

ABSTRACT

Family members of people living with leprosy in Jimma Zone, Ethiopia are subjected to stigma, lack of support, social exclusion, psychosocial problems and continue to experience many challenges related to caring their relatives with leprosy. In effect, harmful effects may arise from internalized conception of anticipated stigma or from the stigma coping response enacted. Labeling thus may negatively affect one's psychological state. Currently, there are no practice guidelines for social work support in alleviating these challenges. Therefore, expounding on the experiences and challenges faced by family members' in caring of people with leprosy is of critical importance in order to develop practice guidelines for social work support.

A qualitative research approach will be employed guided by a phenomenology, explorative and descriptive research design. A sample of participants will be drawn through purposive and snowball sampling and data will be collected by means of semi-structured interviews. Data will be analyzed by applying Tesch's eight steps, (in Creswell 2014 and verified using Lincoln and Guba's model (Krefting 2003, Shenton 2004, Rolfe 2006) to test the trustworthiness of the data.

The key findings of the study will address the experiences and challenges of family members' people living with leprosy and their family members and paves away towards in developing guidelines for social work support.

1.2 Problem statement

Leprosy is one of the serious health problems in developing countries and it negatively influenced the socio-economic status of the people suffering from it(Sori 2018:298).This resonate with Daniel (2011:19), sentiment that leprosy has a long recorded in Ethiopia .Historical data point out that the disease was in Ethiopia before the 16th century. However, medical therapy introduced in the country in 1950.

In several parts of the world, including Ethiopia, persons affected by leprosy especially the disabled ones have been nicknamed by several derogative names that degraded and dehumanized them (Nigatu 2006: 23). It is generally considered normal to listen to these nicknames, derogative words, and tales as it is mostly accepted by many in the society including religious, cultural and social as well as linguistic interactions (Nigatu 2006:27).

Leprosy-related disability is a challenge to public health, and social and rehabilitation services in endemic countries. Disability is more than a mere physical dysfunction and includes activity limitations, stigma, discrimination, and social participation restrictions (Van Brakel 2012). While medical efforts to conquer leprosy have made tremendous progress, it is fair to say that efforts to tackle the disease's social aspects have lagged behind (Fanta 2011:49). Due to the general public's ignorance, misunderstanding, indifference of fear, millions of people cured of leprosy and even their families still suffer from the stigma associated with the disease (Peter 2013:6). The psychosocial aspects in terms of stigmatization, disability, loss of self-respect and loss of self-esteem and ostracizing of affected one, and misconception of the disease by the community have been well identified as a major threat, therefore making patients more vulnerable to destitution and social exclusion (Ajibade et al 2015:10).

Although, there are global and nationwide lawful provisions for the full involvement of all disabled people counting leprosy victims, the deep -rotted attitudes forbidden the victims from the realization of all social and economic benefits (Alemu 2018:5).

Due to the nature of the disease, in Ethiopia persons affected by leprosy are often made a social outcast, which contributes to his/her social and economic downfall (GLRA/ DAWA Bulletin 2008: 28). The medical and surgical cure of the PAL, therefore, becomes deficient if efforts are not made to achieve socio-economic re-integration in to the community (Mohamed 2008:13).

In Ethiopia, thousands of people are living with the permanent disabilities caused by leprosy. Thousands of Ethiopians are suffering from leprosy with stigma, absurd fear, discrimination, disgrace and humiliation by a sibling and members of the society (Girma 2005:28).

According to Desalege (2014:34) stated that these days many people suffering from leprosy settlements, labeled with bad names, social injustice and raving poverty. Thousands are adding up every year with 7% to 14% of disability rate and newly diagnosed cases alone reach up to 5000 annually. The number of new cases in the past twenty years seems to no significant decline. As a consequence, thousands have become disabled and forced to live in stigma and socio-economic complications.

In Ethiopia, Government, (NGOs) Non-Government Organization, (CBO) Community Based Organizations) and (FBO) Faith - Based Organizations have taken a wide variety of strategies to address the needs and the right of lepers to alleviate their chronic challenges by providing different social and development services.

However, the situation still remains unchanged as there are still lots of challenges faced by people living with leprosy in Ethiopia. And the high level of perceived stigma in the families due to having a member with leprosy increases family stigma and the stigma of society towards the family would cause problems for the family. Jimma Zone like other cities the people living with leprosy are seriously affected by the stigma and discrimination due to leprosy (Daughters of Charity Jimma Bulletin 2015:35). According to the Office of Leprosy Association (2018), 960 estimated numbers of leprosy affected people are living in Gingo, Tulema leprosy villages and Mother Theresa destitute center.

In these communities persons living with leprosy and their families who are affected by this disease are highly vulnerable to various challenges emanated from unemployment, most of the youth are participating like human trafficking, juvenile delinquency and stigma and discrimination. As a result, the lepers and their families find themselves living under devastating conditions which force them to live their life in begging, receiving alms and charity around church and street sides of the town. The dropout rate from school is another challenge that is seen in the girls and boys with members suffering from leprosy. The infrastructure of the area is very poor. Moreover, the psycho-social impacts of the disease become hazardous problem, which affects the socio-economic life of the people living leprosy and their families. Still, the family members' are experiencing challenges related to caring people living with leprosy: as a result most of them are subjected for stigma,

discrimination and social exclusion. In most instances, people living with leprosy and their family members are experiencing depression, loneliness, and other negative emotions (Daughters of Charity 2018 39 -45). From the experience of the researcher in Jimma zone , family members' who gives care for people living with leprosy play important role in supporting their relatives but still experiencing stigma and discrimination because of their family relationship. As a result of the stigma and discrimination they are exposed to low self-worth, ignored, shamed and social isolation. Accordingly, the challenges and experiences lead them adopt harmful coping mechanisms such as secrecy and withdrawal. On some cases, the family members' migrate to other places by fearing the attached stigma towards them and also the system of caring their families is not well and appropriate.

There is a shortage of literatures which addresses the experiences of people suffering from leprosy and their family members (ENELPA 2015:23). Till now, there is a shortage of data which addresses the experiences of people living with leprosy. Rarely (if any) researchers involve family members as part of their study (Bobosha2019:31). According to Daughters of Charity (2019), existing evidences shows that there are no studies from the field of Social Work, or from its perspective that have specifically investigated the work related challenges experienced by family members caring of people living with leprosy, how they manage these challenges, and their suggestions for social work support. Most of the studies related to leprosy are focusing on medication and treatment.

A deficiency in knowledge base of certain aspect a researcher discovers could lead to prompt to launch an investigation into an attempt to address this identified dearth (Creswell 2014: 117). According to Williams (2015: 75) assertion that a research problem is an unknown that invites a solution or resolution. Therefore, the problem statement for this study reads as follows ‘’ Although most of the studies conducted on the topic of leprosy are focusing and giving attention on medication and treatment, so there is still a knowledge gap, lack of research and literature regarding people with leprosy and family members' in Ethiopia. The implication therefore is that there is nothing documented in terms of social work support and social work practice guidelines (Hardy 2018:19).

It is for this reason that the researcher engaged on this research project in order to explore and describe the nature of social work services to people living with leprosy and family members' and

the need of PLWL regarding social work services, with the aim of developing guidelines that would inform social work support.

1.3 Rationale for the Study

The researcher interest towards this study emanated from his experience as a social worker in the leprosy villages. During the course of his duties, the researcher became aware that people living with leprosy and their family members live in absolute poverty and are faced with the stigma associated to their difficulties, especially in Jimma Zone, which is situated in South West of Ethiopia. Additionally, family members or caregivers often bear economic and material burdens. They are also exposed to psychosocial burdens. Stigma is the one of the most challenging psychosocial burdens faced by family members or caregivers of people living with leprosy.

Majority of people living with leprosy, including the Ex-leprosy patients and their family members have been stigmatized due to the stereotype towards the disease. This isolation denies equal opportunity and participation to Ex-leprosy patients and as a result forced the victims to live in a sever poverty (Mohammed 2006:26).

In Jimma area, people living with leprosy and their families do not partake in different social services and their social network with other members of the community (non-affected) is limited. Another motivation factor for this research project is the gap in existing literature regarding the nature of social work services to people living with leprosy and their family members in Jimma zone, Ethiopia. Also, the researcher observed that previous studies conducted under the subject didn't gave much attention and focus on social work services for people living with leprosy and their family members. Furthermore, there are no clear policies and practice guidelines related social work services to people living with leprosy and family members (Henok 2016:13).

The researcher also motivated by the fact that ‘ ‘ There is an old age stigma attached to leprosy, and because of this, society maintains negative felling toward people affected by the disease. They are ostracized by society and live sub human lives. They are subjected and legal discrimination which rob them of their human right (Leprosy Mission).’ ’Accordingly, people living with leprosy and family members are experiencing loss of self- esteem and dignity and feel fear. So in order to

address their experiences and challenges this study would be crucial in enabling people living with leprosy and family members' to adjust their difficulties related to leprosy.

Apart from the above motivations, the researcher believes that this project would benefit different role players and planners in the provision of social work support for people living with leprosy and family members'.

Therefore, this study intends to identify gaps in the current form of social work services and explore the experiences of people living with leprosy, together with their families in order to develop practice guidelines for social workers that would assist towards the alleviation of challenges related to leprosy. This means that the findings of the study will assist the researcher to develop the practice guidelines and intervention strategies for social workers. In this study, social work services and social support guidelines that are client and community based would be established.