

The experiences of people affected by leprosy who participated in self-care groups in the community: A qualitative study

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Introduction

Leprosy presents a high burden to the community and it is known as a triple burden disease.¹ The case detection of people affected by leprosy is often too late² and the characteristics of people affected by leprosy in the community are quite varied, as there are still problems of worsening skin lesions, disability, social stigma, missed treatment and inefficient health services that have not directly reached the daily needs of people affected by leprosy.³ The chronic problems in leprosy require complex care of people affected by leprosy.⁴ Those affected by leprosy are generally coached in self-care groups (SCGs) in the community.⁵ A previous study reported that self-care activities are basically the need to care and to prevent progressive worsening of leprosy-related impairments.⁶ Therefore, the experience of those affected by leprosy in joining SCGs should be studied more deeply to know the benefits and the constraints faced by participants, because it will impact on the quality of life of people affected by leprosy in the community.

The Indonesian Ministry of Health reported that 16,131 new cases of leprosy were diagnosed in 2014. The Department of Health found 498 paucibacillary and 3,337 multibacillary leprosy cases,⁷ with the highest number being found in the district of Jember. The Global Leprosy Strategy 2016–2020 was released in April 2016 stating “Acceleration towards a leprosy-free world” based on the principles of initiating action, ensuring accountability and promoting inclusion.⁸ In addition, health promotion programmes for

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people affected by leprosy can be improved through their self-empowerment,⁹ where they can talk about health problems during treatment at public health centres (PHCs). Evidence showed that self-care programmes of people affected by leprosy is very effective in preventing their disability⁵ and it can become a communication forum in solving physical, psychological and social problems.⁴

People affected by leprosy that attend SCGs need good management related to their health care to prevent malfunction and empower them to meet their daily needs. The life of those affected by leprosy in the community during treatment of the disease is very diverse, resulting in a varied perception among people affected by leprosy that will affect self-care strategies in order to support their recovery.¹⁰ This is likely to be influenced by the characteristics of the person affected by leprosy, and their social-cultural, and environmental conditions.³ Therefore, their perception of life during involvement with a SCG is very challenging and needs to be explored more deeply through a qualitative approach.

Furthermore, it is necessary to conduct qualitative research with descriptive phenomenology designed to identify the meaning of experiences of people affected by leprosy in joining SCGs. This can be explored through in-depth interviews related to aspects of self-care and their daily life. Therefore, the aim of this study was to understand the experiences of those participating in SCGs, with the aim improving the functions of SCGs to resolve self-care problems in the community.

Methods

DESIGN

This study uses a phenomenological, qualitative approach and descriptive design to explore and understand people's everyday life experiences.^{11,12} The feelings of people affected by leprosy who participated in SCGs were explored through descriptive phenomenology in order to explain the experiences of each person undergoing care in detail, broadly and profoundly.

PARTICIPANTS

A purposive sampling strategy was used to recruit participants from two out of 17 SCGs in the community (the two SCGs were named "Gotong Royong" and "Cahaya"). Formal letters were sent to PHNs of the two SCGs in Jember, East Java, Indonesia, requesting them to inform those affected by leprosy under their care about focus group interviews, which the investigators had arranged. The two SCGs were chosen because both SCGs have monthly routine activities to discuss all leprosy care and treatment issues for those affected by leprosy in families and communities under the supervision of public health nurses (PHNs) at the local PHCs.

The inclusion criteria of participants in this study were as follows: under multi-drug therapy (MDT), or released from treatment; lives alone or with family; understands the illness process in order to communicate the experience of having the disease; and willing to participate in the research. People affected by leprosy who did not join any SCGs, or who withdrew from treatment were excluded from this study. Both SCGs consented to hold focus group interviews, and 17 people agreed to participate in this study in July, 2014.

The mean age of participants was 49.9 years, with 10 males and seven females. The average leprosy period since diagnosis was 27.1 months, with one person having

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People affected by leprosy participating in self-care groups in the community 3

paucibacillary leprosy and 16 others having multibacillary leprosy. From those affected by leprosy who were selected as participants, two were unmarried and 15 were married, with educational background ranging from never having attended school (one person), 13 having graduated from elementary school, three from junior high school. Six participants were unemployed, four were housewives, and seven others were farmers. The average duration of attending SCGs was 9.8 months.

DATA COLLECTION

The purpose and procedure of the study were explained to the participants and questions were invited. This study was approved by the Research Department of the University of Jember. The participants were informed that they could withdraw from the study at any time. Participants were divided into two groups for interview.

Data was collected using a semi-structured interview guide with open-ended questions.¹² Success in obtaining data or information from the subjects under study depends on the researchers' ability to conduct interviews.¹¹ In this study, researchers used therapeutic communication techniques to obtain information from participants. Investigators listen patiently, interact with participants, and elaborate what is being asked if it is felt that the interviewee did not provide enough information. Investigators used interview guides, field notes, and a tape recorder to support data collection in this study.

The investigator started the interview by asking the participants questions about "How was your experience as a person affected by leprosy in treating your illness while attending the SCGs?" The core question was used to get a general impression of the participants. In this study, some participants found it difficult to understand the question, so the investigator then used the interview guide, which contained additional questions to elaborate on the core question. The interview guide contains specific questions that answer the research objectives. The semi-structured question guidelines in this study are: (1) What are your perceptions related to your self-care? (2) How do you feel your treatment is going? (3) What changes have you made to your daily life pattern? (4) What action do you take regarding health-seeking behaviour related your diseases? and (5) What do you expect from the care giver for your current illness? Investigators try not to provide assessments based on the understanding or experience collected by researchers to the answers given by participants.

DATA ANALYSIS

The investigators (TS, EID and IR) collected and guided the focus group interviews and then transcribed the discussions verbatim.

The data were analysed through seven processes: (1) all the results of the interview were read thoroughly to gain an understanding; (2) each written interview was summarized; (3) relevant parts of the transcribed text were selected; (4) the interpretation was reviewed; (5) the general meaning was identified; (6) links between emerging themes were identified; and (7) draft themes were compiled, for presentation to members of the research team in order to develop the final draft.¹¹ The textual descriptions used in the qualitative study include: (1) use of the categories mentioned by each participant; (2) transcripts of interview results, (3) use of varied results from each participant; (4) narrative or story; and (5) established keywords found based on the interpretation of the researcher and the participants.¹³

Results

The analysis identified five themes surrounding people's experience of participating in SCGs in the community: self-perceived condition, adherence to treatment, ability to do personal care, the kind of help and services received, and acceptance and support of the person affected by leprosy. The results SCGs are described in Table 1.

SELF-PERCEIVED CONDITION

The person's perception of their disease and their own condition is related to their understanding of the disease and their self-image related to their disease. Participants who had spent more than 6 months undergoing leprosy treatment and who obtained good information about leprosy from PHCs, perceived and understood leprosy well:

Actually the leprosy is a little wound that is not considered serious but it gets worse. However if it is treated, it will not be contagious and if the treatment is late it can be contagious.

A disease like this should be treated fast, with the hope of recovery, but if not handled properly, it will be contagious, because the disease is indeed a contagious disease and without fast treatment it will continue to spread continuously throughout the body leading to injuries and disability.

Table 1. Main themes and categories of the experiences of people affected by leprosy while participating in SCGs in the community

Themes	Categories
Self-perceived condition	Understanding of the diseases Self-image related to their disease
Adherence to treatment	Lack of confidence in the treatment provided by PHCs Understanding of MDT short-term and long-term therapy regimens Efforts to reduce the side effects of treatment
Ability to do self-care	Ability to meet basic human needs Control of the living environment The use of personal protective equipment Skin and wound care and prevention of disability Participation in the self-care group
The kind of help and services received	Those based on ancestral cultural/religious heritage Traditional and alternative medicine Modern services from health workers
Acceptance and support for leprosy patients	Family support during treatment Public social acceptance toward leprosy clients Provision of adequate information and health services from public health centers Return to work and acceptance at work after recovery

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People affected by leprosy participating in self-care groups in the community 5

Meanwhile, there were participants who gave an ill-defined description of the disease due to lack of their understanding of the disease, as shown in the following statements:

The first time I felt and saw the sign, I thought it was an allergy.

My skin disease is basically only a skin disease, and I do not know if this is leprosy and if it is contagious to others.

Participants provide description of their own condition related to the state of leprosy:

Let others say anything they want, I do not care, but I am a breadwinner for my family, so I have to keep working to meet all the needs of my family.

When people knew I got leprosy, I felt those people were too quick to stay away from me. . .

I isolated myself at home after the leprosy was detected for three months due to shame.

ADHERENCE TO TREATMENT

Patients who report themselves to PHCs and have been diagnosed with leprosy undergo leprosy treatment. Patients get a package of MDT drugs. Based on the compliance of participants in following treatment, participants in this study were divided into an obedient group or non-compliant group, where the drug administration is related to the discomfort or complaints experienced by participants as side effects caused by the treatment. Adherence to medication was related to lack of confidence in the treatment provided by PHCs, understanding of MDT short-term and long-term therapy regimens, and efforts to reduce the side effects of treatment.

We were taught by public health nurses (PHNs) about leprosy treatment and how to follow leprosy medication related to the time of taking the medicine, regularity and the positive impact of leprosy treatment received every month directly from PHCs.

I took medication for the one-year programme, but I stopped for one month because I was lazy and wondered why it was taking so long with no result, so I had to repeat again for one more year because it was declared zero again by the officer.

We were also worried because after taking the medicine there were some complaints like blackened skin, boils and blisters on the skin, red urine, and lost appetite. The PHNs explained that they were all normal side effects, so we were asked to continue treatment and we were given additional drugs to reduce the side effects.

ABILITY TO DO SELF-CARE

Participants' ability to do personal care was identified as their ability to meet basic human needs, control their living environment, use personal protective equipment, skin and wound care, prevention of disability and participation in SCGs. In meeting their basic needs, patients relate to the characteristics of their daily lives.

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6 *T. Susanto et al.*

The PHNs teach us how to maintain our health. We were asked to eat nutritious foods according to balanced nutrition messages; however poor people were less able to buy fish or meat, and they mostly consume tofu and tempeh.

I have to take a shower twice a day to let the germs that stick to the body get lost due to sweating or after working in the fields.

The environment at home should have plenty of ventilation to keep the air fresh and not moist because the bacteria can grow. If the sunlight can light the house, we should clean the house often by sweeping and mopping the floor.

PHNs give counseling to protect patients with personal protective equipment because the eyes, hands and feet are very sensitive. If outside the house was hot, wear a hat and glasses he said, and if I work on carpentry or building, I should wear gloves to avoid accident because sometimes I cannot feel my fingers.

It is always repeated how to care for hands and feet that are numb or wounded, to prevent disability; the steps are basically soaking and rubbing. Soak hands or feet in a bucket of water, after that, rub with a smooth stone, and lastly smear coconut oil to let the skin change and not dry, otherwise it can develop into numbness and wounds.

At this self-care forum, we discuss various problems experienced by people suffering from leprosy. PHNs distribute MDT drugs and continue to provide health education about healthy life for people affected by leprosy, personal care for skin, hands, feet, and eyes. Sometimes we are given some entertainment to reduce the stress we feel! We are also given a self-gym for exercise to reduce disability and the peripheral nerve damage.

THE KIND OF HELP AND SERVICES RECEIVED

Participants in the study sought help to overcome the problems through mystical ways based on ancestral cultural heritage, traditional and alternative medicine, and modern services from health workers. The three types of services affect the handling of a person affected by leprosy by PHNs. This is closely related to the client's belief.

I did a lot of efforts to eliminate this disease. I did not know initially why the disease resulted in moldy and white skin that was numb, and gradually wounds developed and I lost my fingers. I went to a healer to seek treatment and was given prayers, amulets, and potions but it did not work and the disease only got worse.

I bathed in sulfur water on the mountain but still, my skin was moldy white. Sometimes there were also cuts on the soles of my feet and fingers and I compressed them with cassava because I think cassava caused heat to help my wounds heal quickly but instead, the wound rotted and eventually I got my legs amputated.

I went to the doctor and the doctor said this was a skin disease called leprosy and he was asked me to come to PHCs with a letter from the doctor to get free treatment. So I went to the PHCs and got this MDT package every month, initially I was on 6 months

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People affected by leprosy participating in self-care groups in the community

7

treatment and moved to 12 months treatment; the medicine must be taken every month while checking on the disease and its side effects.

I took a break from the drug and I got great side effects like blistering and hot skin, and there were injuries and disabilities, so I was referred to a leprosy special hospital and treated for a month and there were some of my fingers broken off because of my own defects and my nose is twisted and my ears are tilted and curved.

ACCEPTANCE AND SUPPORT OF THE PERSON AFFECTED BY LEPROSY

Acceptance and support received by a person affected by leprosy are related to family support during treatment, public social acceptance of the existence of the person in public, provision of adequate information and health services from PHCs, and flexibility to return to work and acceptance at work after recovery. A person affected by leprosy receives support from families and social support comes from the group through activities with fellow sufferers.

The family wanted the best treatment for my illness and motivated me to strongly undergo this treatment because my neighbours can also recover without any symptoms remaining, as long as the patient diligently undergoes treatment at the PHCs as directed from PHNs.

Every Saturday in the first week of every month, PHNs at PHCs always guide and coach us about self-care in SCGs forum. Infrequently, health education is also provided on the latest rubbing movements, MDT treatment guidelines and training for leprosy patients.

At this self-care forum, we are also taught skills such as sewing or carpentry or making crafts in order to be able to work. We're also taught to train the movement of the finger so it did not go paralysed. Unfortunately, there was no follow up after the skills were given, especially on how we can start a business or get back to work.

Discussion

SCGs are very helpful for people affected by leprosy in following short-term and long-term therapeutic regimens of leprosy treatment in the community. In SCGs, people affected by leprosy learn to adhere to the ongoing care programme in completing the MDT programme, reduce the complications, and improve independence during and after the treatment programme in order to improve the quality of life of that person in the community. This is consistent with findings of a previous study showing that self-help groups were effective in reducing the level of disability and limitations faced by a person affected by leprosy.⁵ Moreover, self-care training was considered effective for improving emotional and instrumental support from the family.¹⁴

People affected by leprosy who attended SCGs perceived their condition related to their understanding of the diseases and self-image. This finding is consistent with a previous study that described their experiences during treatment as correlated with care seeking and focused on the impact of the disease.¹⁵ Provision of motivation and continuous support for people

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affected by leprosy is needed in order to give positive impact on self-acceptance and constructive effect in perceiving oneself associated with the disease.

The SCGs can be used as a means for improving adherence to treatment. Those affected by leprosy who did not follow the treatment programme properly were concerned with a lack of confidence in the treatment received at PHCs. This finding is consistent with a previous study showing that the leprosy elimination programme is strongly influenced by multiple aspects both from the individual, society, and the health services.¹⁶ Meanwhile, the person's understanding of short-term and long-term MDT therapy regimens, knowledge, attitudes, perception, support from family and healthcare provider support, are correlated with adherence to medication.¹⁷ On the other hand, those affected by leprosy experienced side effects during the treatment and they took steps to reduce their problem. In this study, the average period since diagnosis was 27.1 months and some side effects were reported, including reactions that may occur in leprosy, even after the completion of treatment. These conditions can be minimized by supplemental drugs delivered to reduce or mitigate any likely reactions.^{18,19} This result suggests that continuous supervision through monthly home visits by PHN after MDT administration to improve adherence to medication and monitor the reactions that may arise.

Our study highlighted the ability of a person affected by leprosy to do personal care, with a focus on personal care of skin and wounds, and prevention of disability. People affected by leprosy showed good care of their eyes, hands and feet in an effort to reduce numbness due to dry skin. They also showed awareness in using protective tools in an effort to prevent disability, mentioned by seven of the participants who worked as farmers. According to a previous study, soaking and rubbing treatment,²⁰ use of personal protective equipment,⁷ and exercise²¹ are effective in reducing and preventing disability. On the other hand, people affected by leprosy seek to meet basic needs such as nutritional needs to support daily life and create a better quality of life.⁴ Therefore, continued guidance and coaching in SCGs by PHNs is needed for people affected by leprosy to create self-sufficiency in self-care and basic needs, so that the long-term complications of leprosy will be reduced.

While joining SCGs, those affected by leprosy receive services to reduce their problems. The kind of help that is sought, from traditional and alternative medicine to modern services from health workers, may be related to the participant's gender, marital status and educational background, which is consistent with previous studies showing that characteristics of those affected by leprosy, and their knowledge, are correlated with health seeking behaviour.^{22,23} These findings reflect that the types of services sought by those affected by leprosy vary greatly, depending on their understanding of the disease, past experiences and local socio-cultural conditions. This is in line with previous research showing that health seeking behaviour is highly dependent on the individual, family, and social interests of the community.³ Therefore, the types of actions taken in addressing health problems are also varied since socio-cultural issues are crucial in the cross-cultural services of the community.^{24,25} Thus, it is necessary to develop cross cultural competence and cultural sensitivity in PHNs in providing services to people affected by leprosy to give alternatives in selecting health services.

Those affected by leprosy needed acceptance and support in joining SCGs to complete their treatment, including family support and social acceptance in public. The results of this study show that encouraging people in SCGs can help their ability to adapt, as well as encouraging self-acceptance physically, psychologically, and socially. This is in accordance with studies of social stigma surrounding leprosy in the community,²⁶ which is so varied that

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People affected by leprosy participating in self-care groups in the community 9

it will affect the process of continuous discovery,²⁷ treatment and care for those affected by leprosy in the community.²⁸ Public and community health nursing programmes need to be designed based on a socio-cultural approach to the community, in order to reduce social stigma faced by those affected by leprosy. People affected by leprosy should be encouraged to improve their quality of life after recovering from leprosy and return back to work to increase their productivity. Furthermore, provision of health education needs to be continued by PHNs in communities involving all stakeholders.

IMPLICATIONS FOR COMMUNITY AND PUBLIC HEALTH NURSING

The SCGs could be improved in functioning for those affected by leprosy in their community to meet their basic needs and self-care training, including physical, psychological, social, economic, cultural, and spiritual aspects. Physical aspects are related to hand, foot and eye care. Psychological aspects are related to providing support during leprosy treatment. Social aspects deal with acceptance toward someone affected by leprosy in the community. Economic aspects bring empowerment for this person. Spiritual aspects involve promotion of spirituality in religious forums in the society related to the religious view on leprosy. All these aspects can be applied by community nurses through home visits.

It is necessary to increase the competence of PHNs to prepare leprosy prevention programmes through education and training. Then, the application of transcultural nursing is needed to develop a framework and programme to address the stigma, labelling and social discrimination of a person affected by leprosy. The framework and the programme should be culturally sensitive by emphasising nursing interventions on cultural preservation and cultural care accommodation. PHNs should work attentively by harmonizing with the local culture.

STUDY LIMITATIONS

The current study had a number of limitations. First, the phenomenology approach limited the participants' experience and the description based on the researchers' understanding and definition of the phenomena. An ethnographic approach could be used in future research to identify the self-care of a person affected by leprosy to improve their quality of life in regard to the social and cultural context. To improve the application of self-care in the home by someone affected by leprosy, an observation and participatory research design could be used. Second, the data were gathered only from people affected by leprosy to explore their experience of self-care while attending SCGs and this research did not use any statistical data. In future, PHCs and PHNs as healthcare providers could also be interviewed, to collect supporting data.

Third, this study was conducted in one region in Jember district, East Java. Thus, the findings could not be generalised or applied in other areas in Indonesia. Future research could use a theoretical framework model to guide the next project in self-care, so that valuable information can be provided to policy makers.

Conclusion

This study explores the experiences of people affected by leprosy, while attending SCGs in the community, which aim to help meet their basic needs and encourage self-care, including

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10 T. Susanto et al.

physical, psychological, social, economic, cultural, and spiritual aspects. The experiences identified included the self-perceived condition, adherence to treatment, ability to do self-care, the kind of help and services received, and acceptance and support. In following up with SCGs, those affected by leprosy require supervision from PHNs to provide guidance and coaching in ongoing care. Family support is also needed in carrying out medication, while community awareness is important to reduce negative perceptions and social stigma. Furthermore, the empowerment of those affected by leprosy is needed to improve the quality of life of leprosy patients in the community.

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