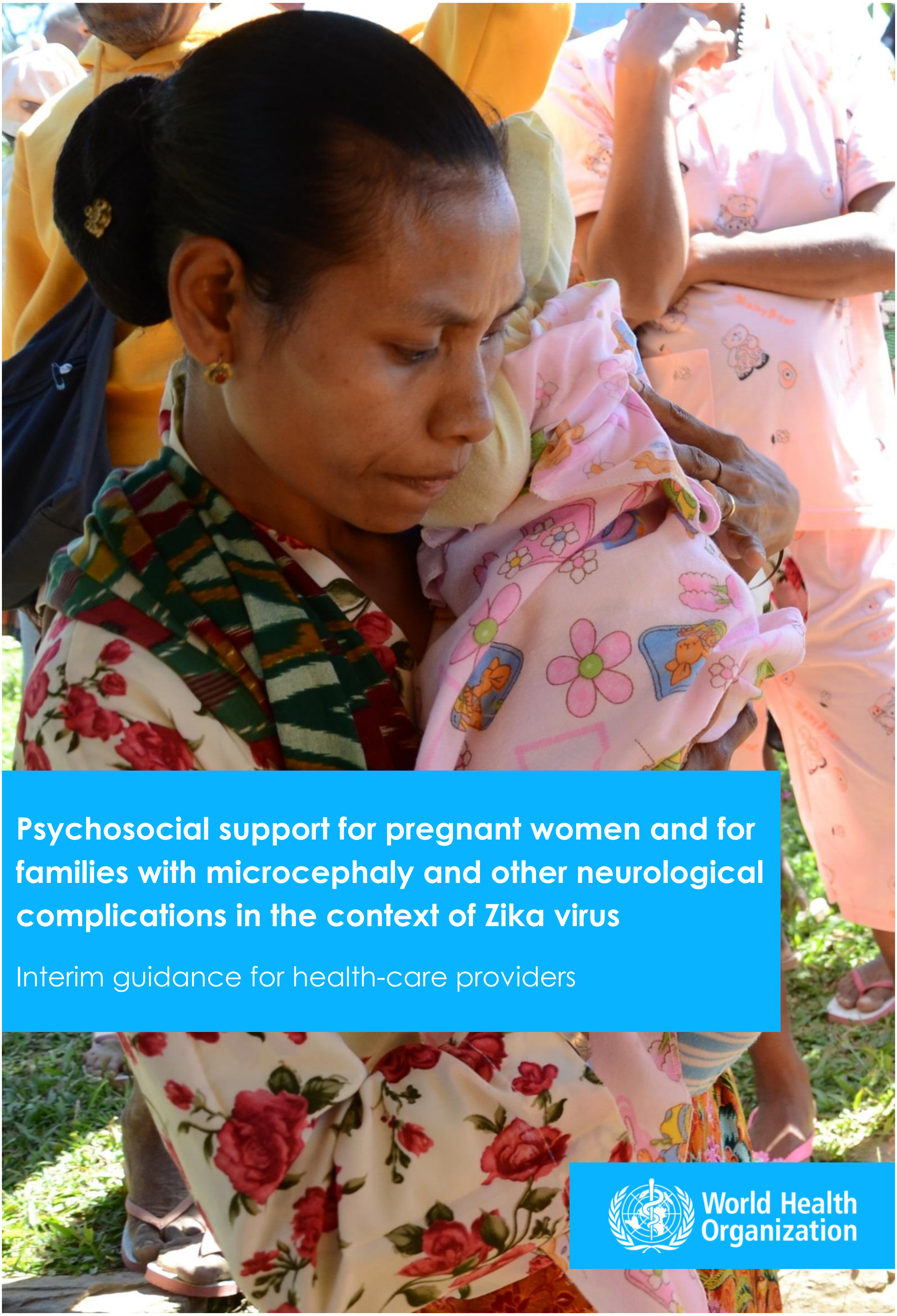

Psychosocial support for pregnant women and for families with microcephaly and other neurological complications in the context of Zika virus

Interim guidance for health-care providers

World Health Organization

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Introduction

On 1 February 2016 WHO announced that a cluster of microcephaly (*1*) and other neurologic disorders reported in Brazil is a Public Health Emergency of International Concern. Several countries have reported an increase in the incidence of cases of microcephaly and/or Guillain-Barré syndrome (GBS) (2) concurrent with Zika virus outbreak (3). A causal relationship between Zika infection during pregnancy and microcephaly is strongly suspected, though not scientifically proven (*4*).

This document describes guidance for a supportive response by healthcare providers (e.g. physicians, nurses), focusing primarily on women affected by Zika virus infection during pregnancy and their families, for their mental health and psychosocial needs.

Healthcare workers need to collaborate with colleagues in other sectors (e.g. social work, education) for a coordinated mental health and psychosocial response.

This guidance for healthcare providers suggests strategies that can be helpful when consulting with the following groups of women and their families**:**

- Pregnant women with suspected or confirmed Zika virus infection
- Pregnant women who know they carry a child with suspected microcephaly
- Caregivers and families of an infant with microcephaly

When caring for pregnant women, it is important to involve trusted people who can support them. These may be the woman's partner, her friends or family members. Bear in mind that these people may need psychosocial support as well.

Psychosocial support for other neurological conditions

Although this document is focused on microcephaly, many of the described supports (e.g., providing accurate information, supportive communication, providing basic psychosocial support, strengthening social supports, managing concurrent mental disorders) also apply to other neurological conditions - such as Guillain-Barré syndrome - that may be potentially associated with Zika virus.

1. Accurate Information

All healthcare providers need accurate information when providing support to women with Zika virus infection during pregnancy

Providing accurate information about a largely unknown communicable disease and its suspected effects is important not only for public health reasons (5) but also because it can reduce anxiety in people and their communities. However, different agencies and different media channels often provide information that may be inconsistent or contradictory. Unverified but plausible-sounding rumours communicated through social media can cause serious distress. New information about the Zika virus and its effects on pregnant women, fetuses and infants, and GBS and other neurological complications will become available over time. It is important you keep yourself updated on this information at all times.

You should also know about other services available to women and families affected by Zika virus infection during pregnancy and/or microcephaly. These may include antenatal and postnatal home visits for women with special needs, health services for assessment of an infant with microcephaly and management of neurodevelopmental disorders, hearing and visual impairment, psychological interventions, women's support groups, parent and community support groups, community-based rehabilitation services and social and educational services for children with disabilities. You should also be aware of any services available for persons with GBS and their families.

- Be up to date with the latest scientific information on the Zika virus and its potential consequences.
- Be aware of the latest guidance on assessment and management of Zika virus and its potential consequences.
- Get acquainted with available services and support / referral systems for people and their families affected by Zika virus infection during pregnancy and/or microcephaly.

2. Conveying health information

Health information should be conveyed in a manner that considers people's well-being

The diagnosis and management of microcephaly and other neurological disorders are immediate concerns for healthcare providers. **The way a healthcare provider assesses and manages these health conditions can have an impact on the psychosocial well-being of patients and their families.** As stigma is a concern, it is important to ensure confidentiality of any information and care provided. The steps below should be considered for protecting and promoting psychosocial well-being in the context of regular physical health care of Zika infection in women during pregnancy and/or microcephaly. Where possible, invite a trusted partner or family member to attend the session. This will help them to learn about the relevant health condition and is an opportunity to encourage them to be supportive. It is important to allocate sufficient time within healthcare sessions to properly implement the steps below.

- Provide accurate and understandable information (see Section 1 on accurate information) on all assessments and investigations before they occur and on the results of those tests.
- Ask the person about what they know about Zika and/or microcephaly or other neurological complications. Take the time to listen to the person's and their partner's/family members' reactions (thoughts, feelings) to the results.
- Educate the person on what you know about the prognosis of Zika and/or microcephaly or other neurological complications.
  - It is important to emphasize that many babies with microcephaly do not develop developmental disorders or other severe neurological complications.
- Check with the person to see if they have understood test results and their implications. Ask them to summarize their understanding of what you have conveyed. Correct gently if there is any misunderstanding.
- Throughout the care, encourage the person and their family members to take notes and to return to the clinic if they have further questions.
- Explain the need for regular follow-up care to monitor neurodevelopment and assess for possible complications.
- Share information about, and refer people to, relevant services to address social, psychological and physical health needs, as appropriate.
- Educate about appropriate measures to control spread of the virus (such as male and female condoms, mosquito repellent safe for use during pregnancy, and insecticide treated bednets).
- Before ending each session, restate and confirm what the next action step is for the person, such as attending another appointment or contacting a service.

- Encourage women to involve and invite a trusted person (partner, friend, family member, or friend) to the session or to any follow-up sessions.
- Ensure confidentiality of any care provided.
- Emphasize that many babies with microcephaly do not develop developmental disorders or other severe neurological complications.

3. Supportive communication

The way you communicate with women and families affected by Zika virus and/or microcephaly or other neurological complications is very important.

They may be confused or feel upset, anxious or angry (see section 4 on psychological reactions). You should try to use simple language, and avoid technical terms to ensure that they understand the information you give them.

Being calm and showing understanding can help people in distress feel more understood, respected, cared for appropriately, and empowered to make informed decisions and plans. However, some healthcare providers lose their good communication skills when they are with someone who is acutely distressed. Health care providers may not communicate well when under the pressure of time or overworked. This is especially common during epidemics.

Listening to someone can be a great support. It is, however, important not to pressure anyone to share their story with you. Some people may not want to speak about their circumstances. However, they may value it if you stay with them quietly; let them know that you are there when they want to talk. Don’t talk too much, allow for silence. Keeping silent for a while may give the person space and encourage them to share with you if they wish. In Box 1 you can find suggestions for things to say and do, and what not to say and do. Most importantly, be yourself, be genuine and be sincere in offering your help and care.

Box 1. Do's and don'ts of supportive communication (adapted from WHO et al, *10*)

DO'S

- ✓ Try to find a quiet place to talk, and minimize outside distractions.
- ✓ Provide actual information, if you have it. Be honest about things you know and don`t know. "I do not know, but I will try to find out about that for you and will let you know as new information on this becomes available."
- ✓ Let them know you are listening; for example, nod your head or say: "hmmmm….."
- ✓ Be patient and calm.
- ✓ Give information in a way that people can understand- keep it simple.
- ✓ Respect people`s right to make their own decisions.
- ✓ Be aware of and set aside your own biases and prejudices.
- ✓ Make it clear to people that even if they refuse help now, they can still access help in the future.
- ✓ Respect privacy and keep the person`s story confidential, if appropriate.
- ✓ Acknowledge the person`s strengths and how they have helped themselves.
- ✓ Allow for silence.
- ✓ Make sure you understand what people say by repeating what you understood to them, and asking them if you understood them correctly.
- ✓ Behave appropriately by considering the person`s culture, age and gender.
- ✓ Be sensitive. Acknowledge how they are feeling about things: "I am so sorry. I can imagine this is

DON'TS

- × Don't pressure someone to tell their story.
- × Don`t take away the person`s strength and sense of being able to care for themselves.
- × Do not blame the person for becoming pregnant.
- × Do not blame the person for not using insect repellent.
- × Don't interrupt or rush someone's story (like looking at your watch or speaking too rapidly).
- × Don`t make up things you do not know.
- × Don`t feel, think and act as if you must solve all the person`s problems for them.
- × Don't use overly technical terms.
- × Don't give false promises or false reassurances.
- × Don't feel you have to try to solve all the person's problems for them.
- × Don't tell them someone else's story.
- × Don't judge what the person has done or has not done, or how they are feeling. Don't say…"You shouldn't feel that way".
- × Don`t talk about your own troubles.