World Health Organization

INTERIM GUIDANCE

Clinical care for survivors of Ebola virus disease

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Contents

Acronyms

AFB	Acid fast bacilli
ALT	Alanine aminotransferase
AST	Aspartate aminotransferase
CBC	Complete blood count
CSF	Cerebrospinal fluid
ETU	Ebola treatment unit
EVD	Ebola virus disease
GERD	Gastro-oesophageal reflux disease
IPC	Infection prevention and control
LFT	Liver function test
MOH	Ministry of Health
NSAID	Non-steroidal anti-inflammatory drug
PHQ-9	Patient health questionnaire 9
PPE	Personal protective equipment
PTSD	Post-traumatic stress disorder
PUD	Peptic ulcer disease
RDT	Rapid diagnostic test
RT-PCR	Reverse transcriptase-polymerase chain reaction
STI	Sexually transmitted infection
TB	Tuberculosis
UNICEF	United Nations Children's Fund
WHO	World Health Organization

1. Introduction

Background

The outbreak of Ebola virus disease (EVD) that began in 2013 in West Africa had by December 2015, resulted in over 28,000 cases. Although estimates of the number of people affected during the outbreak vary, over 10,000 EVD survivors may require convalescent care. A number of both short- and long-term medical problems have been reported in EVD survivors, including mental health issues for both survivors and other family and community members (1-19). In addition, increasing recognition that Ebola virus may persist in selected body compartments of EVD survivors, most notably in the semen of males, brings awareness of the possibility of reintroduction of the virus in areas where transmission has previously been eliminated.

EVD survivors need comprehensive support for the medical and psychosocial challenges they face and also to minimize the risk of continued Ebola virus transmission, especially from sexual transmission. This document provides guidance on providing the necessary care and services for clinical care and virus testing, and should be used to guide the planning and delivery of ongoing health services to people who have recovered from EVD.

Target audience

The primary audience for this guidance includes health care professionals providing primary care to people who have recovered from EVD. This guidance may also be used by family or community members providing support and care to EVD survivors, as well as planners of health care services and policy makers.

Guidance development methods

This guidance was developed by the World Health Organization, Geneva, with inputs and feedback requested from stakeholders including Ministries of Health in Guinea, Liberia, and Sierra Leone; members of the UN Global Ebola Response Coalition; WHO country offices; research and non-governmental health organizations with recognized expertise and interest in the care of EVD survivors (Médecins-Sans-Frontières; Centers for Disease Control and Prevention (CDC), Atlanta (United States of America); US National Institutes of Health, Bethesda (United States of America); Partners in Health, Boston (United States of America); GOAL, Dublin (Ireland)) and other stakeholders.

Due to the severe limitations of the existing scientific evidence base on clinical care for EVD survivors and the urgent need for guidance on this topic, the recommendations in this document have been developed from consensus expert opinion amongst the stakeholders consulted. Although this severely limits the scientific robustness of the guidance, the document still remains a representation of best available practice and will be reviewed as new evidence comes to light.

The unprecedented scale of the West African EVD outbreak that began in 2013 has resulted in many more survivors and thus opportunities to vastly enhance clinical observations and understanding of the many health challenges they face. New findings also come from clinical observations made on the 27 patients with EVD seen in high-resource settings in Europe and North America, where available medical technology often permits more detailed and comprehensive investigation. New presentations and complications of EVD are discovered on almost a weekly basis and new findings continue to be anticipated as capacity to care for EVD survivors in West Africa continues to grow.

WHO will continue to follow the research developments in the area of EVD and health outcomes for survivors, particularly those related to areas where new recommendations or a change in this guidance may be warranted.

Updating the guidance

This guidance will be updated six months after publication, unless significant new evidence emerges which necessitates earlier revision. Comments or suggestions regarding additional issues for inclusion in the updated guidance are welcomed.

Definition of an EVD survivor

For the purposes of this document an EVD survivor is defined as a person:

- With a confirmed positive result on RT-PCR testing for Ebola virus on any body fluid who subsequently recovered

  AND/OR

- Who is IgM and/or IgG positive on serological testing for EVD and has not been vaccinated against Ebola virus

These definitions may be changed during an epidemic to correspond to the local situation on the ground. In most cases, government or laboratory-issued EVD Survivor's Certificates have been issued and should serve as the basis for verification of survivor status. However, cross-checking with ETU records and other databases and, in some cases, antibody testing, may be required.

Principle of integrated care

An intensive integrated program is necessary to address the medical and psychosocial needs of EVD survivors as well as the risk of virus reintroduction. Medical services for EVD survivors should ideally be integrated into existing routine health services and facilities. However, in areas where the necessary services do not exist or are inaccessible to EVD survivors, establishment of EVD survivor-specific services may be necessary. Regardless of the short-term approach to providing the needed urgent care to EVD survivors, the medium and long-term goals must be to strengthen health systems for all persons and for all health problems.

2. Planning follow-up of the EVD survivor

Prior to discharge from the ETU

After an EVD survivor's condition stabilizes, but prior to discharge from the ETU, he or she should receive education and counselling regarding the possible sequelae and psycho-social challenges faced during convalescence. With permission, it is ideal to include consultation with the survivor's close family members, explaining in simple terms the common sequelae and what is known about how Ebola virus can and cannot be transmitted during convalescence (see below under *Monitoring for persistent Ebola virus infection in survivors: Guidelines for testing and counselling*) and what measures they can take to avoid virus transmission (see below under *Infection prevention and control considerations in EVD survivors*). EVD survivors should be given a follow-up appointment to see a care provider within 2-weeks after discharge and specific instructions about who to contact if they encounter health problems or have questions. Issues such as confidentiality, avoiding stigmatization, and cost of follow-up care should be addressed. In cases when significant mental health problems are noted before discharge or anticipated afterwards, it may be appropriate to refer patients directly to a mental health care provider.

At discharge, EVD survivors should be provided with documents containing their unique patient ID, name, age, symptoms at presentation, and any convalescent symptoms at discharge, a brief record of their test results and treatment in the ETU, and their government or laboratory-issued EVD Survivor's Certificate. This information will serve as a 'transfer of care' document for their outpatient management. Survivors should be instructed to bring these documents, as well as documents recording past vaccination, to all future clinic or hospital visits.

Sexual health education and counselling should be offered to all EVD survivors, both male and female, at discharge and at follow-up visits. The potential for Ebola virus persistence in the semen and the measures to prevent transmission should be explained to male EVD survivors as well as their partners (see below under *Semen Testing and Counselling for Male EVD Survivors*). Pregnant survivors should receive counselling on the risks of Ebola virus-associated maternal and fetal complications as well as virus persistence and transmission (see below under *Considerations for special populations: Pregnant women*).

First visit after ETU discharge

The following should be performed at the first follow-up visit after discharge from the ETU (see detailed guidance by type of possible sequela below).

- General medical history and physical examination, including vital signs (temperature, blood pressure, heart rate, respiratory rate), and nutritional evaluation
- Musculoskeletal evaluation
- Ocular evaluation
- Auditory evaluation
- Abdominal evaluation
- Neurological evaluation
- Mental health evaluation
- Sexual health evaluation
- Consultation with social worker to address the following:
    - Stigma issues
    - Economic status and employment
    - Shelter and food security
    - Dependents
    - Social support (family, friends, religious community)

    - Potential substance misuse or dependency (alcohol, marijuana, cocaine, heroin and tobacco)
    - Identification of vulnerable individuals (children, disability, domestic abuse, etc.) for follow up/notification
- Routine laboratory tests:
    - Complete blood count
    - Creatinine
- Optional tests as indicated
    - Ebola RT-PCR or IgG or IgM antibody
    - Hepatic transaminases (ALT and AST) and amylase
    - Thyroid function tests
    - Erythrocyte sedimentation rate or C reactive protein
    - Pregnancy test
    - Malaria rapid diagnostic test
    - Stool examination for ova, cysts, and parasites
    - Urine dipstick for protein
    - Syphilis test (according to national guidelines)
    - HIV test (according to national guidelines)
        - Note: Due to anecdotal reports of EVD recrudescence in HIV positive survivors, some care providers recommend routine HIV testing with, pre- and post-test counselling of all EVD survivors.
- In regions with a prevalence of *Onchocerca volvulus* microfilaria infection >5%, ensure that patients are linked with the neglected tropical diseases eradication program for mass drug administration of ivermectin

All clinic visits made by EVD survivors and other relevant health information should be carefully charted and the records securely stored. Data collection forms specifically designed for follow-up of EVD survivors are available at: www.iddo.org/ebola/tools-resources.

Subsequent follow-up visits

Because some EVD sequelae may appear weeks or months after resolution of acute disease and persist for years, regular follow-up of survivors is recommended for at least one year, regardless of presence or absence of symptoms at discharge or initial outpatient evaluation. One suggested schedule for follow-up evaluation and care is as follows: