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Short Communication

Protecting the Rights of Leprosy Affected People in Rural Community of Jember, Indonesia

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Leprosy patients in the community need special attention and care. Problems experienced by leprosy affected people (LAP) in the community can be solved by the protection of their rights. Such rights of LAPs are to be protected as vulnerable population in the community to maintain the quality of life in the community. The results of the identification of problems faced by LAPs in the community and the fulfillment of their physical, psychological, social, economic, cultural, and spiritual needs are greatly influenced by the factors peculiar to LAPs and the availability of health care resources, and the discrimination of LAPs in particular settings. The problems of LAPs in rural areas of Jember include skin lesions, disabilities, social stigma, interrupted medical management, and unreachable health services. Several efforts to improve clean and healthy life behavior, wound and disability care, social support, health education in reducing community stigma, and sustainable treatment have been carried out as efforts to provide health services. Furthermore, minimizing the impact of inequality in the protection of leprosy patients' rights needs to be greatly reduced in order to reduce the risk of leprosy status as a population at risk in the community.

Keywords : Leprosy Affected People, Protecting Rights, Discrimination, Vulnerable, Rural Areas

Background

The interaction and relationships among human factors, agents and environment affect health status of people. Vulnerable populations at risk are the people having poor physical, psychological, and/or social health determinants. One of the most vulnerable groups are people affected by leprosy especially in rural community. The number of leprosy cases in Indonesia was 20,748 (0.80 cases per 10,000 people) in 2016. However, East Java has the highest number of leprosy cases in Indonesia with 4,267 cases of Multibacillary (MB) and 401 cases of Paucibacillary (PB) types as compared to other part of country (Jember Health Office 2017). The report of the Jember District Health Office up to December 2017 recorded 285 cases of leprosy, including cases where many individuals experienced disabilities and deformities due to late detection (Jember Health Office 2017). Drop out from multi drug treatment has been identified as another important factor for poorer outcomes including disabilities (Qi et al 2017). Disabilities also contribute to social stigma among leprosy

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affected people in the community (Lusli et al 2015, Susanti et al 2018) which can be addressed by right based counselling approach (Lusli et al 2016).

Leprosy Affected People in Rural Settings

People affected with leprosy in rural of communities may be special vulnerable group who may needs a comprehensive and holistic program to improve their health conditions and enhance their quality of life. Self-help care group can play a vital role in this, if designed and used for protection of people affected by leprosy and to fulfill their physical, psychological, social and economic needs in community. It has been observed that LAP who attended the self-care group in community and perceived support during leprosy treatment have better psychological condition and experienced higher social acceptance in the community (Susanto et al 2017).

According to the Jember District Health Office, in 2015 there were 383 cases of leprosy and 361 cases in 2016 (Jember Health Office 2017). There were 378 cases of registered leprosy cases registered in December 2015, 353 cases in December 2016, and in January to 30 June 2017 there were 337 cases registered with a total of 112 new cases. In 2017 there were 3 districts with the highest number of leprosy cases, namely Sumberbaru District, Jenggawah District, and Puger District. Sumberbaru District has two puskesmas areas, namely Sumberbaru Puskesmas and Rowotengah Puskesmas. Sumberbaru District ranks first with a total of 55 cases with accumulations from 2016 to 2017 (Jember District Health Office 2017). In 2017 the number of cases in Sumberbaru Subdistrict was 36 cases divided into 14 cases (11 MB cases and 3 PB cases) in the Sumberbaru Puskesmas area and 22 cases (21 MB cases and 1 PB case) in the Rowotengah Puskesmas area. A total of 4 cases in the Rowotengah Community Health Center area were recorded as being from the age group of children and 1 case was declared drop out due to non-compliance with medication and lack of motivation to recover.

The obstacle faced in the development of leprosy client care in the Jember area health center so far is the provision of care in fulfilling the daily needs of leprosy clients, which in general is strongly influenced by the characteristics of the environment and the lifestyles of leprosy clients. The obstacle in providing such care is also influenced by the community's view of leprosy as an infectious and dangerous disease and caused by a sin. The physical problems of leprosy clients in the community such as the condition of leprosy wounds that are getting worse and the disabilities that arise result in the community perceiving leprosy clients negatively. This has an impact on the psychological and social life of leprosy clients in the community.

The physical problems of leprosy clients arise as a result of lack of information and misinformation, wrong assumptions, superstition, and fear of leprosy. This has an impact on the psychosocial problems of leprosy clients as a result of people's views on leprosy. The negative public perception of leprosy clients has an impact on the emergence of labeling, stigma, and social discrimination on leprosy clients. The community still considers the condition of leprosy as a disgusting disease and leprosy clients to cover up the disease, so that if it has been found to be in an advanced stage and have experienced disabilities. The social discrimination is related to the condition of the disease which worsens and results in emergence of disability in leprosy clients. Social stigma and motivation for healing are linked to degree of disability and drop out from treatment (Mahardita et al 2019).

Lessons from India and other places

It has been reported that many a health problems due to leprosy may be related to environmental and leprosy behavior factors (Peters et al 2014, 2015). These factors, if not handled properly and timely, will increase the number of populations at risk, and may lead to a disease emergence condition. Several factors that influence disease emergence include social events, food production, human behavior, environmental changes, public health infrastructure and adaptation to microbial changes (Huzzein et al 2014, Reinar et al 2015, Qi et al 2017).

Ineffective control of the factors that affect leprosy will cause wider physical and psychological problems for leprosy affected people in the community. Physical problems of leprosy patients arise due to the condition of the lesions on the client's skin which may be associated with physical disability. Psychosocial problems in leprosy clients occur as a result of illness (Kaehler et al 2015, Reinar et al 2016) and arise out of community stigma. Social impact result in problems for patients, families, and even for society in a larger sense. Acceptance of leprosy affected people are still difficult, because people still believe and considers leprosy as an infectious disease that cannot be treated. The community also considers leprosy as a disease caused by God's curse and will have an impact on disability in leprosy clients as a punishment for for their sin or bad deeds (Peters et al 2014, Singh et al 2013).

Leprosy in India has been linked to poverty with most affected LAPs being illiterate, disabled, having comorbidities like diabetes mellitus which correlated with socioeconomic and health status of LAPs (Sharma & Saxena 2019). Government services and certain NGO's have been and are collaborating for strengthening of health infrastructure, disability care and rehabilitation. It has been opined that the independent strategies for handling factors which affect LAPs are dependent upon underlying cultural issues and challenges (David et al 2019). Therefore, protecting the rights of leprosy affected persons should be given priority in community (Sasakawa 2013). Thus there is lot of similarity in socio-economic factors associated with LAPs and such studies will provide some common lessons also.

Physical and psychosocial problems of people affected by leprosy require an in-depth identification and excavation to solve these problems. Exploration of leprosy care issues in the community can be done in depth through qualitative studies related to aspects of leprosy problems (Staples 2004). Qualitative studies use a grounded theory design that produces several approaches for the management of problems of LAPs from several aspects. However, the results of such research have not produced a theory or model in the treatment and fulfillment of the daily needs of leprosy clients in the community. These studies have produced a model in providing an explanation of leprosy so that patients and the public have willing to accept the condition of leprosy.

Conclusion

To conclude LAPs are vulnerable populations in rural communities and are in need of promotion and protection program to safe guard their rights, both from families and communities in increasing their self-reliance through self-prevention and self-care, so that these programs in the community are efficient and beneficial in improving the quality of their lives in the community.

Future perspective

Promotion and protection program need to be encouraged in an effort to increase the participation of families and communities to engage in preventive actions, at primary, secondary, and tertiary of public health services

using levels of prevention in the community at risk. Health promotion is a basic nursing function and includes promoting the health of individuals, families, and communities through individual counseling, public health education programs, and provision of health services.

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