Lived Experiences of Lassa Fever Survivors in Southsouth Nigeria

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Abstract

Lassa fever, a viral disease, was first isolated in the late 1960s and affects 300,000 to 500,000 people, causing 5000 to 10,000 fatalities annually across West Africa. Although there are studies on the causes and prevalence of Lassa fever, there is a paucity of studies regarding the Quality of Life (QoL) and lived experiences of survivors, limiting the ability of governments to adequately meet their needs. The purpose of this study was to describe the Quality of Life (QoL) and lived experiences of Lassa fever survivors in the Southsouth region of Nigeria. Fifteen survivors of Lassa disease were interviewed. Findings revealed seven areas of concerns: culture care and therapeutic communication, emotional support, physical symptoms, social activities, and work productivity. Findings are useful for health care providers.

Keywords: Patient-centered care; Culture; Cultural care; Cultural competence; Lassa fever; Quality of life; Self-fear; Self-stigma; Stigma

Introduction

A rodent of the Arenaviridae family, the reservoir host, transmits the Lassa virus to humans through direct exposure to the rodent fluids such as urine, saliva, and blood or by indirect exposure from surfaces and foodstuffs contaminated by these fluids [1]. The signs and symptoms of Lassa fever include increased body temperature, bleeding, seizures, coma, and death [2] the disease affects all ages and non-gender specific. The high mortality is due to misdiagnosis of early symptoms of Lassa fever: fever, loss of appetite, and weakness, are similar to malaria disease. Lassa fever is a global public health problem and one of the emerging infectious diseases and with scanty information available such as diagnosis, treatments, vaccinations, and control [3].

QoL is fundamental to the human experience and is affected by multiple cultural factors such as age, gender, marital status, and education, place of living, health status, work productivity, and socioeconomic status [4]. In a study carried out in Eastern Province of Sierra Leone, about 70% of Lassa fever survivors developed bilateral sudden-onset sensorineural hearing loss [5]. Lassa fever created self-stigma among survivors, which resulted to other unorthodox therapeutic alternatives [6]. After being discharged home, this study found as expressed by some participants, they faced the stigma of the disease.

Before this study, there was a lack of information on the QoL of Lassa fever survivors and their experiences with coping and living with the damages that the disease has caused. Most studies available on Lassa fever involved hospital-based surveillance which focused on who the disease affected, clinical manifestations, and transmission [7]. To understand the experiences of the survivors and the impact of Lassa fever on their lives, a cultural perspective was used to structure participants’ interviews and interpreted the information shared by the participants. Culture could be viewed as the blueprint for guiding human actions and decisions of any group or individual [8].

For the purpose of this qualitative descriptive was to describe the meanings of the lived experiences of Lassa fever survivors using the research questions (Figure 1):
The following research questions guided this study:

1. What are the lived experiences related to quality of life for adults affected with Lassa fever?
2. How do those who survive Lassa fever describe their lives?

**Figure 1:** A Diagrammatic Connection between Cultures, Care & QoL.

**Note:** The diagram shown above depicts that care to client is client-centered, meaning that client is the source of control and is a full partner in collecting relevant information based on respect for client preferences, values, beliefs, needs and level of literacy. These interactions based on quality of care and ultimately leading to quality of life.

**Design**

The design was a qualitative descriptive approach. After receiving Ethical Committee approval from the appropriate institutions, the recruited survivors were interviewed in person and one-on-one method.

**Participant Selection**

Participants for this study were recruited from among adults, 18 years or older, who had been infected and survived Lassa fever disease and who lived in Southsouthern Nigeria. Purposive and snowball sampling to locate other survivors were used.

**Setting**

Because of the COVID-19 pandemic, I interviewed participants in two settings at a large government facility, a secured conference room where participants were assembled and a secured room where the interviews were conducted on one-on-one basis.

**Data Collection Process**

A semi-structured interviews were conducted in English that lasted 30 minutes with each participant. Data collection focused on obtaining culture beliefs and practices, explicating where they lived, kinship, social activities in their daily lives, cultural practices and beliefs, religious beliefs, and economic issues. Data were gathered by asking each participant 13 structured and open-ended questions as well as follow-up questions where necessary to clarify their responses. Some of the questions asked were (a) “When did you contract Lassa fever disease?” (b) “What has helped you seek out and received care?” (c) “What experiences did you have with the disease?” (d) “What do you think helped in accessing Lassa fever disease treatment(s)?” and (e) “What are your thoughts about this disease and your whole experiences?”

**Data Analysis Procedure**

Raw collected data were transcribed and analyzed after the interview sessions. The immersed data, were then coded for meanings using NVivo 12 software program [9]. And reducing the data into themes.

**Results**

The purpose of this qualitative study was to describe the meanings of the lived experiences on Lassa fever survivors.

**Description of the Participants**

A total of 15 participants participated in this study (Table 1). In-depth interviews and analysis of the raw data led to the discovery of five themes: culture care and therapeutic communication, emotional support, physical symptoms, social activities, and work productivity.
Table 1: Demographics of Participants.

<table>
<thead>
<tr>
<th>P</th>
<th>G</th>
<th>Age</th>
<th>OB</th>
<th>OA</th>
<th>MS</th>
<th>#C</th>
<th>EL</th>
<th>YCD</th>
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<td>Married</td>
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<tr>
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<td>2</td>
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</table>

Note: P = Participant; G = Gender; M = Male; F = Female; OB = Occupation before contracting the disease; OA = Occupation after surviving the disease; MS = Marital status; #C = Number of children; EL = Educational Level; YCD = Year Contracting The Disease.

Theme 1: Culture Care and Therapeutic Communication was essential

Culture care and therapeutic communication by healthcare providers was essential to the survivors’ sense of well-being. Responses from all participants interviewed took early signs and symptoms such as fever, headache, and loss of appetite to be that of malaria, hence, resulted to self-treatment by ways of traditional remedies such as a herb called “agbo”.

Participants felt that healthcare providers demonstrated caring by spending quality time with them, showed respect, asked about their cultural preferences, beliefs, and traditions, explained procedures and treatments, and informed or told them what to expect. The treatments given as expressed by participants improved their general well-being.
Theme 2: Emotional and social support were essential for survival

All participants when initially diagnosed of disease felt frustrated due to conditions which was related to the information received about the disease. They expressed decreased emotional state as well as social support and QoL because they were isolated from family members and friends.

Theme 3: Physical Symptoms

Participants described debilitating effects experienced before treatments and while undergoing treatments. Some of the commonly effects were physical pain, fever, headache, fatigue, abdominal pain, vomiting, joint pain, sore throat, and gravely witnessed the demise of patients who were unable to survive this terrible disease. Physical symptoms formed a major part that affected participants’ QoL.

Theme 4: Social relationships and social stigma were common among survivors

Participants stated that Lassa fever interfered with their family and community social activities. Participant 4 reported, “I was breastfeeding a baby when I had the disease and had limited access to my baby”.

Theme 5: Work Productivity

Reduced work productivity while with the disease and during the course of their treatments as described by participants. The participants reported the disease effects on their QoL and day-to-day activities presented enormous challenge to them. These included lost earnings as well as the burden of the disease on their physical and psychological state.

Discussion

This study supported Usifoh et al. (2019) [10] found that Lassa fever disease created self-fear and self-stigma among survivors, resulted in self-health seeking behaviors, promoted self-medication and other unorthodox therapeutic alternatives. Three participants in this study experiences self-fear and self-stigma.

This study findings were also supported by those of Coyle (2016) [11] that access to diagnostic laboratory existed, hence self-diagnosis, which led to misdiagnosis and culminated in their being treated for malaria, instead of Lassa fever disease.

Limitations of the Study

The findings of this study were self-reported data from the participants who are living evidence of the effects of Lassa fever disease. Though all the participants shared experiences that were in accord with previous studies, however, this study was limited geographically to Southsouth Nigeria.

Recommendations

Future research could also focus on how the healthcare providers perceive lived experiences of Lassa fever survivors and include healthcare providers who work in acute and primary care settings. It is also important to evaluate the lived experiences of Lassa fever survivors with other groups such as those under 18 years old who survived disease.

Implications

The initial earlier symptoms of Lassa fever disease are similar to malaria: fever, headache, and weakness. Hence, they started self-medicating for malaria. When initially hospitalized, misdiagnosed, and malaria treatment continued until later stages of the disease, blood samples finally sent to the only designated diagnostic laboratory if results come out positive for Lassa fever virus, then immediate right treatment start. This late diagnostic test often led to complications, long hospital stays and in some cases the demise of some Lassa fever patients.

By providing adequate information on Lassa fever disease will positively enhance Lassa fever survivors’ well-being. This study can serve as a blueprint for other studies on the views, QoL and experiences of Lassa fever survivors thereby leading to a better understanding of the disease.

Conclusion

Physical symptoms are just one of the debilitating aspects of Lassa fever disease, emotional distress, reduced social activities, and non-work productivity are also frequently reported. Together, the physical symptoms and emotional distress caused by Lassa fever disease presented a serious barrier to Lassa fever patients’ day-to-day activities, work productivity, and healthy social lives. Findings from this study may provide a better understanding of the everyday life experiences of survivors of Lassa fever. A better understanding of experiences of Lassa fever survivors will lead to an increased awareness of the resources that these individuals need which hopefully lead to improved interventions for survivors.

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References


