

Dealing with stigma and its impact on Lassa-fever survivors in Ondo state

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Abstract

Lassa fever is a viral hemorrhagic fever caused by a rodent-borne arenavirus that is endemic in West Africa. Globally, people living with diseases like Leprosy, Tuberculosis, HIV/AIDS and Lassa fever have been stigmatized. Although awareness is being created and treatment provided there are societal factors that drive stigma. Treatment of Lassa fever is mainly supportive and societal attributes contribute to stigmatization of the disease as well as the spread of the disease. Unfortunately, effective strategies to create awareness, educate people and reduce levels of stigma associated with Lassa fever in the community have not been fully utilized. Thus, the study examined the effect of stigma among the Lassa fever survivors in Ondo state.

The study utilized the qualitative survey method. Six interviews were conducted to examine the effect of stigma among 6 Lassa fever survivors. The respondents consisted of 5 males and 1 female between the ages of 36-57 years old; who had attained a level of formal education and were employed in public and private sectors. They resided in semi-urban areas. Thematic analysis was used to determine the factors that caused stigma among the survivors.

A total of 6 persons (5 males and 1 female) were interviewed. They all (6) reported that they had experienced some form of stigma while they were suspects to being treated for Lassa fever. Four had little knowledge of Lassa fever while 5 were not aware of the symptoms. All (6) of the respondents were scared of contracting Lassa fever and were alienated at one point in time or the other by significant others, health workers and members of their immediate community. Lassa Fever survivors had experienced stigma and struggled to cope with their diagnosis, treatment and care. Stigma had a negative impact on the survivors as they had experienced some initial alienation from members in their communities. Findings highlight the need to educate people and engage the community to create care, treatment and support programs to reduce the stigma associated with Lassa fever as well as provide psychosocial counseling to survivors, their significant others, treatment partners and relatives.

Introduction

Lassa fever is a viral hemorrhagic fever caused by a rodent-borne arenavirus that is endemic in West Africa. The virus was first identified in the town of Lassa in Nigeria in 1969. It is a zoonotic disease whose animal reservoir is the multimammate rat *Mastomys natalensis* [1]. The transmission route is through direct exposure to the excreta of infected rats, or from person to person via contact with contaminated body fluids. Lassa virus causes symptomatic disease in about 20% of infected cases and the overall case fatality rate is about 1% but increases to 15% among patients on hospital admission. It is endemic in West Africa resulting in about 400 000 cases annually, causing about 5000–10 000 deaths [2]. Lassa fever outbreaks have been reported in Liberia, Central African Republic, Guinea, Sierra Leone and Nigeria [1]. The sero-prevalence of LF in Nigeria is about 21% [3]. Since 1969, several outbreaks have been reported in various states in Nigeria including Plateau, Nasarawa, Taraba, Yobe, Ebonyi, Edo, Rivers, Imo, Anambra and Ondo [4-7].

Globally, people living with diseases like Leprosy, Tuberculosis, HIV/AIDS and Lassa fever have encountered some form of stigma. Although awareness is being created and treatment provided there are societal factors that drive stigma. Treatment of Lassa fever is mainly

supportive and societal attributes contribute to stigmatization of the disease and thus the spread of the disease. Unfortunately, effective strategies to create awareness, educate people and reduce stigma of Lassa fever in the community have not been fully utilized. Therefore, the study examined the impact of stigma associated with Lassa fever survivors in Ondo state.

Methods

The study adopted the cross-sectional survey to identify the types of stigma-associated with/encountered and experienced by the survivors. The qualitative research method utilized in-depth interviews to collect the data and the purposive sampling technique was used to select the respondents. This study was conducted between May and November 2018 in three Local Governments Areas (LGAs) in Ondo State where

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Key words: lassa fever, survivors, stigma

Received: February 27, 2020; **Accepted:** March 31, 2020; **Published:** April 03, 2020

Lassa-fever cases were reported and managed-Owo, Ose and Ondo West. Six survivors were interviewed, comprising of 5 males and 1 female (Ondo Town, Owo).

Ethical approval and permission to conduct the study was obtained from the Institutional Reviews Board of the Nigerian Institute of Medical Research and additional approval was obtained from the Ondo state Ministry of Health. All participants were provided with verbal and detailed written information about the study and were made aware of their right to decline to answer questions. Participants who agreed to participate gave their written consent, they were de-identified and enrolled for the study. The interviews were conducted in English and interview guides were used for the in-depth interviews. The topics for the in-depth interviews covered individual knowledge, perception and experiences of living with Lassa fever, any challenges that they faced, challenges in the health systems, their coping mechanisms during and after treatment, as well as options to improve quality of care for Lassa fever patients. The interviews were digitally recorded after gaining permission from the participants. The recordings of the interviews were transcribed verbatim, the data was analysed using the Nvivo software to provide emerging themes. The coding framework was developed using themes emerging from the data, the topic guides and study objectives.

Results

A total of 6 persons were interviewed. 5 were males and 1 was a female. They were between the ages of 36-57 years old, who had attained a level of formal education with the minimum qualification being a primary school leaving certificate and the highest qualification being a BSc/MBBS. They were employed in both public and private sectors while four (4) were self-employed. They resided in semi-urban areas. The profession of these survivors spanned from a teaching, business, trading and 2 were healthcare workers who had attended to Lassa fever suspects previously.

All respondents reported that they had experienced some form of stigma while they were suspects and being treated for Lassa fever. Majority of the respondents had little knowledge of Lassa fever and were not aware of the symptoms. All the respondents were scared of contracting Lassa fever and felt alienated at one point in time or the other by significant others, health workers and members of their immediate community who they felt had minimal understanding of the disease. They reported that they were initially reluctant to accept a positive Lassa fever result and thought they would die.

Also, all the respondents reported they were provided with prompt treatment and management when they reported to health facilities as their samples were taken and treatment commenced promptly.

Themes

The themes that emerged from the interview were:

1. Sigma (Self Stigma and Societal Stigma)
2. Knowledge, education and training of Lassa fever and its symptoms
3. Coping strategies and psychosocial care

1a) Self-stigma

The respondents reported that they had experienced self and societal stigma at various levels. Some of the drivers for self-stigma were: i) Denial ii) the Fear of being re-infected and infecting others.

Most of the respondents were in denial initially when they reported to health facilities and a health-worker had informed them that they had tested positive for Lassa fever. There was also the fear of infecting their spouses, children, relatives and themselves in future. More than half of the respondents who had been on treatment had asked if there was a cure or of it was a disease they could contract again as they live in constant fear of being re-infected. Another respondent said, "I am afraid to sleep with my wife because I don't want her to have Lassa fever, she earns a monthly salary unlike me that is into business" (Respondent 3).

All the respondents were in fear of disclosing their status to their relatives while those that had to disclose ensured that it was not discussed with others.

1b) societal stigma

The drivers for societal stigma were: i) Alienation ii) Community's response to Lassa fever.

Another factor that had an influence was how the society perceived it. Members in the society saw it as a contagious disease and as such, made efforts to stay away from people who were speculated or confirmed to have Lassa fever and their family members or people they had contact with. A respondent reported during the interview that, after he was discharged from the hospital, immediate neighbors avoided buying goods from his shop. Another respondent stated that he believed the community had little knowledge of the disease and health facilities should organize programs to educate people about Lassa fever. He stated that if they are informed, survivors and their relatives may not be alienated rather they will have to take the required safety precaution. However, another respondent said, "my family, neighbors and medical team have been very supportive, they have been following up with me since I left the hospital to make sure I am okay" (Respondent 5).

2. Knowledge, education and training of Lassa fever and its symptoms

The respondents feel that once the society and communities are educated about Lassa fever, its causes, prevention and treatment, they will know how to handle it better. Also, it will help them adopt proper hygiene practices, clean and take care of their environment better. It will equip them with the knowledge/facts they need to support health care officers and device means to observe precautionary measures while aligning with their customs, culture and traditional practices. They believe that everyone should be involved, ranging from neighbours, traditional rulers, health workers, politicians, environmentalists, teachers and religious leaders.

3. Coping strategies and psychosocial care

All the respondents indicated that their diagnosis and treatment was not a phase they wanted to relive again as it was difficult to cope with the drugs, being marked as a "Lassa Fever Person" to being reintegrated back into the society after their treatment. Thus, they believe that if counselling centres and help lines are introduced and located in close proximity, it will help reduce stigma and provide them with opportunities and platforms to discuss ways and strategies to cope with surviving Lassa fever. It will also equip relatives who serve as treatment supporters with the needed skill to take care of Lassa fever survivors. Self and Societal stigma were findings that corroborate previous studies on "Dealing with the Unseen: Fear and Stigma" in Irrua, Edo State by

Asogun *et al.* [8]. It also corroborates another study done by Mayrhuber *et al.* [9] on Ebola Survivors: We are Survivors and not a Virus: Content analysis of media reporting on Ebola survivors in Liberia [10-13].

Conclusion and recommendation

Lassa Fever survivors have experienced stigma at various levels and struggled to cope with their diagnosis, treatment and care. Also, stigma had a negative impact on the survivors as they had experienced some initial alienation from members in their communities. Findings highlight the need for continuous education and engaging the community to create care, treatment and support programs to reduce the stigma associated with Lassa fever as well as provide psychosocial counseling to survivors, their significant others, treatment partners and relatives.

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