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WHO MEETING ON SURVIVORS OF EBOLA VIRUS DISEASE: CLINICAL CARE OF SURVIVORS

Meeting report

Freetown, Sierra Leone, 3-4 August 2015

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WHO Meeting on Survivors of Ebola Virus Disease:
Clinical Care of EVD Survivors
Freetown, 3–4 August 2015

Meeting Report

Background

The unprecedented outbreak of Ebola virus disease (EVD) that began in West Africa in December 2013 has had a devastating impact on the region. With over 27 500 cases registered to date and despite a very high case fatality rate, there are likely over 13 000 EVD survivors in Guinea, Liberia, and Sierra Leone, a far greater number than all previous EVD outbreaks combined. Limited systematically collected data and accumulating anecdotal reports, demonstrate that EVD survivors still face myriad physical and mental health challenges after recovery from the acute disease. However, there are very limited data on the true frequency of the various reported health problems, their pathogenesis, or the best practices for clinical management.

Scope and Purpose

The meeting assembled stakeholders engaged in or seeking to provide care and/or conduct scientific research regarding EVD survivors. Clinicians, scientists, epidemiologists, and other public health practitioners shared their expertise and experience in order to advance networks and access to clinical care for EVD survivors, build consensus on best clinical management, share research data, and identify key knowledge gaps, with the goal of enhancing quality of care for EVD survivors everywhere.

Specific Objectives

The specific objectives of this meeting were to:

- Identify existing clinical services available to EVD survivors in West Africa and help link them to survivors in need of care
- Share expertise and experience regarding clinical management of EVD survivors to build consensus on best clinical management practices
- Identify gaps in clinical services and develop plans to meet them, including provision of technical expertise and infrastructure
- Discuss and develop common protocols for data collection and best clinical management of EVD survivors
- Review key research questions regarding EVD survivors, including the evidence for various health problems post-EVD and their pathogenesis, to enable improved care of survivors for this and future outbreaks.

Opening Remarks

Anders Nordström, World Health Organization (WHO) Representative to Sierra Leone, welcomed the participants. In his general introduction he highlighted the aim of securing the maximum support for EVD survivors.

The Sierra Leonean Deputy Minister of Social Welfare, Gender and Children´s Affairs, Hon. Mustapha Bai Attilla, emphasized the importance of understanding the needs of EVD survivors for the post-Ebola recovery phase. With immense medical and social challenges, Ebola affected communities require urgent support. Therefore, the President of Sierra Leone has launched a six to nine month recovery programme, working with partner organizations like WHO, to assist EVD survivors back to a normal life. EVD survivors need to be included in the planning process and lessons must be learned from their experience in order to be better prepared for future outbreaks.

The Deputy Minister of Health and Sanitation, Hon. Foday Sawi Lahai, thanked all participants for their support in finding best practice solutions for the clinical management and social support of EVD survivors. In his speech he also emphasized the need to include the EVD survivors themselves in planning activities to improve medical and psychosocial care.

Bruce Aylward, WHO Assistant Director General responsible for WHO’s Ebola response, stressed the importance of the EVD survivor’s voice in the meeting and the importance of the meeting itself in setting the global agenda for the post-Ebola recovery phase in West Africa. He mentioned specific issues, such as the necessity to improve collaboration and the sharing of information, which need to be discussed and that decisions must be made with urgency, flexibility and clear timelines to move the agenda faster.

Review of Literature on Health and Psychosocial Problems of EVD Survivors

(Daniel Bausch, Epidemic Clinical Management Team, WHO)

There are few published reports on the health and psychosocial problems of EVD survivors. Most of these papers have been published during the recent Ebola outbreak in West Africa. A study conducted in Kenema District, Sierra Leone, in October 2014, describes the most common symptoms a group of 81 EVD survivors have self-reported following their discharge from the Ebola Treatment Unit (ETU). Their symptoms included joint pain, headache, muscle pain, sleeplessness, visual problems and depression. These reports show great similarities to two controlled studies, which were undertaken in Kikwit, Democratic Republic of the Congo *(Rowe, 1999)*, and Bundibugyo, Uganda *(Clark 2015)*: fatigue, sleep disturbance, blurred vision, arthralgias, myalgias, hearing loss, abdominal pain, and anorexia were the most common symptoms, many of which were still present at the end of the follow-up period (Democratic Republic of the Congo: 21 months; Uganda: 29 months). Interestingly, no differences in basic clinical laboratory parameters, including C reactive protein, were detected. Special attention on the high percentage of ocular findings seems to be necessary. Studies on EVD sequelae have described ocular symptoms like vision loss, uveitis conjunctivitis and blurred vision in a great number of EVD survivors (Bwaka et al. 1999, Kibadi et al. 1999, Wendo 2001, Clark et al. 2015, Nanyonga et al. 2015).

Another important issue is delayed virus clearance in immunologically protected body compartments, such as the male gonads/semen, chambers of the eye, placenta and fetus, and possibly also the central nervous systems and articular cartilage. There is no evidence that EVD causes a chronic infection, but the immune system seems to take longer to clear the virus from these compartments (e.g. Ebola virus has been detected in a survivor's semen 82 days after disease onset).

The pathogenesis of EVD sequelae and delayed virus clearance is not well understood. There is some evidence for a sustained immune activation or a delayed hypersensitivity reaction to persistent virus antigen. Immune complex deposition could also be an explanation, especially for the arthralgias. Ebola virus antigen has been noted in the brain, eye, pancreas, thyroid, and lung of macaques with significantly delayed disease after treatment (Larsen et al. 2007) *(Larsen, 2007).* There is some evidence showing a correlation between the severity of the disease and the frequency of sequelae. IgG titres were found to be significantly higher in EVD survivors with arthralgia than in those without *(Rowe, 1999)* and sequelae were also more frequent in those with surrogate clinical markers of severe disease (seizures and melena)*(Clark, 2015).*

The WHO Ebola Survivors Support Network (WHO ESSN) has been set up to assist governmental and nongovernmental partners in the coordination of plans for EVD survivors, both in terms of service provision (first priority) and scientific study (secondary). The objectives of this network are to strengthen the links between all actors involved in the care of EVD survivors, to exchange best practice solutions and to identify research gaps. The Sierra Leonean Ministry of Health and Sanitation and Ministry of Social Welfare, Gender and Children's Affairs together with WHO have, to this purpose, set up a Comprehensive Care for EVD Survivors platform, working on the following task groups: _______(https://sites.google.com/site/evdsurvivors/)

TG1 EVD Survivor Cohort

- ➔ Geolocation - Survivor Population Density & Catchment Areas

TG2 Survivor Care Needs Assessment

- ➔ Care Needs Report Integration of MHPSS Care Needs Assessment

TG3 Harmonization of Clinical Data Collection Forms and Information Flows.

- ➔ Bases for National EVD Archive Database

TG4 Service and Programme Costing and Financing

- ➔ Cost Assessment and Overall Programme Costing
    - Assessment and documentation of service costs in SL
    - Projection of global volumes of each type of required service
    - Global costing for each type of service for EVDS cohort/sub-cohort
    - Bundling of service costs and other possible cost structure solutions
- ➔ Structured Funding Proposal to potential Donors

TG5 Location/distribution of service scenarios following criteria for equitable effective access

- ➔ EVDS Service Network Map

TG6 Facility Network Improvement

- ➔ Network Improvement Plan
    - Infrastructure at facilities
    - Equipment / supplies
    - Human resources - Hiring - Training

TG7 Referral Pathways & Case Management

- ➔ PROVEN referral pathways to required specialized services

TG8 Three Country Meeting for Care Guideline Final

- ➔ Comprehensive Care Guideline for EVD Survivors

TG9 Systematic Monitoring, Evaluation, Analysis & Report Process

- ➔ Systematic report on service process results & care outcomes

In summary, EVD survivors experience many different physical and mental health sequelae, most of which appear to be treatable. More studies, especially those including control groups, need to be conducted to learn more about the true frequency and duration of various sequelae post-EVD, to better understand the pathogenesis and the relationship between acute disease severity and sequelae, as well as the effect of given treatment options. More data is also required regarding the mid-term and long-term consequences for Ebola-affected communities.

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The Survivors’ Sounding Board

(President of the Sierra Leone Association of Ebola Survivors)

The aim of the Sierra Leone Association of Ebola Survivors (SLAES) is to effectively contribute to the elimination of EVD and to participate in the national development programmes. The members of SLAES have voluntarily begun to strengthen community sensitization by measures such as visiting quarantined households in order to raise awareness about the signs and symptoms of EVD and to inform communities about the necessary steps to take. SLAES has conducted anti-stigmatization campaigns in all 14 districts of Sierra Leone, lobbying traditional leaders to adopt laws to prevent the stigmatization of EVD survivors. SLAES has also successfully advocated for improved health care for survivors. The association consists of district and regional structures and maintains mutual communication with all partners and networks. The SLAES programmes are categorized as follows:

1. Short-term plans:
    - Advocacy on EVD survivors health care, especially in remote communities
    - Strengthening of the EVD survivors network
    - Nutritional support
    - Office equipment and funding
    - Advocacy for scholarship/educational opportunities for EVD survivors
    - Anti-stigmatization campaign.

2. Mid-term plans:
    - Capacity building and empowerment opportunities for EVD survivors
    - Technical training on psychosocial care
    - Micro-finance scheme
    - Advocacy on EVD survivors health care
    - Anti-stigmatization campaign.

3. Long-term plans:
    - Adult educational facilities for illiterate EVD survivors
    - Shelter facilities for EVD survivors
    - Anti-stigmatization campaign
    - Advocacy for EVD survivors health care
    - Agricultural and nutritional support for EVD survivors.

SLAES is very concerned about EVD survivors not being involved in the national post-Ebola reconstruction activities. The association calls for increased involvement in these discussions and is asking the Ministries for additional support for EVD survivors, especially those in remote communities. Stigmatization remains of great concern for the EVD survivors, who feel that the authorities are not