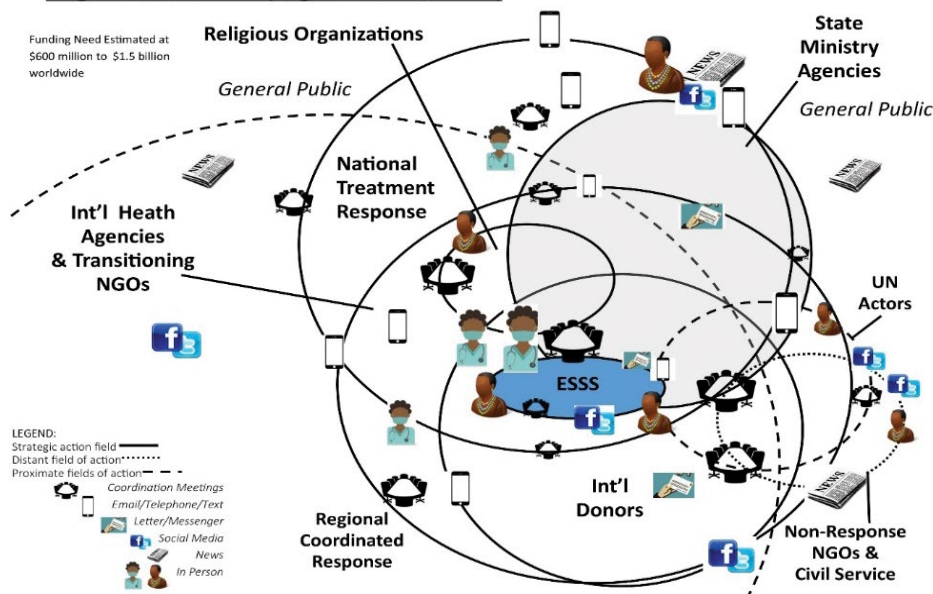


Diagram 2 Peak Phase (August-December).

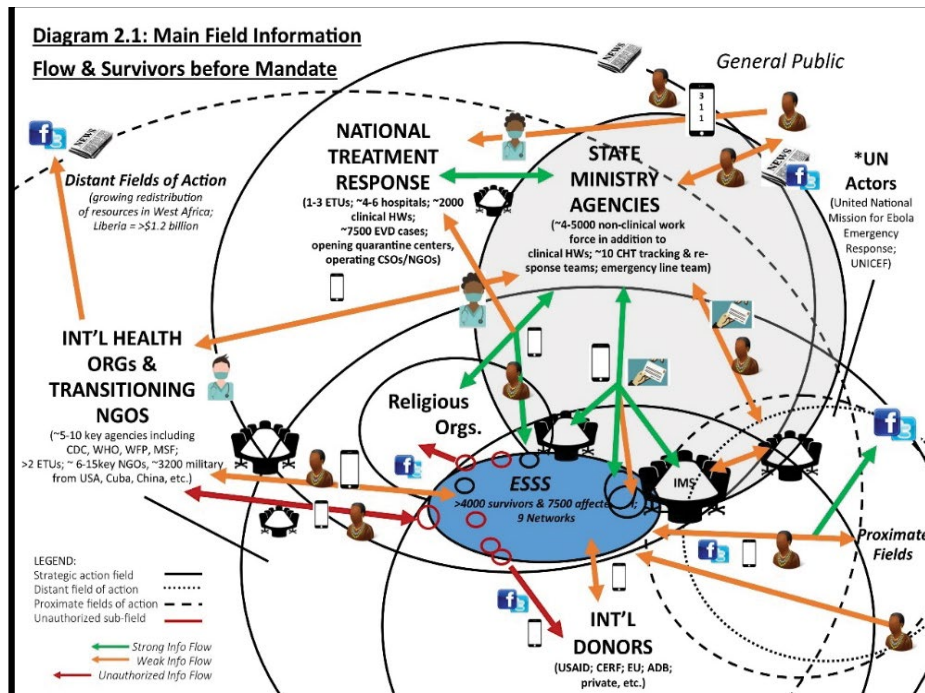


Diagram 2.1 Main Field Information Flow and Survivors before Mandate.

and agency activities to combat the disease, but also in working with EVD survivors and vulnerable families. As shown in **Diagram 2.1**, communication chains changed and grew more complex, often deviating from older response channels. Although the IMS and the Ebola Emergency 311 Hotline were in place, they were relatively new systems not experienced in country. Many Peak Phase actions recommended by external partners like the CDC/WHO and sanctioned by the state were strange concepts to Liberian citizens requiring great adjustment, such as calling for an ambulance or burial team to tend to victims. Some were so culturally foreign (body burning, forced body removal and forced quarantine) that they increased fear and distrust amongst the population of new state and response CAS protocols. These failures drove a political wedge between some in the state and the incoming response agencies, but ministry leadership continued further collaboration. Maintaining cooperation becomes important in public policy issues when extreme emotion may drive irrationality [21].

As the number of victims grew into the thousands, the number of small pockets (clusters like the NESNL within the ESSS) supporting survivors developed. They offered their members more than just jobs but stipends (ranging from \$100-450 USD/month) and non-food items grew. In Phase 2, there were 9 identified ESSS clusters, 6 which were unregistered with the state [10]. Each cluster (**Diagram 2.1**) was actively tracking survivors for membership, soliciting organizations and donors for portions of the increased funds and resources, and representing members' issues in key response coordination meetings. The MOH grew weary of its inability to track actions between survivors and external partners. The quality of information tracking worsened as these clusters reported duplicate membership and used different tracking and reporting systems.

Several clusters were also suspected of including ghost membership, in which a number of listed member names may be invented or include real persons falsifying their status to claim emergency benefits. Ghost membership was a common issue of corruption in Liberia since wartime, now repurposed into a new form of fraud during the outbreak. Likewise, donors, eager to allocate their funds, and implementers, under pressure to spend grants quickly, frequently communicated with the ESSS through new channels including private meetings, phone calls, and even as abrasively as entering former hot zones and unloading supplies directly in the affected households (HH), with no official registries and without state guidance. These actions resulted in poor distribution and power struggles that could not continue.

Transition of System Structure

By October 2014, the driver of change in the next phase transition of the ESSS included: 1) controlling financial allocations and resource distribution, and 2) improved communication that increased accuracy of tracking and reporting mechanisms. Towards the end of the Peak Phase and into the decline phase, the state ministry agencies enacted a series of policies that revised the interactions between old and new actors as they increasingly transitioned into strategic action fields supporting survivors. While these policies were often state imposed, they allowed what Innes and Booher [14] refer to as collaborative rationality.

Firstly, in October 2014, all clusters or groups working with survivors had to register with the state and submit all reports, partnership agreements and membership lists or identified survivor databases to the newly formed, joint MOH/MOG division, associated with the IMS. Secondly, the state in its role as the internal government unit (IGU) of the survivor network,

facilitated the first national meeting of all identified survivors in Monrovia on contact lists. In this large meeting with attendance in the hundreds, survivors were asked to formally register with the state to confirm their recovery-status under set protocol including documentation, and to encourage their peers to do the same, to be prioritized for benefits [21].

Next, two led survivor clusters, the Ebola Survivors' Association (ESA) and the MOH-supported National Ebola Survivors' Network-Liberia (NESNL) were charged with taking the lead on communicating these new policies, including traveling into rural sectors. The NESNL had no resources, so the state supplied the leadership with office space within the main MOH-IMS building, as well as resources including computers and phones. With the NESNL housed in the MOH, dialogue with state authorities facilitated engagement and consensus for action, and served as a direct communication tool that quickened decision-making approval among key departments also set up in the main building. The state also disbanded several fraudulent groups posing as clusters. Additionally, another key policy stated that all implementing agencies had to undergo state-led training of protocol in working with vulnerable populations including survivors and children [22].

The increased frequency of interactions with actors and the state drove further dynamic change, measured in decrease of conflicting survivor datasets and the establishment of a universal registration toolset by December. Additionally, attendance in IMS and key state-led coordination meetings grew which streamlined information sharing, in which the ratio of meetings by those with survivor issue minutes improved from about 1 per every 4 meetings in October to 4:4 by November [10].

Survivor input also expanded and permeated new fields through participating in key strategic and coordination meetings. Likewise, their voices became a universal symbol of overcoming Ebola in distant fields; their testimonials were shared nationally and internationally through social media and news outlets, promoted by international actors in all fields including UN agencies like UNICEF and the I Survived Ebola campaign, donors like USAID, as well as INGOs like Save the Children and More than Me. Yet the state struggled to track social media of survivor adults but were more effective in protective regulations in stories involving affected children. The media increased prioritization of survivor funding and programs by donors and incoming or transitioning NGOs in Phase 3.

These qualitative changes in the Peak Phase in communication and information exchange helped solidify consensus for change in a more democratic and systematic fashion. Secondly, it reestablished the ministry agencies not only as IGU but in its

traditional cultural role as managing authority, which was needed to create improved field stability through setting signals and boundaries reflected through protocol and policies that oriented old and new agencies (**Diagram 2.2**). Set policies provided tags for competing fields, particularly donors and international health organizations/transitioned response NGOs, of acceptable boundaries for actions involving survivors, and revised a new shared culture amongst actors. For instance, the MOH began regulating the range for one-time relief stipends and salary pay for survivors that agencies allocated, initially raising the minimum-wage and lowering high-payouts by specific agencies that were causing disgruntlement amongst the ESSS.

Ongoing Needs

However, these boundaries were not always respected and the communication remained weak between state and international implementing partners, particularly in cases of high transition and rapid employee turnover; many project managers and consultants only were hired for short stints, and their replacements had to re-orient to the system culture and operations. There was also increasing external pressure by regional and international teams to maintain strong budget expenditures, which could be stalled by following state mandates. The more state compliance protocols were established, the greater the bureaucratic inefficiencies. For instance, a project manager may need to have Memorandums of Understanding (MoUs) signed with multiple departments in multiple state ministries, which was not conducive to timely action in an every-changing emergency response cas. This was one reason, a number of unauthorized communications and partnerships continued even after state protocols were set. **Table 1** demonstrates the key actors who acted as strategic action fields (SAFs) interacting with survivors through the ESSS, their changing level of communications, and the shifting power dynamics between the actor and the state agencies (MOH/MOG) in terms of policy protocol compliance and feedback loops.

Fraud and poor allocations of resources also continued through the next phases of the emergency. Survivor clusters were also identified later as still existing without proper registration, often soliciting funding that could not be accounted for officially. Moreover, competition continued to grow amongst the clusters for funding for their members and their priority of needs, as well as recognition and dominance within the ESSS. Some clusters stopped complying with the MOH, such as no longer attending mandated meetings, and operated independent of authorization. This tension revealed a point of disagreement and the need for new boundaries [14].

By December 2014, this ongoing gap in collaboration between clusters signalled to the MOH and the Incident Management

Table 1 Summary of SAFs Interacting with ESSS and Power Dynamics with State Agencies.

Key SAF	Phase Transitions		
	1	2	3
Religious Organizations	*	***	***
National Health Treatment Response	*	***	***
Implementers-Transitioning INGOs and Health INGOs	-	**	***
Donors	-	*	***

Communication about ESSS- Low*; Medium**; High***; State Agency Adherence- Strong (Green); Weak (Yellow); Contentious (Red)

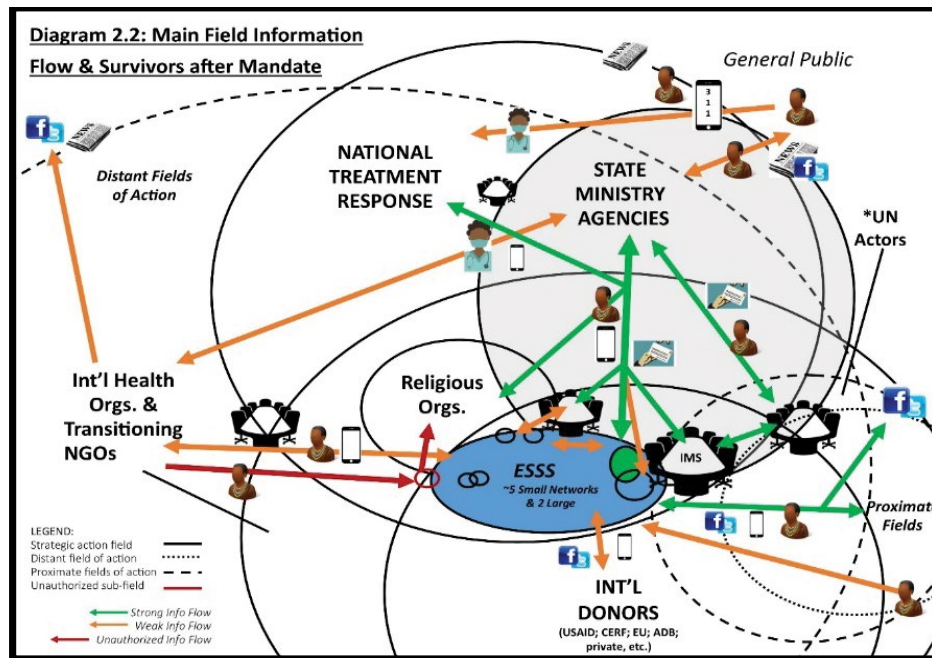


Diagram 2.2 Main Field Information Flow and Survivors after Mandate.

Team the need to impose a more authoritative transition. This move was further advertised to entities through a series of actions towards the end of Phase 2. Primarily, the November 2014 inauguration of the NESNL that included key actors like UNICEF, as well as official newspaper coverage, demonstrated the growing partnership transition between the state and this cluster to dominate the rest of the crisis [23].

Decline Phase

Phase 3, the decline of the outbreak, experienced a shift in the system fields. International donors and agencies fields transitioned into large strategic fields that eventually outsized both the fields of the state ministry agencies and national treatment response. However, these four SAFs overlapped in their coordination mainly through formal meetings established through the IMS and coordinated email groups, co-led by the GoL agencies, the US military, key UN agencies, and international response agencies. The number of meetings drastically increased as too did the number of agencies. Other additional meetings were established by proximate fields of operations with national and international operators, including by UN agencies like UNICEF. These meetings had selective membership, such as between mostly international agencies coordination and few ministry representatives, often relating to niches of relief work efforts, such as the management of ETUs, CCCs, or health infrastructure. Divisions in UNMIL increasingly joined supporting Ebola, but it remained mostly a distant field when it came to supporting Ebola survivors. The regional coordinated response increasingly overlapped as a proximate field with the main Liberian SAFs, resulting from Liberia's early peak phase. Lastly, the ESSS grew in size and resourcing, while remaining strategically within close coordination with the state ministry agencies, yet at the center of where many SAFs and proximate fields overlapped through coordination meetings. Thus, the visibility of the ESSS advanced.

Key Issues

International funding support for the crisis reached into the billions of dollars. This pledge of aid helped shape a quickened recovery; however, EVD rates had fallen significantly, most in part to the learning and leadership of the original field actors operating on the ground since the beginning of the outbreak. Most particularly, under the command of the Executive, the MOH and MOG joint effort provided rational and legitimate decision making for state implementers, however depleting government coffers. In Phase 3 (January-May 2015), the state became heavily reliant on external sponsors for funding support, to build new quarantine centers, fund ETUs, hire new staff and back-pay old staff who had repeatedly worked without salary.

Innes and Booher [14] demonstrate how sponsors are crucial for legitimacy, which provided a new challenge to the state for maintaining its leadership. The MOH and MOG opened new or more frequent dialogue through a series of continuous meetings with key donor agencies, like USAID-DART/OFDA, EU, and the African Development Bank (ADB), for improved collective action. Donors double-checked that their funded implementers frequently attended coordination meetings, as well as have all MOUs approved by MOH and CHT leadership as part of auditing procedure [20]. Other similar examples of collaboration happened at top decision making levels and were enforced onto ground operations. Work efforts and funding streams further aligned towards a common vision set by the IMS members and the government to start recovery efforts and stop pocket outbreaks (**Diagram 3.1**). Most relevant to work involving survivors, the ESSS was brought fully into the center of the key action fields through crucial state policy mainstreaming the NESNL as the main source of information flow (**Diagram 3.1**).

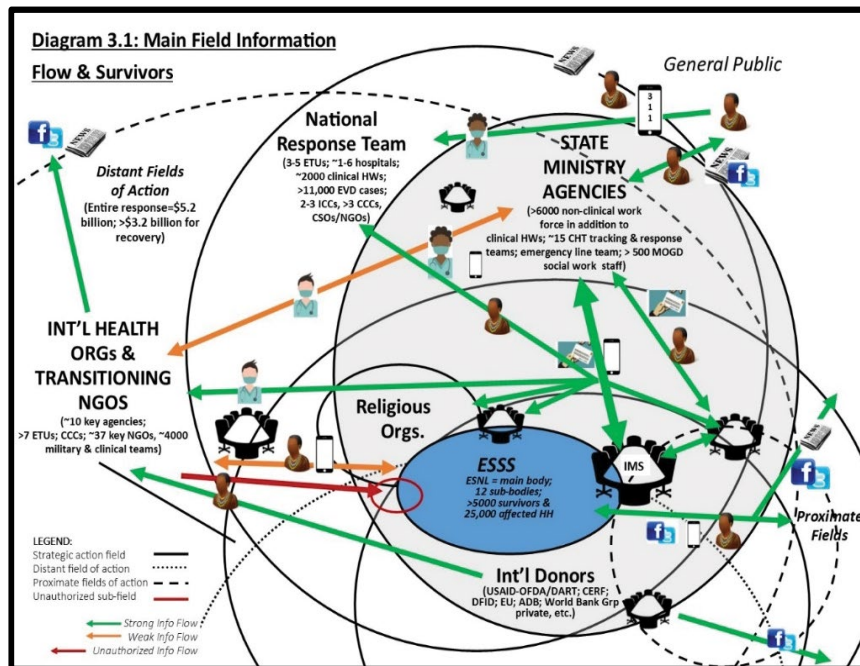


Diagram 3.1 Main Field Information Flow and Survivors.

Transition of System Structure

Firstly, the NESNL became the umbrella body of all the survivors. The state informed the other clusters like the ESA that they would have to join the NESNL umbrella, following the elected leadership of the network, or else disband. This created tension amongst clusters, several groups vented their resistance through national newspapers and advocated for partner support against the mandate in response meetings [18]. At one point, confirmed authorization was sent from the President to legitimize this decision by the MOH-MOG. Small pockets of unauthorized operations continued for a time, but eventually the government halted them. Monthly ESSS meetings transitioned into NESNL-facilitated meetings where its membership continued to increase beyond its original 1,500 members, and finalized a registry of over 5,000 identified survivors by May 2015 [19,20]. Furthermore, these meetings were decentralized to county level with NESNL again facilitating the communication process with MOH funding. County subgroups were established under the NESNL for survivors to join for a support network.

The central NESNL became permanently housed in the MOH and closely collaborated with MOH-MOG authorities, including providing update reports daily and provided ongoing space to share key information on behalf of survivors with all actors in the IMS and Response Pillar meetings. All communications were funneled through the NESNL in established MOH/IMS communication channels not increasingly providing tags to all response actors as well as survivor membership. The NESNL increasingly used posts on its Facebook page to reach current and potential members. By March 2015, they reported over 2,000 members.

Secondly, the social media and news campaigns championing the stories of survivors dominated most outlets, and positioned funding support for the ESSS as one of the key priorities for a

few brief months in the third phase. The state ministry agencies further compelled all implementers using these funds to help survivors to submit budget and work plans to the NESNL not only for approval that would be communicated back to the MOH, but also to provide lists of survivors and affected families who were confirmed victims and thus approved for resource support [23]. The NESNL collaborated with large implementers like the National Institutes for Health (NIH), CDC/WHO, Academic Consortium to Combat Ebola in Liberia (ACCEL), and UNICEF to establish large scale programs with systematized operations for all registered survivor members and their families to benefit from, including free physical and mental health care, community awareness building by CHT, recovery stipends, temporary jobs and vocational training, and education grants [1,2,20,24]. Overtime, the decision by the MOH/MOG developed the ESSS through the NESNL into a uniformed body with a set boundaries and cultures of operations.

Contention continued within the ESSS as the NESNL formed its role as the leading body. The main contention came from other large clusters which were merging under the NESNL that their original leadership have equitable chances at leadership positions within the future NESNL. The purpose was to help democratically represent the needs of their original membership now being joined to the NESNL roster. These positions would play a vital role in determining where, how and how much benefits and funding were allocated among survivors and affected families. By May 2015, over a dozen major organizations had reported to the MOH/MOG their budgetary plans to distribute over \$1 million USD alone in food and non-food items (NFI) kits, vocational training, health and mental services, volunteer stipend pay, etc.

As a result, the central NESNL management rose from 4 key staff to the formal election of 7 stable central positions housed within the MOH, and 66 delegates in 11 counties. The building blocks of other MOH-supported networks were repurposed for the NESNL,

including legal policies and MOUs, as well as the establishment of an election commission for transparency, which ameliorated contention amongst the clusters forced to come under the NESNL and yet worried about equitable chances at having their leadership voted into key positions.

As the third phase came to a close towards recovery efforts, the repurposing of the NESNL as the singular representative body moved the ESSS away from micro-perspectives that insularly considered the short-term needs of the survivors and transitioned the ESSS to expand its vision for a coordinated, unified effort in the long-term. The NESNL measured more systematically within its meetings and monthly surveys the common needs of the survivors, siloed into key advocacy priorities. The NESNL further established the first core mission and values of the ESSS, establishing itself as a union-like agency for survivors and their families, receiving and transmitting updated information through its communication chains, and coordinating a more equitable distribution of benefits for all members. By the recovery phase, the ESSS operations and set protocols had all but eliminated discord amongst cluster incumbents and reaffirmed the state ministries as lead facilitators in public and private partnerships involving survivors and their families.

Conclusions

Current state of ESSS

The ESSS as an emerging system played an increasingly important facilitation role for helping survivors' voices to be heard by key actors in a variety of action fields throughout the crisis. "Inequity is shaped by the way economic, social, and political actors view what is just and what is not, as well as by the relative power of those actors and the collective choices that result. It is the joint product of all relevant actors combined" [12]. Over the course of the crisis in Liberia, it primarily fell upon central state ministry agencies to formally coordinate and set policies for the ESSS to respond more systematically to the increasing need of survivors and affected households. The state agencies faced an ever-changing response CAS with a variety of actors, flocculating communication chains, and resource and funding partnership compliance issues. However, over the course of 16 months, the priorities of survivors who were disproportionately affected by the crisis took precedence amongst the multitude of actors who joined efforts with MOH/IMS guidance. Because of this, the ESSS gradually transitioned into a legitimate network, authorized by the state as the official body or union for EVD-affected persons, under the leadership of the NESNL.

The NESNL functioned as the umbrella organization that clusters came under while still maintaining some autonomy as decentralized groups so long as they reported directly to the NESNL and complied with its mandates. Secondly, they had to report all identified survivors to the IMS survivor registry and at-risk disease-affected households, particularly vulnerable children, to the Division of Child Protection. The formal transition continued to meet moments of resistance from some clusters. Yet the policy process that led to the restructuring of the ESSS into the NESNL provided notable change in dynamics, and mainstreamed more effectual, timely information sharing, partnership coordination, and collective action in an equitable manner impacting more survivors.

In Liberia, this emerging system is effective in its capacity beyond the short-term and mid-term goals of the response and recovery, but may yield sustainable action in the government policy to continue to support EVD survivors for years to come. The NESNL continues to operate as a formal organization with leadership staffed by the state. Budget constraints continually plague the NESNL efforts to meet with survivors in decentralized and centralized meetings. They currently utilize social media and news to transmit key messages to members and their families. The NESNL will need to rely on outside donor support and implementer programs to address the changing needs of survivors.

This national ESSS also plays a sustainable action role outside of Liberia. The NESNL members travelled to Sierra Leone and Guinea to train through knowledge sharing forming survivor support systems that were not as advanced. NESNL leaders continue to conduct trainings and advocate for survivors internationally. Yet, the slow maturation of the Liberian ESSS serves as a reminder of what could have been achieved had previously documented systems informed its emergence. The question remains if the ESSS could have transitioned between phases more quickly and systematically with previous knowledge application from prior outbreaks?

Informing future disease survivor support systems

An established DSSS body, such as the Ebola Survivors' Network, can serve multiple purposes. Examining the ESSS development, the response system in the future can anticipate fields of actions and potential partnerships at different phases within the response.

Documented action recommendations for future DSSS include:

- When a disease first outbreaks, the state and key health agencies most likely to interact with survivors should allocate immediate funding and human resourcing for the establishment of a formal body to track and organize survivors. This action may include several parts: forming primary leadership; a basic IMS system with track and registry tools for the initial DSSS linked to communities and ETUs/quarantine centers; clear assigned IGU roles of specified ministerial departments to guide and coordinate with the DSSS leadership. **Diagram 4** demonstrates the potential roles within an emerging DSSS structure.
- The state can then negotiate with agencies transitioning into strategic action fields, as well as with proximate fields, the purpose and system of the DSSS, primarily to coordinate allocation of initial investment and programming. Instead of handling actual budgets, the alternative strategy is for the DSSS to be trained to navigate external investments by consulting on resourcing priorities and tracking equitable distribution amongst identified and registered survivors, as in the case of the NESNL.
- Eventually, the DSSS (like the NESNL) may select to transition into a lead representative body that provides a safe space for sharing, advocates for survivors' long-

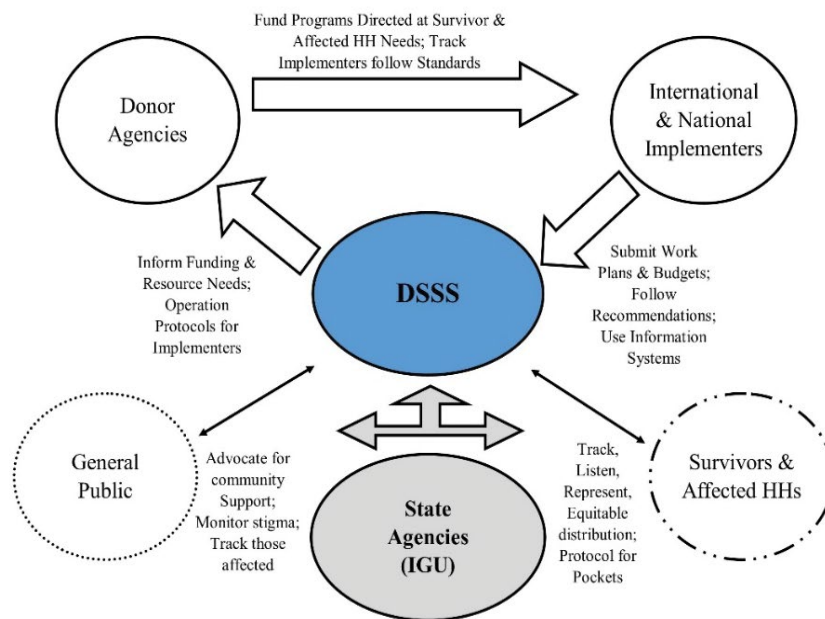


Diagram 4 DSSS Structure.

term recovery and reintegration, and consults on annual prioritization of requested resources and programs, as the needs of survivors change over time. This transition should consider how leadership at central and decentralized levels are selected, such as through voting or merit-based hire by government agencies, as well as the leadership's individual roles and responsibilities, reporting mechanisms, administration and budgeting, and communication patterns with disease survivors, donors, and implementing agencies.

- Advocating for both state and international donors to allocate annual funding for cost-efficient DSSS operations within their budgets can sustain progress support over time. This paper advocates for this prioritization of continued funding for the NESNL by GoL and international agencies, including USAID and WHO/CDC. The NESNL serves not only the 5,000 identified survivors, but it may also facilitate guiding support for the estimated 25,000 direct and indirect affected households in Liberian communities that were former hot zones.
- Additional funding for NESNL and future DSSS networks can support regional partnerships between countries affected by the outbreak as it transitions into a pandemic, linking network cells together for knowledge sharing and transnational coordination. These DSSS transnational partnerships including collaboration between the Liberian NESNL and emergent ESSS networks in Guinea and Sierra Leone should be maintained for two reasons: the likelihood of the disease reemerging is high following current disease trends; and secondly, the negative impacts of diseases like Ebola on affected persons and their households continue long beyond the outbreak ends. Stigma, income, and physical and mental health issues

[16,19,25,26]. Regionally, there remain at least 10,000 survivors and their affected households and communities.

- As a contingency plan, the ESSS leadership may act as consultations on the startup of a DSSS in the case of outbreaks involving new strains of EVD or other communicable diseases. This role may include site travel but only on a voluntary basis and under strict protection protocols, as EVD survivors may not be immune to new strains or diseases. Chronic diseases and contagious viruses are on a steady rise globally [3], including Zika, Middle East respiratory syndrome (MERS) and small resurgent pockets of Ebola. In early 2017, a new Ebola outbreak occurred in the Democratic Republic of the Congo with confirmed cases and survivors of the disease. National and international agencies must back public health systems to improve the quality and frequency of knowledge application from previous outbreaks. For the public health community, the findings from the Ebola outbreak case which demonstrate how response systems and survivor networks were set up may be applied to a variety of different diseases and/or disaster response situations. The foundational concepts of the work outlined in this manuscript can be applicable for response to public health and humanitarian efforts, particularly in low resource, underserved settings.
- The Liberian ESSS is a key case study of an emergent system responding the needs of survivors and their families at the meso-level, within the response cas. Sole [6] emphasizes that while we cannot foresee the future, past experiences can influence policy action. Modeling the process under which a system undergoes can capture. The rate of change, and political and cultural values that influence bonds [21]. By retaining core knowledge and training through the NESNL leadership, and careful documentation of the ESSS

phases, this system may serve as a learning tool informing more effectual policy process for future outbreaks using deconcentrated processes between the network and state ministerial agencies. The ESSS offers a roadmap for an effective DSSS, established prescriptively in anticipation of needed survivor services rather than reactively as the infection count grows.

Limitations

This research is a qualitative analysis which attempts to compile a thorough timeline of the Liberian Ebola outbreak and recovery at different phases. As previously mentioned, two of the authors were actively involved in the response. One author helped in the establishment and leads management of the ESSS throughout its infancy into its current role at time of developing this work. His first-hand knowledge and recount of the ESSS formation serves as a body for this analysis. The other author worked as an international technical adviser to the ESSS throughout Phases 2-3, and at different times worked as a consultant with some

of the first programs utilizing Ebola survivors in ICCs, as well as programs providing psychosocial support to survivors, their families, and communities. Disaster responses provide challenges to capturing timely, accurate data, as primary focus goes to targeting and isolating the outbreak. Archival documents were a challenging to find as there were limited knowledge management systems in place during Phases 1-3. The authors specifically triangulated collected information using various resources in its literature review, archival review, and interviews to minimize potential inaccuracies and perspective biases. The third author is an expert in public health and infectious disease epidemiology. This research recognizes that there are limitations in the qualitative analysis, which would have been better accounted if access to more complete IMS meeting notes and reports was found, and more interviews with leaders of SAFs completed. As a second measure for accuracy and transparency, the analysis was provided to representatives at the Ministry of Gender and former response coordinators working in proximity with the ESSS and Ebola programming.

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