THE POWER OF BEING TOGETHER

A STUDY OF SELF-CARE GROUPS OF PEOPLE AFFECTED BY LEPROSY, IN SUBANG DISTRICT WEST JAVA, INDONESIA

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Master’s Thesis in Medical Anthropology
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<tr>
<td>IEC</td>
<td>Information Education &amp; Communication</td>
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<td>LEC</td>
<td>Leprosy-Elimination Campaign</td>
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<td>MB</td>
<td>Multi-Bacillary</td>
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<td>MDT</td>
<td>Multi-Drug Therapy</td>
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<td>NFI</td>
<td>Nerve Function Impairment</td>
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<td>NGO</td>
<td>Non-Governmental Organization</td>
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<td>PAL</td>
<td>Person Affected by Leprosy</td>
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<td>PB</td>
<td>Pauci-Bacillary</td>
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<td>POD</td>
<td>Prevention of Disability</td>
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<td>RFT</td>
<td>Released from Treatment</td>
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<td>SCG</td>
<td>Self-Care Group</td>
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Summary

Self-care groups (SCGs) have been started in Indonesia in 2000. A SCG is a group of people affected by leprosy (PALs), when still on or after finishing medical treatment, who gather regularly with the aim of supporting one another in solving problems due to leprosy, primarily in the prevention and reduction of disability. Visible physical impairments that might occur as a medical consequence of leprosy have an important role in making the PALs to be stigmatized. Thus, SCGs can be considered as one kind of intervention for the reduction of stigma of leprosy. The objectives of my study are to explore the experiences of the PALs who are members of SCGs, to know their perceptions on their ‘leprosy-affected life’ before and after joining the SCGs. By exploring their experiences and also experiences of the health workers who are involved in this activity, I tried to identify the limitations and the strengths of SCGs as a [self] stigma reduction programme. Theoretical concepts that serve as the framework of my study are stigma, disability, self-care/self-help groups, and social capital.

The fieldwork took place in Subang district, West Java Province Indonesia, in where the first groups of SCG in Indonesia were established, from the end of May until the end of June 2007. Various qualitative techniques were used to generate the data: fifteen PALs from two SCGs were interviewed to gain a good understanding of the PALs’ perceptions and experiences on their ‘leprosy-affected’ lives and to know their experiences in the SCGs. Some family members of twelve PALs were interviewed to get their perspectives on the PALs’ experiences. The facilitators of the two SCGs were interviewed to get their perspectives on the SCGs’ members and to know their experiences as facilitators. Participant observation by living with a PAL and his family and being a villager provided me more insight regarding the PALs’ daily lives, and by attending the SCGs meetings I could see the activity in reality.

Suffering from leprosy had been a long lasting experience for the PALs and self-stigma was prominent among the PALs. The major causes of self-stigma were feeling of shame because of the perceived infectiousness of leprosy, fear of being stigmatized and fear of not being able to earn a living. Higher self-stigma of a PAL occurred if he/she experienced the ‘enacted stigma’, i.e. being stigmatized by the community. The presence
of SCG was seen by the PALs as an opportunity to get over their long lasting illness experience.

Contrasting experiences of the two SCGs show, that there are certain conditions that are influencing the SCG’s chance to be able in achieving its aims, and thus, in fulfilling the PALs’ hope. At the beginning of a group formation, a competent facilitator and/or group leader are needed to create ‘group spirit’, so that the group may start ‘performing’, as a social structure, to achieve its aims. Once a SCG starts performing, its group members may achieve many advantages, such as being able to control and to reduce their impairments. Furthermore, being aware of their ability increases the members’ self-confidence and self-esteem, and thus diminishes their self-stigma. Enacted stigma in the community impedes the group dynamic, whereas community’s acceptance of and connectedness to the SCG may give advantages to both sides, i.e. the community and the SCG’s members. This norm of reciprocity may create the community’s sense of belonging of the SCG. Members of SCGs, to a certain extent, are disabled, because of their physical limitation. Inability to earn a living may cause self-stigma, and therefore, working capital that was loaned to one of the groups helps the SCG members in earning a secure living.

Some practical recommendations for enhancing the success of SCGs have been made, directed to the health providers. The community needs to be sensitized about leprosy [and the SCG concept], before a SCG is being started, through continuing information, education and communication (IEC) activity; the principle of SCG is that members play the most important role in taking care of their disability, by practicing home-based-daily-self-care using local materials. Thus, community-based SCG would be suitable, and furthermore the connectedness between SCG and the community will be developed; SCG is a promising holistic approach to a PAL, therefore, the group facilitator has to be provided with more skills, such as skill to counsel a member who needs more psychological support; IEC to PALs regarding their long lasting affliction should be continuously given to them, at any time during their medical treatment and after they are released from treatment (RFT).
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Chapter 1

Introduction

Around five years ago, I started my endeavour in the leprosy world. In doing my work as a medical doctor, I often saw leprosy patients who became miserable due to their sickness. The misery happens not mainly due to the bodily symptoms that could include the pain and fever, but often it is due to the experiences of being avoided by friends, the feelings of embarrassment, etc. In other cases, I could [still] see some patients who seek for help in the health centre when they were already in the advanced stage of leprosy, with severe physical deformities. When we asked them, what made them coming so late to seek help; it would not be a surprise if one of the answers would be because they were embarrassed to do so. In short, I have seen many constraints in the efforts of controlling leprosy that are related to the social aspects of it, and stigma of leprosy is one of the crucial causes. I am a medical doctor who is personally interested in the social aspects of leprosy [and other communicable diseases, in general], i.e. the problems that happen ‘out of the clinic’. I agree with many opinions that say that if these aspects are being neglected, the aim of ‘the elimination of diseases’ or ‘the eradication of diseases’ would only be nice slogans. In fact, many efforts have been done in both the medical aspects and social aspects of leprosy. One programme that aimed to touch both aspects is the Self-Care Group (SCG).

1.1 Statement of the problem

Leprosy is still a public health problem in some parts of the world, including in Indonesia. One of the aspects in the complexities in fighting against leprosy is the fact that there is a stigma attached to the disease. Stigma of leprosy is recognized to have a major impact on the effectiveness of controlling the disease. Moreover, from the viewpoint of the people affected by leprosy (PALs) the consequences of stigma might affect them throughout their life time in which many life chances of the PALs are reduced.

Recourse to earlier studies all over the world show that stigma of leprosy is a socio-cultural construct (Boonmongkon 1994; Alvez-Moreira, et al. 2002; Idawani, et al.
2002; White 2002; Alubo et al. 2003; Burathoki et al. 2004). It is constructed basically due to people’s fear and disgust, because of the socio-cultural meaning that was attributed to it and also because of the disfigurement and disability that the disease may cause. One of the impacts of stigma on the PALs is that being stigmatized or fear of being stigmatized leads them to internalize stigma and causes self-stigmatization. Due to self-stigmatization PALs may have low self-esteem, and then they may restrict themselves from having social activity.

Earlier research (Bijleveld 1982; Elissen 1991; Idawani et al. 2002) shows that self-stigma is common among the PALs in Indonesia. It is very prominent in Indonesia that suffering from leprosy creates feeling of shame or *malu* in the PALs. Their fears and worries of being stigmatized often outweigh the actual stigmatization or the ‘enacted stigma.’ Bijleveld (1982), Elissen (1991), and Idawani et al. (2002) who conducted qualitative researches in three different places in the country, respectively North Sulawesi, South Sulawesi, and Aceh, find the similar phenomena. The form of self-stigmatization occurs frequently, in particular if there are visible impairments. The PALs feel ashamed and inferior because they are aware that the society have bad notions of leprosy; they know this because the PALs have shared the same notions before they contracted the disease themselves (Bijleveld 1982). Therefore, they would usually voluntarily withdraw from certain social relationships. Nevertheless, self-stigmatization sometimes intertwines with the enacted stigma of the community. Enacted stigma manifests in kinds of avoidance or keeping distance by the community and the fear of contracting the disease is the main reason for such action.

The World Health Organization (WHO) estimates that more than three million people all over the world are living with disability\(^1\) from leprosy (WHO 2005). Moreover, in Indonesia, almost 9% of the 19,695 newly detected patients in 2005 have visible disability (Ministry of Health of Indonesia 2006a) and many more of the affected people are in the same condition. However, the disabling effect of leprosy is mostly preventable by early detection and adequate treatment. For the PALs who had developed physical impairments, one simple way in which PALs can prevent or minimize the complications of leprosy is by practicing regular self-care of their physical impairment at home.

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1 In the context of leprosy, ‘disability’ is the general term that is used to refer to impairment, activity limitations or participation restriction. The WHO divides disability into grading (see Annex 1)
Self-care groups (SCGs) have been started in Indonesia in 2000. A SCG is a group of PALs, when still on or after finishing medical treatment, who gather regularly with the aim of supporting one another in solving problems due to leprosy, primarily in the prevention and reduction of disability. Thus, SCGs can be considered as one kind of intervention for the reduction of stigma of leprosy. In its implementation, the health care workers act as the facilitator while the PALs themselves are the main actors in the group. Two studies, from Ethiopia (Benbow & Tamiru 2001) and Nepal (Cross & Choudary 2005) show that SCGs have a positive impact on the members. The study in Ethiopia shows that SCGs give good results regarding the reduction of deformities, such as improvement of wounds on the soles. Furthermore, some good unexpected results happen, in terms of the improvement of the PALs’ self-esteem and their social participation (Benbow & Tamiru 2001). Cross and Choudary, in their study in Nepal also found a number of positive outcomes. Group members have taken up responsibility for managing and monitoring their own wounds and supplying their own wound healing materials. They also report increased confidence to participate in society, restored dignity and self-respect, and a sense of belonging within the community (Cross & Choudary 2005).

One-hundred-and-five groups were established in Indonesia from 2000 up to early 2007 and 41 groups are still in planning. The 105 groups are spread over 17 provinces and among them 64 groups run regularly once a month, 7 groups run irregularly while 34 groups had been closed (Ministry of Health of Indonesia 2007). In my previous work as a provincial project officer and leprosy doctor, I was involved in setting up and supervising the SCGs in North Sulawesi province from 2003-2006. Groups’ reports and my personal observation show that successes but also failures happen in many groups. However, there has not been done any study yet of the SCG in Indonesia. Thus there is little information which may corroborate the claims that SCGs lead to a reduction in disability and that SCG membership reduces self-stigmatization. It was not clear either that why some SCGs succeed and why the others don’t. Therefore, I would like to start up the exploration through my own study.

Throughout this study, I analyse how the efficacy of a SCG as a [self] stigma reduction programme, is influenced by various factors. The factors are stigma of leprosy and leprosy-related disability in the PALs level; stigma of leprosy in the community level,
and the quality of human resources in the health service level. To understand how these factors influence the functioning of a SCG, and how the factors are interrelated, I present a problem analysis diagram (see Annex 2).

In the following section I present some further information regarding leprosy and its medical consequences that may cause social consequences. I will also present the leprosy situation in Indonesia in general, and specifically in Subang district, and what interventions that have been implemented. Afterwards, I will explain the objectives of my study and the questions that will be answered through the study.

1.2 Leprosy: more than just a medical problem

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae*. Its main targets are the nerves and skin, though other organs may be affected as well. The major host of *M. leprae* is the human being. Therefore, people who suffer from leprosy are the main sources of infection, particularly those with multi-bacillary (MB)\(^2\) leprosy who haven't been treated with the combination of two or three anti leprosy drugs, commonly known as the ‘multi-drug therapy’ (MDT). In fact, however, it is assumed that *M. leprae* is not very virulent and that most infections do not result in symptoms. It is estimated that the bacteria produce symptoms in less than 10 percent of the human population, and only then after prolonged exposure and a five-year incubation period (Bryceson and Pfalzgraff 1990).

Early symptoms of leprosy can be self-limiting and skin-lesions can heal spontaneously. The most important portal of entry and exit of *M. leprae* is the respiratory system, particularly the nose. Transmission of the *M. leprae* through skin lesions probably plays a minor role only, since the bacteria do not normally penetrate intact skin. A broad range of signs and symptoms can occur when a person develops leprosy. The most important and characteristic symptoms and signs involve the skin and are related to, or a consequence of, peripheral nerve damage. One of the crucial factors that determine which symptoms emerge is the capacity of the host to mount an effective immune response to contain and eliminate the infection. Inadequate protection will lead to clinical disease.

\(^2\) The WHO classifies leprosy into multi-bacillary (MB) and pauci-bacillary (PB).
Among communicable diseases, leprosy is a leading cause of permanent physical disability due to the nature of the causative agent that targets the nerves. The damage of the nerves starts with leprosy reactions. A leprosy reaction is the sudden appearance of symptoms and signs of inflammation in the skin lesions of a person with leprosy. There may also be swelling, pain and tenderness of nerves, often accompanied by loss of function; sometimes loss of nerve function occurs without other signs of inflammation, making it much less obvious — so called ‘silent neuritis’. Nerve damage may manifest itself through dryness of the skin, loss of sensation, often in hands and feet or muscle weakness. In case of the latter, there may be inability to close the eye or paralysis of muscles in hands and feet. Visible signs such as clawing of fingers and toes, ‘absorption’ of digits due to repeated injury and dry skin are secondary to impairment of motor, sensory and autonomic nerve function (main source: www.leprastichting.nl).

Prevention of disability is therefore a main aim in any leprosy control programme. Early detection of leprosy and adequate treatment are by far the most effective measures to prevent disability. However, since 10-20% of patients will develop new sensory or motor impairments during or even after medical treatment, early detection and adequate treatment of leprosy reactions and nerve function impairment (NFI), and subsequent steroid treatment are also of vital importance. If people have already developed irreversible neural impairment or even secondary impairments (such as wounds and contractures), the key issue is preventing these from getting worse. The main basic strategy is ‘self-care’: teaching the PALs how to look after their damaged eyes or limbs, how to prevent injury in everyday activities and how to treat wounds. They will have to do this conscientiously for the rest of their lives. However, Barret argues that, ‘which is basic is not always easy’ (Barret 2005: 218), in which poverty and other constraints in the PALs’ lives may hamper the practice of daily self-care.

The World Health Organization acknowledges that despite the fact that the leprosy burden has been reduced substantially, in which over the last two decades the global case-load has fallen by almost 90%, new cases of leprosy will continue to appear for the foreseeable future in most of the currently endemic countries. There are seventeen countries, which each reported more than 1,000 new cases in 2005. Together, they contribute 94% of new cases detected in the world. Among those countries, India, Brazil and Indonesia are the three biggest contributors (WHO 2005).
Reacting upon the current global leprosy burden, the WHO and the other major stakeholders have developed the ‘Global Strategy for further reducing the leprosy burden and sustaining leprosy control activities 2006 – 2010’. It is suggested that every national leprosy control program in the ‘high burden’ countries uses these guidelines as a means to develop their own national policy. One of the major challenges is to further reduce stigma and discrimination against affected persons and their families and promote correction or deletions of outdated legislation (WHO 2005).

1.3 Leprosy in Indonesia

Before I describe the leprosy situation in Indonesia, I will give a brief overview of the country. Indonesia is a large archipelago country consisting of more than 17,000 islands. The five main islands are Sumatra, Java, Kalimantan, Sulawesi and Papua. Indonesia is one of the most populous countries in the world with more than 220 million inhabitants in 2006. More than half of the populations are living in rural areas (Central Statistic Bureau Republic Indonesia 2004). As a large nation Indonesia is characterized by wide cultural diversity and different religions. About 90% of the populations are Moslem, making Indonesia the largest Moslem country in the world. The rest of the populations are Christians, Buddhist, Hindus and Confucians.

Indonesia is rich in natural resources. The main source of income is the agricultural sector, with transition to trade and industry in some places. The nation’s economic growth was rapid in the early 1990s until a severe economic crisis occurred in 1997. Furthermore, there is an enormous gap between the few extremely rich and the many very poor, in which around 17% of the populations are living in the condition below the poverty-line with a daily income less than US$ 2 (Central Statistic Bureau Republic Indonesia 2004). Politically and administratively the country is subdivided into 33 provinces. The Provinces are subdivided into districts and municipalities, which in turn are subdivided into sub-districts. Then, sub-districts are subdivided into villages.

Through Acts legislative Law 22 and Law 25 1999, a new policy of district autonomy, with a decentralization of power to the district level, has been implemented starting 1st January 2001. On the one hand, the implementation of this policy has brought the new atmosphere of ‘ownership and self-regulating’ in local government at
the district level. The shifting of the power from the central to the local enables the local authority to identify their resources and needs in almost every sector (Ministry of Internal Affairs of Indonesia 2002), including the Health sector. One consequence is that it becomes increasingly difficult to maintain the local authorities’ interest in sustaining the leprosy control, since in most places the disease is perceived no longer a problem and as there are competing priorities.

In the past, leprosy control in Indonesia was conducted through a vertical programme. All patients were treated in leprosy hospitals that were owned by the government, which were located in some big cities. In the same compounds of the hospitals, there were also ‘colonies or settlements’ where patients had to stay for many years or even for a life-time of treatment. Leprosy treatment was gradually being integrated in the general health service in 1969 (Ministry of Health of Indonesia 2006a). Nowadays, basic treatment is provided through health centres in sub-districts or in villages. Hospitals in higher administrative level serve as referral centres. However, referral of leprosy patients to a general hospital is still problematic in some places. This may be because of the medical staffs’ incompetence of leprosy or because of hospital’s discrimination against the PALs.

At the health centre, leprosy services are provided by a leprosy health worker. The leprosy health worker is recruited from the general paramedical health worker. To be capable in doing their job in leprosy control, a general paramedical health worker in a health centre is trained for five days in the principles of leprosy control, such as how to diagnose and to treat patients and also how to do the ‘prevention of disabilities’ (POD) examination, and then he/she will be a leprosy health worker. However, in general, leprosy health worker has tasks in some other health centre’s programmes too. In general, the medical doctor of a primary health centre acts as the supervisor. The medical doctors are usually trained in a five-days-training of the principles of leprosy control too, in particular the medical doctors of health centres in high endemic area of leprosy. However, not every health centre has a medical doctor. In district level, the district health service has a district leprosy supervisor (wasor kusta kabupaten) who is responsible to supervise the health centre. In provincial level, the provincial health

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3 POD (Prevention of Disability) is the peripheral nerve function examination that has to be done regularly to detect nerve function impairments.
service also has a provincial leprosy supervisor (*wasor kusta propinsi*). Both the district and provincial supervisors are trained for three weeks at the national leprosy training centre.

Regarding medical treatment, the usage of the WHO recommended MDT had been started since 1982, and the drugs are given to the patients for free. From 1982 till the end of 1997, the MDT regimens were 24 dosages for MB type and 6 dosages for PB type, but afterwards the regimens have been changed into 12 dosages for MB type and remain the same for PB type, following the WHO’s guidelines. Once a patient has taken the regiments completely, they would be ‘released from treatment’ (RFT), and thus they would be declared cured. Theoretically, on the last day of their treatment, the patients will be informed to come to health centre whenever they notice any leprosy-related symptoms, such as the tingling feet, the old patches becoming swollen; all symptoms that are related to leprosy reaction, because they are still in risk of getting leprosy reaction.

During the nineties, Indonesia had been working hard in detecting and treating the leprosy patients. Active and passive case finding methods had been employed, while at the same time also increasing people’s knowledge and awareness of leprosy through health education activities. ‘Leprosy Elimination Campaign’ (LEC) was conducted in the whole country, with special attention given to the high endemic places. As a result of the continuous efforts, Indonesia had detected and treated thousands of patients, and had achieved the WHO’s target of elimination of leprosy at the national level, i.e. the number of registered cases less that one per ten-thousands populations, in 2000. However, from 2000 to 2005, the leprosy situation had never changed in terms of the number of newly-detected cases, in which fifteen-thousands or more cases had been detected every year. This situation suggests that transmission of leprosy is still going on. The case load of leprosy is unevenly distributed in Indonesia, in which the highest leprosy burden area is mainly in the eastern part of the country (see map in annex 3).

Furthermore, leprosy burden is not only limited to the remaining high case loads in some places, but also to the fact that there are many PALs, including the ones who had finished their medical treatment, who still need to be taken care due to their leprosy-related disability. In 2005 almost 9% of the 19,695 newly detected patients have visible disability and many more of the affected people are in the same condition.
Due to their disability, many PALs have to deal with physical, psychological, and social problems in their lives. In relation to that matter, ‘care and rehabilitation’ is a part of national leprosy control programme, and SCG (which will be discussed later in a separate chapter) is one component of that programme. Some other components are the routine peripheral nerve function examination or the POD examination for ‘on-MDT’ patients and reconstructive surgery. Furthermore, to help the PALs in dealing with other problems such as socio-economic problems, collaboration with other stakeholders such as the ministry of social welfare and national and international non-governmental organization (NGO) has been developed too (Ministry of Health of Indonesia 2006a).

1.4 Leprosy in Subang district

In this section, I will provide some information regarding the location of my study. I will briefly elaborate on the general situation in Subang district and an overview of the leprosy control programme.

Subang is one of the twenty-five districts and municipalities of West Java province in Indonesia. It is located in the northern part of West Java, and it is easily accessed from different parts of West Java and the western part of Central Java (see map in Annex 5). The total land area is 205,176 ha and the total population based on the 2005 census is 1,391,997 people with composition of 699,783 males and 692,214 females. Topographically, Subang is divided into three morphological zones. The three zones are the mountainous zone in the Southern part, the lower land in the middle, and the coastal zone in the Northern part. Related to its topographical situation, Subang is a fertile land with different kinds of natural resources such as rice fields that are covering almost every part of the district, tea plantation in the mountainous areas, while the rubber-tree, sugar cane, and various kinds of tropical fruits plantations are covering the lower land areas. Thus, in general, the main source of income is from the agricultural sector, besides other sector such as fishery, tourism and industry. Administratively, the district is subdivided into 22 sub-districts and 252 villages; each sub district consists of 6 to 18 villages. The population of Subang consist of the Sundanese ethnic group as the majority, and the minority of different ethnic groups that have been living there for
many generations. Particularly in the lower land and the coastal land, there is also a mixture of the Sundanese and the Javanese. Regarding religions, more than 80% of the people are Muslims. Since the district autonomy law had been implemented, the development in Subang district has been growing quite rapidly after a fall during the national crisis in the late nineteen-nineties. (Main source: www.subang.go.id).

Regarding the health services in Subang district, there are thirty-nine health centres, in which each sub district have between one to two health centres depending of the number of the population that has to be served in the particular area. In general, the health centres in Subang have in-patient facilities besides the basic health care, and every health centre is staffed by at least one medical doctor and a number of paramedical staff. In terms of accessibility, the health centres are relatively easily accessed, furthermore the public transportation is available. In the villages, there are seventy-two sub-health centres / health posts, and a midwife usually is the responsible person in every sub-health centre / health post. Three government and private hospitals in the capital of the district and its surroundings provide the first level of referral services.

The aged disease leprosy has been and still is troubling the people in Subang. During the implementation of the LEC in Subang from 1996 to 1998, more than one-thousand people were detected as suffering from leprosy and approximately two-hundred-and-fifty of the newly detected sufferers had developed visible impairments due to leprosy. In the last five years annually two-hundred people on average are newly detected as suffering from leprosy. The sufferers are detected in different parts of the district (see map in annex 6). Furthermore, approximately ten per cent of the newly detected sufferers had developed the nerves impairments and even the visible physical impairments (District health service of Subang 2007).

Fortunately, the local health care providers are not denying nor neglecting the situation. Leprosy services are provided at the health centre level. With the technical support from the provincial level, the human resources in the health centre, i.e. the medical doctor and the leprosy health workers, have been trained in the principles of leprosy control [that was mentioned in the previous chapter]. Generally, the leprosy health workers do the routine tasks, while the medical doctors are the consultant and the motivator. In the district level, a supervisor ("wasor") and a co-supervisor [who is
also a leprosy health worker in one of the health centres] are trained at the national leprosy training centre, to assist the leprosy health workers with technical guidance. Principally, the district was/or goes to each health centre once every quarter, but some extra visits are made in case necessary. Because of the high burden of leprosy-disabled people and the availability of human resources in leprosy services, Subang district was chosen by the West Java provincial health service as the location for the implementation of the SCG concept in 2000. These groups are the first SCGs in Indonesia.

Awareness of leprosy as a public health matter can be seen also in the policy-maker level. Besides the moral support that is continuously given to the ‘working people’ in the field, funding is also continuously provided through the district budget – besides the budget from the provincial level and foreign aid - in the last five years. In terms of proportion of the amount, the district budget for leprosy control was approximately 20% of the total budget for leprosy control in 2002. The district budget keeps on increasing, and it is more than 40% of the total budget for leprosy control in 2007, which is including some budget for the SCG programme. This is a quite rare situation, but preferable, since in many other places in Indonesia in general; leprosy control is highly dependent to the foreign aid.

1.5 Objectives and study questions

In relation to the aforementioned situation, the objectives of this research are to explore the experiences of the PALs who are members of the SCGs. I want to know their perceptions on their ‘leprosy affected life’ before and after joining the SCGs. From their experiences as well as from the health workers and other volunteers who are involved in the activity, I tried to identify the limitations and the strengths of SCG as a stigma reduction program. Through my study I aim to come up with some suggestions for the development of successful SCGs in the future, which can help in reducing self-stigma of their members.

As previously mentioned, it is a fact that stigma of leprosy is much related to the disability that the disease causes, and that self-stigma is common in Indonesia. As SCGs’ main aim is the prevention and reduction of disability and the focus of my study was on self-stigma of the PALs, and therefore my main study question is:
How does the functioning of a SCG for the PALs affect the self-stigmatization of its members?

The main question has been divided in the following sub questions:

1. What are the reasons and motivations of the PALs to become a member of SCG?
2. To what extent and in what way are the PALs stigmatized by the community?
3. What do the PALs expect from their participation in SCG, what are the group activities, what factors influence the successful functioning of SCG, and what advantage do they get from SCG?
4. To what extent and in what way do the PALs experience a change of their ‘leprosy affected life’ after becoming a member of SCG, in particular related to stigma?
Chapter 2
Theoretical Concepts

In this chapter I will review the theoretical concepts which serve as a framework of my study. Those concepts are stigma, disability, self-care/self-help groups, and social capital.

2.1 Stigma

Goffman (1963), in his classic essay on stigma, argues that stigma is a deeply discrediting social label that changes the way an individual is viewed as a person, and ironically, also may change the way an individual views himself. In everyday lives, stigma is socialized through interpersonal communication and lived engagements. It is shared and interpreted continuously through utilization of language and symbols. Thus, stigma can be viewed as interpersonal in nature (Yang et al 2007). As previously mentioned, stigma is a social construct that is attached to leprosy and the sufferers.

There are several categories of stigma when it comes to the process of stigmatization. ‘Felt stigma’ or ‘perceived stigma’ refers to the fear of being stigmatized and ‘enacted stigma’ is the actual stigmatization done by the society” (Scambler 1997 in Heijnders 2004: 438). Moreover, it is argued that the strong fear of being stigmatized might lead the PALs to internalize the stigma and lead into self-stigmatization (Heijnders 2004, Barret 2005). Self-stigma may disrupt people’s lives even more than enacted stigma. It may cause emotional stress, anxiety and problems with self-esteem. Due to these circumstances, self-care routines might be abandoned and thus it may worsen the impairments. In the context my study, I aim to know what type of stigma is experienced by the PALs, how they experience the stigma, and how stigma affects their lives.

Van Brakel concludes in his review on measurement of stigma that the spheres of life of PALs affected by stigma are similar, despite the cultural diversity. They include mobility, interpersonal relationships, social status, employment opportunities or job security, family relationships, marriage, leisure activities, and attendance at social and religious functions (Van Brakel 2003). However, as it is previously explained, the way
they are affected by stigma varies in different contexts in accordance to the local meaning and interpretations of leprosy.

Regarding the effects of stigma, Goffman argues that there are some ‘normal’ people who share the stigma together with the stigmatized, so-called the ‘courtesy stigma’. This kind of situation, Goffman states “provides a reason why such relations tend either to be avoided or to be terminated, where existing” (Goffman 1990: 43). Therefore, PALs may leave their families, spouses and children due to fearing the repercussions of the fact they had leprosy (Kaur & Van Brakel 2002), or in some cases they may be asked by their families to leave (Barret 2005).

In terms of disease control, stigma may affect many aspects of leprosy control. Stigma may influence the health seeking behavior of the affected people, delaying the PALs to seek help (Boonmongkon 1994; Alubo et al. 2002; Burathoki et al. 2002; Idawani, et al. 2002; Moreira, et al. 2002; White 2002; Van Brakel 2003). This situation, to a certain extent, gives the opportunity for the disease to spread. As the disease develops without treatment, the PALs will be at higher risk of developing deformities. Thus, a vicious circle of leprosy occurs. Stigma of leprosy, as it is previously mentioned, might be internalized by the PALs and appear as self-stigma. Self-stigma might lead the PALs to the feeling of hopelessness and worthlessness that decrease their self-confidence and self-esteem. This situation, then, may hamper their motivations in lives, including to taking care of their impairments. In my study stigma is a central concept as I aim to know whether self-care groups can help its members to regain their self-respect and motivation in lives, and thus, to diminish their self-stigma.

2.2 Disability

There are three influential models of disability and Devlieger et al (in Hammel 2006) put them together, as the ‘cultural models of disability’. They argue that though these three models originated in very different times, they are all evident in contemporary societies, demonstrating the persistence of certain patterns of thought in shaping the ideas about disability. Firstly, the oldest model of disability is the ‘moral/religious model’ that explains disability as punishment from God for sins that one has committed. Secondly, the model that arises during the enlightenment period in western history is the
‘individual/medical model’ that explains disability as a failing of one’s bodily structures and or bodily functioning. Thirdly is the social/political model that explains disability as the loss or limitation of opportunities to participate in the society (in Hammell 2006: 55-67). Since as early as 1980, the WHO has been trying with its three dimensional concept of disability to take into account the fact that it is not sufficient to perceive disability merely as a physical or mental characteristic. Instead, it has to be seen in relation to the expectations a given society has of an individual. The International Classification of Functioning, Disability and Health (ICF) of the WHO define disability as an umbrella term covering impairments (problems in body functions and structure), activity limitations (difficulties in performing a task or action) and participation restrictions (problems in involving in societal level). It denotes the negative aspects of the interaction between an individual and the individual’s personal and environmental contextual factors (WHO 2001). Thus, disability is a socio-cultural construct. What counts as impairment will vary between cultures, as will the response to it and the value attributed to the person perceived to have the impairment (Groce 1999; Hammell 2006). In my study, the members of SCGs were mostly impaired as the consequence of leprosy.

Dominant groups within the cultures hold the power both to legitimate what is normal and to construct what constitutes impairment. Wendell argues that “classifying people on the basis of perceived deficiency is a social practice that involves the unequal exercise of power and that this has major economic, social and psychological consequences for some people’s lives” (1996 in Hammell 2006: 32). The relative powerlessness of disabled people leads the disabled people to marginalization. Moreover, marginalization is often designated towards people who are perceived as backward, inferior or lesser being. In many cultural contexts, women are among these groups (Kern 1999; Hammell 2006).

Despite the condition of being marginalized, some studies about ‘disabled people’ in different contexts show that the disabled people are annoyed that they are portrayed as helpless victims (Holzer 1999; Rozing 1999). Some of the ‘disabled people’ may function well, or at least pretend to function well, in their community depending on their physical impairments and also on their position in the social hierarchy. However, most of the ‘disabled people’ do not have choice due to their complex unfortunate status, e.g. economically poor, which is a common status of the PALs. These groups, commonly,
may create sympathy, and they become recipients of many charitable activities. However, charity is temporary. Furthermore, it creates dependency of the disabled people on the ‘abled’ powerful ones. It may perpetuate the superiority and inferiority ideas among those two groups. Thus, it is not a perfect solution in terms of empowering the disabled people, and one alternative is to enable them to solve their own problems in lives, by providing them with the needed knowledge and skills. In her socio-ethnographic study among mentally-handicapped women in Mexico, Holzer found that the disabled people there want to be empowered and they want to have responsibilities of their own lives, for instance, by visiting one another, joining the festivities, or even by earning their own money. Furthermore she argues that, it was possible for the particular group of people there to participate in everyday social activity ‘just as they are’, because they are accepted by the local society (Holzer 1999).

As previously mentioned, visible physical impairments have an important role in making a PAL to be stigmatized, and therefore they might face restrictions in societal lives. Furthermore, physical impairments may cause limitations to carry out basic daily activities. Self-care groups of the PALs are principally aimed to enabling the members to solve the problems due to leprosy independently, e.g. to take care of their physical impairments and to prevent them of becoming worse. In my study, I aim to explore how in reality, SCGs encourage and support the members in managing their physical impairments. I also want to know whether through the impacts of SCGs, the PALs may function better in their social lives despite their physical impairments.

**2.3 Self-care / self-help groups**

Self-care or self-help groups are a growing phenomenon across national borders, which began to increase in the period of the 1970s in western-industrialized countries (Trojan 1989). A self-care/help group consists of a group of people who share the same problem, e.g. chronic-illness, disability or other life-disrupting problems, who come together to support and help one another in overcoming the unfortunate situations (Steward 1990; Adamsen 2002). Thus, reciprocity and trust are the basic principles of the self-care/help groups. Earlier studies on different kinds of disease-related self-care groups show that members of those groups experienced positive changes in their
psychosocial well-being e.g. reduction of emotional stress, less stress through stigmatizing reactions of others, improved familial relationships and improved social participation. Furthermore, through the knowledge that they gained through the groups, members become more aware of the situation in which they need help from the health-professionals. Then, they will utilize the professional service purposefully (Trojan 1989).

The capability of individual member in dealing with their situation is enhanced by the fact of being with peers in the group. Borkman argues that people assimilate knowledge better when it is presented by peers, namely the experiential knowledge, rather than if it is merely advised by health-professionals. Furthermore, by seeing peers’ success – peers as role models – one may be encouraged of one’s own capabilities in doing similar tasks (1976 in Steward 1990: 1061). In my study, I aim to see how the fact of being with peers in a SCG affects a PAL’s skill and motivation in taking care of their impairments. However, apparently, the success of the group may depend on a degree of homogeneity among the members, in terms of, for instance the disease they suffer from or the severity of the disease, sex, age and social status (Adamsen 2002). Homogeneity among the members is important in maintaining the mutual goals within a group. Handy (1985) in Benbow and Tamiru (2001) argues that group development is a dynamic process, and a group may develop well and successfully achieve its goals, if it passes through the four stages as follow:

`Forming` or starting is when a group of people come together with an apparently common objective. `Storming` or conflict takes place when individuals within the group begin to express their previously unspoken reasons or agendas for joining the group and try to move the group in the direction they choose. It is essential that the objective of the group is clarified and individuals either agree to the objective or leave the group. `Norming` or sorting out occurs when conflicts between individuals are resolved and the group starts to identify itself as a single unit, working towards the agreed objective. Finally, `performing` or producing takes place when the group starts to achieve the objective. Some groups reach the `producing` [performing] stage quickly, whilst others vacillate between the `storming` and `norming` stages, due to various agendas people bring and which can only be dealt with over time. Most groups that fail do so in the `storming` stage (Benbow & Tamiru 2001: 312).
In many self-care/help groups, we may find initiators and facilitators who are either volunteers or representatives of professional groups, nurses, social workers, psychologists, etc (Adamsen 2002). Besides the members, this group of people also has the role in determining a group’s success. Facilitators’ capability in understanding the dynamics in the groups is crucial for them in order to react appropriately (Benbow & Tamiru 2001; Adamsen 2002).

Self-care groups, in particular SCG of the PALs in Indonesia, are the core of my study. According to the SCGs manual the general objective of a SCG is to prevent or reduce disabilities in their members (Ministry of Health of Indonesia 2006). In my study, to understand the dynamic within the groups, i.e. the process of group formation, activities in group-meetings, the relationships among members themselves and between members and facilitators, is important. It may show which factors in the groups that are supporting and or constraining SCGs as a ‘disability-reduction program’, and thus, in diminishing self-stigma of the members.

2.4 Social capital

There are many different ideas and definitions of the concept ‘social capital’ that was introduced in the past decades by Bourdieu, who defined it as “the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition” (Bourdieu 1980 in Portes 1998:3). In Bourdieu’s definition, social capital can be understood as the ability of an individual or a group of individuals to benefit from the resources that belong to a social structure, only by being connected through a certain kind of social relationships to that particular social structure. In short, social capital is a resource within social structures and social relationships. Social capital is relevant to my study in knowing whether the members of SCG get advantages from their membership in SCG as a social structure, and in what way they benefit from it. Besides the SCG, there are other social structures that are connected to the members, i.e. the families of the members and the community of where they belong. In this study it is important to know how SCG and its members are connected to those social structures.
Recent studies, regarding social capital as a social determinant of health, produces a model of social capital that disaggregates the resources into two components, i.e. ‘the cognitive social capital’ and ‘the structural social capital’. The cognitive component covers how people perceive support, reciprocity, sense of belonging and social trust in their community. The structural component includes the quantity of social relationships, such as membership of networks that may show the extent and intensity of people’s connectedness in the community (Bain & Hicks 1998 in Harpham et al 2002: 106). Furthermore, both the cognitive and structural aspects of social capital can be ‘bonding’ referring to the connections between similar individuals, or ‘bridging’ referring to the connections between dissimilar individuals, or ‘linking’ referring to the connections across different levels of social status (Naraya 1999 in Harpham et al 2002: 106-107).

Kawachi et al. argue that social capital may affect health through several different mechanisms. First, social capital may affect the health behaviours by enhancing the diffusion of health information; this will promote the adoption of healthy behaviour norms such as doing physical exercise. Second, social capital may affect health by increasing access to local services and amenities. Finally, social capital may affect the health of individuals via psychosocial processes, by providing affective support and acting as the source of self-esteem and mutual respect. They further argue that health benefits are more likely to happen in a community that is cohesive and in which members know and trust one another (Kawachi, et al. 1999: 1190-1191). In the context of my research, I aim to see in what way the SCG members and SCG as a group are affected by the social capital of their larger social environment.
Chapter 3
Methodology

In this chapter I will discuss the methodological approaches used in this study. It includes the study type, study location, study populations and the sampling, the data collection techniques, the data processing and data analysis, and some ethical considerations. I will also reflect on my position as a researcher during the research process, and the limitations of my methodology.

3.1 Study type

The main focus of this study is to explore the experiences of the PALs, who are members of the SCGs, in order to find out how the functioning of a SCG for PALs affects the self-stigmatization of its members. Therefore, a qualitative approach is used, as Hardon et al argue, ‘qualitative research may produce more insight and in-depth information’ (Hardon et al 2001: 187).

To a certain extent, this is mainly an exploratory study because of the relatively short duration of my study and the fact that this is the first study regarding SCGs in Indonesia. A ‘mini-ethnography’ of two SCGs will be presented, and through the descriptions, the comparative element regarding the influencing factors on self-stigma of the PALs may appear as well.

3.2 Study location, study populations, and sampling

The fieldwork of this study was carried out from the end of May until the end of June 2007, in the Subang district, West Java Province, Indonesia. Specifically, it was conducted in two places where SCGs exist. My study populations were the SCGs, the PALs - in particular the members of two SCGs, the family members of the PALs, the facilitators of the SCGs and the community of those two places where the SCGs exist.

Although I chose to focus on two SCGs in particular, there are, in fact, four running SCGs in the Subang district. They are located in four different sub-districts, which also means in the working areas of four different health centres. Two of the
groups were started in 2000, one group was started in 2003, and the last one was started in late of 2006. The two groups that were started in 2000 were the first SCGs in Indonesia. The group that was started in 2006 doesn't only consist of PALs, but it also has members who are suffering lymphatic-filariasis. Since in this study, I mainly wanted to focus on the PALs, the last SCG was not part of my sampling frame.

Out of the three ‘pure leprosy’ SCGs, the SCGs that became my samples were one of the pioneers, i.e. the group in the working area of the ‘Tambak Dahan Health Centre’, and the one that was started in 2003 in the working area of the ‘Compreng Health Centre’. The samples were not chosen randomly but based on the suggestion from the district leprosy team, for the following reasons: 1) geographically, the locations of those two SCGs are relatively close to one another; 2) according to the local leprosy team, one group [2000] is more successful than the other [2003], in terms of the achievements of the members in reducing their physical impairments and in maintaining the existence of the group. Since my intention was to get some contrasting experiences from the members in different SCGs, I thought that the suggestion was appropriate and very useful, and, therefore I chose those suggested SCGs as my samples.

All ten members of the ‘Tambak Dahan SCG’ became my participants. While studying in the ‘Compreng SCG’, only five out the nine members became my participants. Thus, there were 15 participants in total. Of the four members in the Compreng SCG who did not participate, one member had moved temporarily for work and the others refused to participate. According to the information that I received from the group facilitator who helped me in contacting the members, the reasons why they did not want to participate were that they were embarrassed of their condition and therefore, they did not want to be visited at home.

The characteristics of my participants were as follows: all participants had already been ‘released from treatment’ (RFT), which means that they had completed their medical treatment that was provided by their health care provider; the ratio of male to female participants is 3:2. More specifically, there were six males and four females in the Tambak Dahan SCG and three males and two females in the Compreng SCG. The ages of the participants in the Tambak Dahan SCG were fifty and over, while there was a wider range of age in the Compreng SCG, with the participants ranging in

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4 It was difficult to know the definite age of the members since they usually said ‘around fifty’, ‘around fifty-five’. 21
age from thirty-five to sixty-five. Specifically, seven participants were in their fifties (47%), five members (33%) were over sixty, two members (13%) were in their forties, and only one member was in his thirties (7%). All participants are Moslems. Most participants (73%) had little formal education, i.e. primary school or less, and the rest of the participants had not had any formal schooling. With regard to the occupation, fifty-three percent of the participants do manual labours as (temporary) agricultural labours and drivers, thirteen percent are vendors, and thirty-four percent are unemployed (housewives and retiree). Regarding marital status, thirteen participants are married and two are widowed. All participants have existing physical impairments and or visible symptoms during the study. The detailed characteristics of the participants can be seen in Annex 7.

I selected two participants from the Tambak Dahan SCG and two participants from the Compreng SCG for case studies. In Tambak Dahan, I got the impression, through my first interviews, that all participants have ‘similar experiences’ in the SCG. They started the group together, with the exception of one member who joined the group in 2002 right after she was diagnosed with leprosy, and they all used to have more severe physical impairments from leprosy than they have now. Therefore, I selected one male participant and one female participant. The male participant happened to be my ‘host-family’ in the village. In Compreng, I selected the participants based on their contrasting ‘appearances’ during the first interviews. One seemed to be disappointed about his life, while the others seemed to be more easy-going about his life. Moreover, these two participants allowed me to visit their houses to meet their families. Both of the selected participants were men.

Besides the members of the SCGs, my other resources of information were the local leprosy team, more specifically the district coordinator of the leprosy control (the district wasor), who provided me with some documents regarding the leprosy situation in Subang, and two facilitators of the SCGs, who are also the leprosy health workers in the health centres. Other resources of information were family members - spouses, parents and children - of the SCG members, and the community, more specifically, a village leader of the village of Tambak Dahan SCG, two religious leaders (one of Tambak Dahan/Bojong and one of Compreng), and some common villagers in the village of the Tambak Dahan SCG.
3.3 Data collection techniques

I used several different techniques to gather the data in the field: utilization of the existing documents, in-depth interviews, participant observation, and informal conversations. I was guided by the data collection tools (see Annex 8) during the data collecting. Each data collection technique will be described in detail in this section.

Documents study

A book that contains the background of the establishment of the SCGs in Subang and reports on all the SCGs in Subang, including the basic data of all of the members and their physical (impairments) conditions, before and after joining the SCGs, were valuable resources that I collected from the district wasor. Through this documentation, I could grasp the idea of what had been achieved by the members of SCGs, in particular regarding the progress of their physical conditions.

I was also given some documentation regarding the leprosy epidemiological situations in the district for the past five years by the district wasor. These documents were useful for me to have in order to get a general idea about how big the leprosy problem in this area.

In-depth interviews with the members of the SCGs

To gain a good understanding of the PALs’ perceptions and experiences on their ‘leprosy-affected’ lives and to find out about their experiences in the SCGs, I conducted in-depth interviews with the fifteen members of the SCGs. Some of the variables and themes were: 1) their background information such as current age, education level, religion, and occupation; 2) concerning their leprosy experiences: awareness of the symptoms of leprosy, from whom they sought treatment (health seeking behaviour), what kind of health education that they received from the health workers, their reactions / emotional feelings after being diagnosed as having leprosy, their relationships with family/friends afterwards, experience of ‘leprosy-reactions’, etc; 3) concerning their SCG
membership: their motivations for becoming members, the activities in the SCG, their feelings as members, etc.

Most of my participants from Tambak Dahan SCG were ‘formally’ interviewed once, except for the members whom I selected as ‘case studies’ who were interviewed twice or even thrice. However, I had more than three ‘informal’ interviews / conversations with most of the PALs since I was living in their village during my field work, which made it easy for me to meet them. I just needed to adjust my visiting time with the available time of my participants and all interviews took place at the members’ houses.

The participants in Compreng SCG were ‘formally’ interviewed once and the interviews took place at the health centre. The use of the health centre as the venue to conduct the interviews was based on the preference of the members as communicated to me by the facilitator. Later, I met and talked with them again on the day of the SCG meeting. For the members whom I selected as ‘case studies’ I also made home visits, after I got permission from them, and had one to one-and-a-half hours of interview with them there.

As part of the interviews with all PALs, I cross-checked the information that I got from the ‘SCGs reports’ regarding the participants’ physical (impairments) conditions before they joined the SCGs. I was quite surprised that all the participants could explain every detailed of their physical conditions then, even though they experienced those conditions mostly more than seven years ago.

_In-depth interviews with the family members [of the four participants for case studies]_

My original plan was to interview the family members of the four participants for case studies. It happened as planned on the two participants of Compreng SCG, but not of the two participants in Tambak Dahan SCG. In the Tambak Dahan group, as I mentioned before, I conducted all interviews at my participants’ homes. Whenever I visited them, there were always some family members, such as their spouse, parents, or [adult] children, who accompanied my participants. They all were willing to talk, giving their comments and impressions on the participants’ conditions and behaviours. Some of them openly said to me that they were really pleased to have somebody who wanted to
listen to their stories. So, I ended up interviewing the family members of all ten participants.

I was definitely helped by the presence of the family members, because in many cases, they were the ones who encouraged my participants to be honest and not to be shy with me. In some cases, in particular with the elderly participants, the family members assisted the participants in answering my questions due to the memory difficulties of the participants, and/or language difficulties (some participants do not speak Bahasa Indonesia fluently, thus they mixed it with the local Sundanese or Javanese languages). In some cases, I also found an interesting situation where the participants seemed to hide some ‘real’ information from me, but I just couldn’t probe more. When I finally had a ‘private moment’ with the family members, they came out with the ‘clarifications’ of the stories that I was supposed to hear from the participants. The topics that I asked the family members about were mostly the same as of the PALs such as the awareness of leprosy symptoms, relationships between the PALs with them, etc.

_In-depth interviews with the facilitators of the self-care groups_

I interviewed the facilitators of the two SCGs, to get their perspectives on the SCGs’ members and to find out about their experiences as the facilitators of the groups, as well as their experiences as health workers in general. I was also interested in finding out what efforts and struggles that they had been facing in facilitating the groups. Thus, some of the themes were their capability as leprosy health workers/SCG facilitators, e.g. as a counsellor, as a health educator; their perspectives regarding the activity and the interaction within the SCG, stigma of leprosy in the community, etc.

Both facilitators were also the leprosy health workers in the health centres. The two facilitators were both men in their thirties, and both have educational background in nursing. I interviewed each facilitator once, and the interviews took place at their offices (the health centres). In both cases, they addressed me formally by my professional title [‘Doctor Tiara’], nevertheless, the atmospheres of the interviews were informal and I was sure that they didn’t feel inferior to me. We also exchanged our mobile-phone numbers so that we could call or send SMS to each other whenever they wanted to
share additional information, and we did make phone contacts many times during the
course of my study. I also had many informal conversations with them during the
regular SCG meetings, and during my ‘stays’ at the health centres. Often times, our
conversations were not only about my research focus, but also about many other
aspects of leprosy, such as the medication for patients who caught recurrent leprosy
reaction, etc. I’ve told them before hand that it’s not only me who could ask information
from them, but also the other way around.

Participant observation

During my field-work, I stayed in the village of Tambak Dahan SCG, i.e. Bojong village,
by renting a room in the house of one of my participants. As a ‘villager’, I regularly
interacted with the community in the village and I attended some regular events in the
village, such as the weekly village meetings (minggon desa), the weekly female-prayers
and worships (rotinan). On those two occasions, my original plan was to conduct some
focus groups discussions to find out the villagers’ knowledge about leprosy and SCGs,
and how they treated the PALs in order to find out about the stigma of leprosy in the
community. However, it was difficult for me to conduct a formal group discussion
because the people were eager to see me ‘talking and teaching’ them instead of
discussing the topics together. This made it difficult for me to organize the formal
discussions. I tried twice but it just didn’t work as planned. Therefore, I decided on a
different approach and from then on I just talked with different villagers on an informal
basis, still on the occasions of minggon desa and rotinan. This worked well and they
usually came to me with a lot of interesting information on how they perceive leprosy,
the PALs and the SCG. I also had informal conversations with different villagers in some
small shops in people’s homes that sell basic necessities (warung) when I occasionally
had my meals there or was just buying daily needs there. I also, occasionally, hung out
at my neighbours’ houses in the afternoons and chatted with them. Different topics
emerged in these conversations, and many of them were quite useful for my study, such
as their awareness of leprosy symptoms, their attitudes towards the PALs, their
familiarity with the SCGs, etc. Besides interacting and talking with different villagers, I
also observed the interactions of my participants with their families, with the other
villagers, with the health workers, and with the other participants. I observed my participants’ daily lives, how they took care of themselves, and I also attended the SCG’s regular meeting.

In the village of Compreng SCG, I wasn’t able to do as many activities as I had done in the Bojong village. It would have been ideal if I had also spent some time living in the community, but my situation didn’t allow it. The fact is that the stigma of leprosy in that particular place still exists and that the SCG is not yet well-known by the community. This created many barriers to open communication, therefore, it was not a feasible idea for me to 'become an insider' in the very limited time that I had available. As a result, my research there consisted mostly of half day visits, located mainly in the health centre or sitting in a warung which belonged to one of my participants. Thus, I didn’t have the opportunity to meet with and talk to as many villagers as I did in Bojong. My observations of family interactions were limited to the participants’ that I included in my case studies. However, I did manage to meet a religious leader who lives in this village, and he provided me with some important information regarding the challenging situations related to people’s perceptions on leprosy in his village. During the regular SCG meetings of both groups some themes that I observed were discussions about the members’ skill in doing basic self-care of their physical impairments, the interactions among members and between members and facilitators, the topics of their conversations, the gestures and face expressions of the members, etc.

3.4 Data processing and data analysis

Data collect personally by me. I have a hired research assistant, but his job was only to transcribe the recorded interviews that I had conducted. My research assistant was Yanto, a young man with an undergraduate background in economics. At the moment he works temporarily in the Tambak Dahan health centre as a computer programmer, with the hope that he will be hired on as a permanent civil-servant in the district government of Subang. Before he started doing his work, I explained to him how important the data are to me and how private they were for my participants. He and I agreed that we would always keep the data as our private properties.
I made a weekly working plan to guide me, in order to make sure that I didn’t miss any important work. Sometimes I needed to reschedule some plans due to unexpected matters, such as bad weather, but overall everything went quite well. I digitally recorded all the first interviews which I referred to as the ‘formal ones’ and they were all transcribed by my research assistant during the same week. Every evening, I listened to the interviews that I had done during that day – that had already been transferred from the recorder to my computer. I started my analysis by making notes and remarks and I ‘prepared’ the codes right away. By doing it this way, it gave me the advantage that if I missed something, I could do additional interviews with my participants straightaway, even though the transcripts were still in the process. I made some notes about my observations, including the short videos that I made, and my informal conversations on a daily basis, and I made summaries of these data too. Once I received the transcripts from my research assistant (which usually took three days to one week after I handed the recordings to him, depending on how many interviews needed to be transcribed at the same time), I then sorted the data by theme, coded it into categories, and summarized it in compilation sheets for interpretation. In the presentation of my findings, I made minimal editing and I put the stories in chronological sequence.

3.5 Ethical consideration

I had to deal with different levels of gatekeepers before I could even go to the field. A combination of formal and informal requests for permission was used until I managed to ‘legally’ start up the study. When I was in the field, I openly revealed my status as a student researcher to anyone that I encountered during the course of my research. I openly and honestly discussed the aims of my study with all my participants, including my willingness to come up with some recommendations regarding the developments of SCGs in the future. Regarding the aim of making some recommendations, my participants, in particular those who belong to ‘the successful group’ became enthusiastic about sharing all their experiences.

Taking into account the possibility that my participants were, to a certain extent, vulnerable due to their condition, I was always careful in making contact with them so
that they would not be marginalized due to their participation in my study. I asked them in advance whether they voluntarily wanted to participate and I also told them that they had the right to withdraw from my study at any time. I always asked for verbal informed consent from my participants before conducting any interviews, home visits, or in making any recordings. I also made sure that all information that I received was and will be kept private and confidential. However, the fact remains that, on many occasions, there was a lack of privacy and confidentiality when I conducted the interviews because my participants were always accompanied by some family members or even friends. As a temporary villager, I also did my best to follow the local norms and customs within the community, such as the ‘dress code convention’ that adult women are not supposed to wear shorts in public places, otherwise people might stare at them and perceive them as impolite and the custom that people usually greet each other, verbally or non-verbally by using gestures, in the streets even if they don’t really know each other, etc. However, it was not difficult for me to follow these ‘rules’ since those are the common rules that can be found in many different places in Indonesia, in particular in the rural areas.

3.6 Reflections on my position in the field

While conducting my research, besides being a student researcher, I could not hide my other identity as a medical doctor, particularly a medical doctor who has experience dealing with leprosy. Thus, I could not avoid the situation of having several different roles while I was in the field. As expected, I gained some advantages being known as a leprosy doctor. One example is that some ‘ordinary’ villagers, in informal situations, visited me at my home and consulted me about their ‘skin problem’ to find out whether it was a symptom of leprosy or not. For me, this became a useful source of data for my study regarding people’s awareness of the early symptoms of leprosy, moreover regarding the stigma of leprosy in the community and I was able to gain this insight without conducting any ‘official activity’. On the other hand, when I saw my participants who did not take care of their physical impairments, I sometimes felt the urge to ‘act and teach.’ I needed to control impulses to avoid being patronising or preaching. By doing so, I hoped that my participants would feel respected and they would honestly
explain what their reasons were for not taking care of themselves. Though, at the end, I always ‘intervened’ by asking them what they had learned from the SCG concerning what they were supposed to do to care for their impairments. After that, I motivated them to treat their impairments following what they had learned in the SCG, because for me, as a doctor, it is a moral obligation to do so.

My status as a leprosy doctor gave me advantages during the data generating, in the sense that, I could easily understand the PALs’ explanations when they were describing their leprosy-related experiences such as their leprosy symptoms, their medical treatment, etc. For instance, I could understand when they told me that ‘their feet were tingling’ [due to leprosy reaction], that they felt that ‘their leprosy symptoms became more obvious after taking the leprosy medicine’ [due to the side effect of the leprosy drug], etc. Because of that, I was able to ‘probe’ more in knowing about their perspectives on those experiences.

I was aware that my being a leprosy doctor might influence the way that people in the field presented themselves to me or the way that they acted in my presence, which might affect the findings of my study. However, as mentioned before, I explained to them openly my reasons for being with them, my study objectives and my willingness to make recommendations for the development of successful SCGs. Thus, in my opinion, my being a leprosy doctor did not influence the findings of my study.

In the beginning, because of my status as a medical doctor, I was concerned that my participants might perceive me as their ‘superior’ and that they might react ‘unnaturally’, just to impress me. I managed to avoid this problem and built a rapport with them by trying to be a real ‘insider’ and become a part of their daily lives. One simple way that worked was by letting my participants ask me about my personal life, in the same way they usually ask each other. I went everywhere, mostly without being accompanied by the local health workers, and I always dressed, as I mentioned before, in the way the other villagers did.

As an ordinary human being, I sometimes felt uneasy when I had to deal with the participants who faced problems not directly related to their health, but that were the result of leprosy, such as economic problems. It was not easy for me to hear their stories and even to see the realities without having the ability to offer solutions. On the other hand, I did not want to pretend that I could solve their problems either. Instead, I
could only become a good listener and show my empathy which was appreciated by them.

3.7 Limitations

I am aware that many of my questions to the participants were about their situations in the past, which might affect the recall accuracy. However, since I used the triangulation strategy, I think this effect was minimized. Moreover, it seemed that the experience of suffering from leprosy was an easily ‘remembered event’ for most of all my participants.

As I mentioned before, I could not conduct the same level of activities in my two different study places. The limitation is that the data that I’ve got in the village of Compreng SCG might not be as complete as the data I’ve got in the village of Tambak Dahan SCG. Thus, a complete comparison, particularly regarding the community’s perceptions in relation with leprosy and SCG of those two places, was not possible.
Chapter 4
Suffering from Leprosy: A Long and Lasting Endurance

In this chapter, I would like to describe how the PALs experienced their ‘leprosy-affected life’. I will also describe how the PALs perceived being cured of leprosy (from their viewpoints). The descriptions in this chapter are based on the (retrospective) in-depth interviews with the fifteen PALs who are members of the two SCGs and the (retrospective) in-depth interviews with some family members of the twelve PALs.

5.1 Experience as a PAL

Sulaiman and Salwa from Tambak Dahan SCG and Jamal from Compreng SCG recount their experiences as PALs. Their experiences will serve as illustrations for the analysis of this chapter. Sulaiman was about thirty-eight year-old when he was diagnosed as suffering from leprosy. He consulted a friend who was a PAL, when he had suspected that he was suffering from leprosy, and his friend ‘referred’ him to the health centre.

“It was around [19]95... My feet were tingling, so painful... I could not feel my soles, my fingers became slightly clawed... then I realized that the panu [white skin patches due to fungal infection] had become red and swollen, [the patches were] not itchy. Then I remembered that Irwan [the group leader] had suffered from kusta... and the signs were similar as mine... I went to Irwan’s place and I asked him... I was so afraid... he encouraged me not to be afraid because his condition was worse than mine... Irwan took me to Mr. Marwan [the leprosy health worker of Tambak Dahan health centre until 1998] at the health centre and I was examined by Mr. Marwan... I was not told [upon the diagnosis] what disease I was suffering from, he [the leprosy health worker] told me later on [during the medication]... probably he was afraid that I would feel more ashamed, which was true, I was too shocked, I was not prepared... but I knew it [the disease that he was suffering from] from Irwan, because I was given the drugs that he used to take [during his leprosy medication]... [I was told] hmmm... not to be afraid of infecting my family as long as

5 All names in the case studies are pseudonyms
I take the medication regularly... I was not taught how to take care of my hands and feet...
I was so scared that I would infect other people, my family... I was thinking to get divorced [with my wife] but she rejected... but she was also afraid that I might infect my twin daughters [they were toddlers when Sulaiman was diagnosed], she didn’t allow me to hold my daughters, and I used different plates and glass [at that time they thought that leprosy could be transmitted from a patient to the others by sharing eating utensils]... but my wife has been taking care of me very well, she fed me with nutritious food... she worked hard to earn money for the family when I was sick...
I was so desperate that I couldn’t be cured... but I put my life in God’s hands. Besides the health centre, [I] visited the ustadz [Islamic priest] for advice and [moral] support; [I] tried everything that could support me.
The symptoms [of leprosy] appeared every now and then during the treatment... then I was [declared] cured in around 98... but in 99 it [leprosy] relapsed... It was painful as if I was [touching his elbows] in electric shock... that’s how I felt that it [leprosy] had relapsed again.”

Salwa was about forty year-old when she was diagnosed as suffering from leprosy. She went to seek treatment at the health centre based on her ‘non-PAL’ neighbour’s advice.

“In [19]97, I noticed the red patches; they were spreading all over my body, my face... I thought that I was bitten by insects [even though they were not itchy] while I was working in paddy field, so I just ignored them and kept working... Then I realized that I couldn’t close my eyes properly [demonstrating how her eye-lids were at that time]... I couldn’t feel my feet; I didn’t realize when my sandals were left behind me... I couldn’t feel anything when my chicken was pecking on my feet... I fell from my bicycle once, and I didn’t feel the pain even though there was a wound at my sole, I only realized it when I saw the blood... I was lucky that in a village gathering, a neighbour of mine saw my condition. She told me that I might have suffered from leprosy just like Hajj Ridho [also a member of the SCG]... she told me to go to Tambak Dahan health centre as soon as possible otherwise my toes would become clawed like Ridho’s... she told me to look for Mr. Marwan at the health centre, so I went there with my husband...
Mr. Marwan examined me thoroughly... I was asked to undress... [He examined] my skin, and then he examined my eyes, hands, feet [she was explaining the POD examination, also using her gestures], then he told us [she and her husband] that I was suffering from leprosy... he gave me the drugs, and I took my first day’s drugs right away because he asked me to do so... He told us that my urine would turn red and not to worry about it... that I would be cured as long as I took my medicine everyday... I was told to come to the health centre once a month to get my drugs... he specially told my husband that I wouldn’t infect him or my children...

[However,] my heart was so desperate... I was thinking of people who had lost their fingers and toes... they even lost their legs... could I be cured... oh I was so afraid that I would infect people... and I was so embarrassed... I did not know exactly whether they [the friends] were disgusted by me, by my condition. What I was sure that I was not confident enough to be among them..... What if they reject me, what if I come to them and they avoid me. I did not want it to happen so I just withdrew and stayed home...

I had never missed taking my drugs, I completed my treatment timely, one year... the skin patches were still there for over two years... and they became swollen whenever I was too exhausted working in the paddy field... I told myself oh, it [leprosy] relapsed again…”

Jamal was about twenty-nine year-old when he was diagnosed as suffering from leprosy. He was in an advanced-stage of leprosy when he went to the health centre.

"Six years ago, I noticed the red patches at my arms and chest... I didn’t know exactly when they [the skin patches] appeared... I ignored them... I kept working at the paddy field... I guessed it was two or three months later when I felt this strong pain here [touching his elbows] and my hands became clawed... and the tingling feet too, still I ignored them... [I asked him whether he, then, had thought that he had suffered from leprosy, but he denied it]. I didn’t take care of my self... then I got this wound at the sole of my right foot, it smelled bad... finally I went to Compreng health centre... my father forced me... I was [directly] examined by Mr. Iskandar [the leprosy health worker], and he told me that I had suffered from leprosy... I was too late... I regretted everything and I was hopeless that I could be cured... my wife was not here with me [her wife was, and still is, working in Middle East as Indonesian domestic worker]... I didn’t go to the health centre [regularly]
and Mr. Iskandar had to bring the medicine [to his house] for many times... that was
how I could complete my [12 months] medication... I didn’t take care of my wound...
I stayed in a separate house [that was owned by his cousin who was not using it
temporarily] because my wound smelled really bad... [According to his father whom
I also interviewed, his reason of doing this was to protect his son from other
people’s recognition of Jamal’s obnoxious smell. He didn’t want his son to be
humiliated]... my father took care of me; [he] brought me food everyday... I was
hospitalized once, because my wound had caused me high fever... I was warned by
the doctor that I had almost lost my right foot... [Jamal’s ulcer got healed not long
after the operation, but some small wounds developed every now and then]... My
friends had been avoiding me since I fell sick. From some distance, I could see that
they were busy talking to each other [sighed deeply]... but once I was around them,
they would disappear one by one... it happened more than once... I could never find
a job... I couldn’t earn money for my children [looked desperate]... I have never
been cured... look at me [showing me his clawed hands], they were getting better
sometimes... but how could I be so sure”

Awareness of leprosy and history of treatment-seeking behaviour

Before I started interviewing the PALs (and their families), I was worried that it might
seem harsh (for some people) if I used the term ‘kusta’ (the Indonesian term for
leprosy) directly. My worry was based on a previous study in Indonesia that argued that
some PALs were reluctant to mention kusta openly [as the disease that they suffered
from], as an attempt to avoid the shame of admitting that they suffered a stigmatized
disease (Idawani et al. 2002). Furthermore, I wanted to know how my participants call
the disease that they suffered from. Therefore I usually asked my participants how they
called the disease that they were suffered from. My worry appeared to be not proved
since all my participants openly said that they had suffered from kusta.

Of the fifteen participants, five were diagnosed in the nineteen-eighties, five
were diagnosed in the nineteen-nineties, and five were diagnosed in the two-thousands.
Thus, they were all diagnosed when leprosy service had been integrated in the general
health service. All participants were diagnosed by the leprosy health worker in the
primary health centre [even though there were two participants who did not go straight
there, which I will discuss later]. Eight participants were diagnosed when they were in
their forties, three participants were diagnosed when they were on their sixties, two participants were diagnosed when they were on their thirties, and two participants were diagnosed when they were on their twenties.

All participants remembered the signs and symptoms that they had when they were diagnosed for the first time. However, none of them could say when exactly the onset of the first signs of leprosy appeared. When they were diagnosed, eight participants already developed visible physical impairments such as ulcers of the soles, clawed fingers, and ‘lagophtalmos’ (not able to close the eyelids properly). While the other seven already developed [invisible] physical impairments such as anaesthetic palms/soles and some of them were in the episode of severe leprosy-reactions, which means that they were already at risk of contracting worse impairments.

Regarding their efforts of seeking treatment, a participant admitted that she went to a ‘dukun’ (traditional healer) before she went to the health centre, but since the symptoms got worse she decided to go to the health centre. Three of them – who happened to live in a close neighbourhood – said that they were informed by friends and neighbours that they might be suffering from leprosy, so they sought for help at the health centre ‘immediately’; Sulaiman and Rosinah were encouraged to get treatment from the health centre by another PAL, i.e. Irwan who had previously contracted leprosy, while Salwa was informed by a ‘non-affected’ villager who noticed that she had similar symptoms as what a PAL had. These could be the examples of the awareness of leprosy and the ‘non-existing’ stigma of leprosy in a community.

On the other hand, Eni, a female participant was misinformed by a medical doctor in Kalimantan as having allergic reaction when she was [still] having ‘red patches’ on her skin in 2003 [The doctor’s ignorance of leprosy is quite common, especially in places where leprosy is rare]. She only received a proper treatment two years later, when she came back to Java. She was already in a more advanced condition, with an ulcer at the sole of her right foot when she went to Compreng health centre.

Besides doctor ‘delay’, there was also ‘patient delay’. Jamal admitted that he had noticed the symptom when he felt the ‘tingling’ at his hands and feet, but he just neglected it until he caught severe physical impairments. Eight of the participants could not recognize ‘the white or red patches’ as early signs of leprosy and only sought for help when they caught the painful ‘leprosy reactions’, and one of them [Johan] was
diagnosed in a village survey. None of the participants said ‘denial’ as their reason of delaying for treatment seeking, however, it seemed that ‘denial’ happened in the case of Jamal. I did not find any difference between male and female participants. I did not find any economic reasons as constraints to seek for treatment among my participants, even though some of them were quite poor. An answer that I received from a family member of a PAL might partly be the reason:

“That is our advantage of living in a village; if we don’t have money we could borrow some from our neighbour. We always help each other. I could never imagine being poor and living in a big city where everyone is busy with themselves…” (Ira, 48 year-old, the spouse of Sulaiman).

The fact that all health centres in Subang are relatively easily accessed might have been a reason that no participants had geographical difficulties to seek for treatment.

*Information received upon diagnosis from the health worker*

All fifteen participants said that they were told by the leprosy health worker that they were suffering from leprosy. Though, it was not always informed right upon the diagnosis, as can be seen in the case of Sulaiman. The reason of not communicating the diagnosis openly right in the beginning might be due to the leprosy health worker’s fear of embarrassing the patient even more, as it was also found in the earlier leprosy studies in Indonesia (Billeveld 1982; Idawani et al. 2002).

Sulaiman and Salwa, who were diagnosed in the nineties, were not taught how to take care of their physical impairments even though they had already developed physical impairments then, neither did the other participants who were diagnosed in the eighties and the nineties. I think it was probably because in the eighties and the nineties, leprosy health workers were still focusing on finding and treating as many cases as possible, which was partly influenced by the national priority. Thus, they were not yet prioritizing the POD in general or the importance of a patient’s self-care at that time. Whereas the participants who were diagnosed in the two-thousands were informed how to do daily self-care in order to prevent the impairments from getting worse. Moreover, they were encouraged to join SCG.
“My mother [and me] were told that she was suffering leprosy, she was given a blister-pack of medicine… it was for one month… as I remembered… she was told to take the medicine regularly, and to join the self care group. She was taught how to soak the feet… and to scrub…” (Ningsih, 50 year-old now, a daughter of Ani)

“I was told [by the leprosy health worker] that I was suffering from leprosy… told to take the medicine regularly for one year… also to join SCG” (Eni, 42 year-old when she was diagnosed as having leprosy in 2004)

In general, the PALs said that they were treated kindly by the leprosy health workers, and it encouraged them to follow the treatment at the health centres. According to the PALs they were assured by the leprosy health workers that they would not be infecting their families once they have taken the medicine and that was very important for them.

Reactions after being diagnosed

Despite they were already suspecting that they were suffering from leprosy when they consulted the leprosy health workers about their health condition, all participants thought that being declared as suffering from leprosy was a ‘shocking event’ for them. Four out of fifteen said that they just accepted what had happened to them and put their lives in God’s hands. However, when they were telling me their stories about what had happened in the past, their bodily expressions showed that they were quite worried then. They were sighing and even crying while telling me their stories. Sulaiman, Salwa, Jamal and the other eight participants openly told me that they felt ashamed, worried and depressed. Their reasons of feeling ashamed, worried, and depressed were mostly their fear of infecting the family and relatives and fear of being avoided and humiliated by friends and neighbours because they were perceived to be infectious. These following quotes provide more information on the participants’ emotional feelings

“Hmmm... my feeling was... [Looked hesitant]... people said that it could be transmitted... so I was confused and sad” (Irwan, in his forties when he was diagnosed as having leprosy in the 80s)
“I was so embarrassed, having the ulcers, how could I go to the mosque, I felt that I was not a healthy person…” [looked sad] (Hajj Rahman, in his forties when he was diagnosed as having leprosy in the 80s)

“I was afraid that people would humiliate me” (Rosinah, in her forties when he was diagnosed as having leprosy in the 80s)

“I was so embarrassed... I was worried that people might humiliate me because of my appearance... my reddish patches...” (Sangaji, in his forties when he was diagnosed as having leprosy in the late 90s)

“Then... I thought that I would rather die than being ill and sad...” (Johan, in his twenties when he was diagnosed as having leprosy in the 80s)

“I was so sad, people would avoid me... people said leprosy is infectious... so I was embarrassed that I would infect people” (Eni, 42 year-old when she was diagnosed as having leprosy in 2004)

Besides Jamal, two male participants also said that the reason of their desperation was their fear of not being able to earn a living for their families. As it was mentioned previously that the majority of my participants were manual labours, so it was understandable that their physical limitations due to leprosy would restrict them from working. The condition, then, shocked them since they were the breadwinner of the family.

“Oh... I was so afraid... How could I earn a living for my family that I was sick...” (Soleh, in his forties when he was diagnosed as having leprosy in the 90s)

“I was desperate and worried... how and when could I be cured... I needed to work” (Rohim, in his forties when he was diagnosed as having leprosy in the 90s)

The PALs’ ‘first reactions’ after being diagnosed already show how they had the fear of being stigmatized due to their illness. They worried that people might humiliate them due to their appearances, e.g. reddish skin-patches, ulcers. They even perceived
themselves as ‘infectious’ and that was why they felt ashamed and even depressed. They were not sure that they could be cured, and that has sometimes led them into hopelessness. They started to stigmatize themselves.

What they did afterwards would explain further how self-stigma of leprosy affected their lives. All participants said that they reduced their routine activities after being diagnosed. Nine of the fifteen PALs, no big difference between male and female participants (five males and four females), withdrew from their routines and had preferred to stay home. They were afraid that people might avoid them and that would embarrass them. To add to that, those nine members were also ashamed of their appearances after taking their drugs, in which their patches had become more obvious, because of the effect of leprosy drug. Six of them (five males and one female) said that they just did not feel healthy enough to do their daily routine, they perceived themselves as sick people and they were afraid that people would not be happy to have them around, thus they just withdrew. A participant who is a Hajj said that he felt embarrassed to go the mosque because he was having an ulcer at his sole. However, four male PALs said that they kept working every now and then, because they needed to earn a living.

Regarding their willingness to follow the medication, all fifteen PALs except one, i.e. Jamal who was feeling hopeless and worthless, said that they had put all efforts to follow the medication so they would not be a source of disease. They followed the medication with a hope that they would be cured. Sulaiman and Eni had also used religious activities as a source of support, in particular the emotional support, to deal with the situation:

“I went to the weekly female prayers every now and then... just for silaturahmi [meeting each other with an aim to support each other] with the other muslimah [female Muslims]... I needed it, a religious support... but I covered my ulcer with bandage if I went there, otherwise I would feel embarrassed” (Eni, 42 year-old when she was diagnosed as having leprosy in 2004)

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6 One adverse effect of ‘Lamprene’ or ‘Clofazimine’ (one component in the MDT package) is discolouration of skin, in which in most patients the colour of the skin patches may become reddish-black, and thus more recognizable.
What I had been describing here shows how the PALs have been stigmatizing themselves. They did that because they were aware that the society might be having the bad notions of leprosy, which the PALs might have shared before they contracted the disease themselves (Bijleveld 1982). Self-stigma had made the PALs retreat themselves from certain social relationships such as meeting with friends or participating religious activity. It could be a way to protect them from experiencing the enacted stigma, a way of anticipating. Then, how were the realities that the PALs had experienced, in terms of their relationships with family, friends, and the community? How did their social environment treat them? In this following section I will discuss how the PALs had experienced the stigma in reality.

*Experience of enacted stigma*

Despite the PALs’ fear of negative attitudes and conducts towards them by their social environment that had led them into self-stigmatization, I could hardly find any experience of enacted stigma among my participants. In general, all PALs received total support from their family and spouses. Though, there were some ‘domestic isolations’ appeared in the narrated experiences of Sulaiman and Jamal. However, by taking into consideration their families’ reasons of taking such actions, I would still say that none of the participants were stigmatized by their own families.

I will continue with the bigger societal environment that includes friends and relatives. I found different experiences among my participants in the two SCGs. None of the ten participants from Tambak Dahan had experienced enacted stigma from friends and relatives. The following story of Sangaji shows the situation. Sangaji was on his early forties when he was diagnosed as suffering from leprosy. He had been earning his living as a vendor, but after he felt sick he mostly preferred to stay home.

"My skin patches turned reddish-black after I had taken my [leprosy drugs]... I was afraid that my friend would humiliate me due to my appearance... I had preferred to stay home but I needed to earn a living, and it was a harvest season of the paddy rice. It was a good chance to earn money... I prepared some *es mambo* [local ice cream]... I tried my luck... I was nervous when I went to the paddy field... Most of
the people in the field were my friends and they knew that I was suffering from leprosy... But, my ice was sold out... They [his friends] were not afraid of me.”

On the other hand, three of the five participants from Compreng had experienced enacted stigma from friends and relatives. Jamal and Tauhid had been so hurt and offended by the stigmatizing behaviour, that they both were emotional during the interviews.

“"My neighbours had been making stories about me... [crying]... they didn't even want to shake hands with me anymore... they said that I was contagious... They used to look up to me…” (Tauhid, about sixty year-old when he was diagnosed as having leprosy, in 2002)

It might have been intertwined with the enacted stigma by the friends and relatives that the same two participants had also been experiencing enacted stigma by the community.

"I was almost fired by the village leader... I was as an Islamic-guru [which was appointed by the village leader instead of working as a formal government employee]... my task was to serve the [Islamic] wedding and funeral ceremony... they [the villagers] said that I might infect my clients [crying]... [Luckily] the village leader consulted the health centre, and he didn't fire me... but I had lost my dignity” (Tauhid).

The preceding section shows that suffering from leprosy had not been an easy experience for all the PALs. There are challenges in terms of the medical aspect of the disease, starting with the [relatively simple] matters such as the lengthy period of taking the medicine and the discolouration of skin and urine as the adverse effects of the drugs. The more serious problem is the possibility of getting the (severe) leprosy reactions, with a risk of developing permanent physical impairments. Nevertheless, the medical aspect is not a solitary matter; there are also social consequences that had to be dealt with by the sufferers, as what had been described here. Both aspects are intertwined; the [medical] symptom may cause the social consequences, for instance the physical impairments due to nerves damage and the perceived infectiousness of
leprosy are partly the cause of stigma. On the other hand, social matter may cause the medical problem, for instance self-stigma that causes the feelings of hopelessness may de-motive the PALs in taking care of their sickness.

5.2 Perceptions of being cured: feelings of uncertainty

When a PAL has completed their medical treatment, i.e. the complete course of MDT, he would be declared cured by the health care provider, regardless that the PAL has permanent impairments. Furthermore, a PAL is still at risks of getting the episodes of leprosy reaction, which is related to the complex immunological/biomedical phenomenon of leprosy. In a simple way, it can be said that ‘the more severe or advanced stage of leprosy when one starts one’s leprosy treatment, the more likely that one would experience the episodes of leprosy reaction even long after one has completed one’s medical treatment.’

During the in-depth interviews with the PALs and their families, I found out that the two medical aspects – the persisting permanent physical impairments and the experiences of leprosy reactions after completing a course of treatment – are the sources of uncertainties among them regarding their status as being cured. All PALs perceive being cured as not having the leprosy signs. Furthermore, suffering from leprosy reactions after completing the course of treatment is perceived as ‘kumat’ or ‘kambuh’ – two Indonesian terms which literally mean relapse. Narrated experiences of Sulaiman, Salwa and Jamal show their uncertain feeling of their status as ‘cured.’ The following quotes from some other participants show their uncertain feelings too:

“I was cured... but sometimes it [leprosy] relapsed... my knees were painful, my feet became week... so I asked Mr. Marwan [the ex-leprosy health worker of Tambak Dahan health centre] to examine me at my house, he told me that it was a leprosy reaction... hmmm... so I got it [leprosy] again...” (Irwan, in his forties when he was diagnosed as having leprosy in the 80s)

“If the ulcers are healed... that means I’m cured... so then [after completing the treatment course] I think I was not yet cured [because the ulcers remained]” (Rahman, in his forties when he was diagnosed as having leprosy in the 80s)
“I was not sure [of being cured], hmmm... I still had the tingling feet... after [completing] the medicine it was still the same... it [the symptom] came every now and then...” (Rosinah, in her forties when he was diagnosed as having leprosy in the 80s)

“[The impaired hand] was sometimes still swollen, doctor.... Even though I have taken all the drugs... it came again... relapsed” (Soleh, in his forties when he was diagnosed as having leprosy in the 90s)

“Well... okay... taking the medicine, and they [the health workers] said that I was cured... but how could it be... what about the persisting ulcer...” [Showing the expression of confusion] (Johan, in his twenties when he was diagnosed as having leprosy in the 80s)
Chapter 5
Self-care Group: A Hope of a New Change

As mentioned before, the concept of SCG is implemented in Indonesia by taking into consideration that there are still many PALs including the ones who had finished their medical treatment, that are still facing the consequences of leprosy such as the persisting physical impairments due to permanent nerve damage. A self-care group is defined as a group of PALs, when still on or after finishing medical treatment, who come together with the aim of supporting one another in finding solutions for problems they face due to leprosy, primarily in prevention and reduction of disabilities. In other words, the aim of this activity is to empower the PALs to do daily self-care at home and to develop responsibility for their wellbeing in the individual level. Furthermore, SCG is aimed to enable the members of SCG in supporting one another in finding solutions for their physical, social, or economic problems due to leprosy, as a group. The main principle of a SCG is that its members play the most important role in the prevention of disabilities. The members are supposed to practice daily self-care at home by using local materials such as water and salt/soap for soaking the insensitive hands and feet instead of antiseptic liquid; and clean clothes to cover simple uninfected wounds instead of white bandages that are covered with antibiotics. The members may use the group meetings to control their improvements and to exchange experiences.

In the following paragraph, I would first describe the process of setting up a SCG in Indonesia, the implementation of the group including the organizational issues within the group, and the expectations of the leprosy control programme towards the groups within a certain period of time (Main source: Ministry of Health 2006b). After that, I will describe the findings of my study regarding how the two SCGs in Subang district work in reality and how their members and other people who are involved in the groups, i.e. the facilitators, experience being in those groups.

The national leprosy control programme provides a certain amount of budget as a standard package to start up a SCG that will be distributed through the provincial health service. Principally, the package for one SCG from the central level is limited for one year. This budget is used to provide a group with the self-care kit, transportation
fare for members or the snacks costs for the meetings, transportation fare for facilitator, etc. It is hoped that after a year, SCGs that want to continue their existence would try to find other sources of funding. The provincial health service will include a number of SCGs in their annual budget, and they will consult the potential district health services where SCG maybe be started. Potential districts mean that there are motivated staffs who are supported by the local health services and that there is a high burden of PALs with disability. The district health service through the district wasor, who knows their local leprosy situation, will contact the health centres, and together they will discuss the possibility of starting up a SCG. Then, the leprosy health worker will start contacting the PALs, especially the PALs who have developed physical impairments, as the potential members of the SCG. A first meeting will be held to introduce the concept to the PALs, and it is crucial that the PALs are informed about the aims of SCG in the first meeting. Though, the aims of SCG need to be explained over and over again.

Once a SCG is started, the leprosy health worker [or somebody who volunteers] is the one who is involved regularly in the group, while the district wasor acts as the motivator and supervisor. In the group, the leprosy health worker acts as the facilitator and the group members by consensus will choose one member to become their group leader. The tasks of the facilitator are to attend the group meeting [as long as the group needs him/her], to select the group members, to introduce the aims of SCG to the members, to teach the members how to do self-care, to motivate and to lead the group discussion (in the beginning), to guide the group leader to become acquainted to his/her task, and to monitor and to evaluate the group. In the beginning, the group leader’s tasks are usually more ‘spiritual’ by for instance encouraging the members to participate actively in the group activities and to practice daily self-care at home. Ideally, later on the group leader will take over the tasks of the facilitator, in order to lead the group independently from facilitator and health centre. Thus, the group leader needs to be trained and guided by the leprosy health worker to become used to his/her tasks. In general, this is done by ‘on-the job training’ and there is not always a special training.

The venue of the meeting is decided by the group members and also the frequency of the group meeting. It needs to be central for everybody, and not too far and difficult to reach. It should be large enough to sit comfortable in a circle with space in the middle for each member in turn to sit for demonstration, as well as for everybody
to soak his/her feet. Furthermore, it needs to have water supply and members should feel comfortable, relaxed and free to speak. Ideally, the venue for the meeting should be in the members’ own environment.

The main activity in a group meeting is to demonstrate and practice basic self-care i.e. the method of soaking hands and feet for about 20 minutes in soap or salt water, rubbing off thick parts of the skin, and then oiling the wet skin. This should be daily practiced by everyone with insensitive hands and feet, dryness of the skin, wounds, and other impairments due to nerve damage. By doing so, more advanced secondary impairments such as deep and infected ulcers may be prevented. It is hoped that practicing together may increase the group feeling, and also that practising together gives an opportunity to check if all members do the exercise correctly. Apart from the basic self-care, some members will need to do exercises for their hands, feet or eyes, depending on their individual impairments (e.g. a paralysed drop foot needs different exercises than a slightly weak drop foot). Every member, who has learned his/her exercises already in a former meeting, then will take an opportunity to demonstrate it. In this way, members will be examined, in the sense that the facilitator, the group leader, and the other members will do the ‘inspection’. When there are new signs and symptoms of leprosy, the facilitator and the group leader will do further examination. A simple recording system is used in SCG, in which there is an examination book for every member. The book contains the ‘physical impairments’ data of the members. Progress and failures of the members’ physical impairments will be recorded in the books by the facilitator in the beginning and preferably by the group leader later on. The members will discuss whether exercises are carried out correctly or what could be improved by exchanging experiences and encouraging one another.

Furthermore, during the SCG meetings the members would be informed on how to protect their impaired hands and feet during daily activities, such as by wearing proper footwear to protect the insensitive feet, etc. It is also important that through the group, the facilitator may identify members who need specialized treatment such as with deep ulcers or severe leprosy reactions who need to be referred. In other words, a PAL, in particular the one that has been RFT, is relatively within the reach of health care providers by becoming a member of SCG, and this condition might be useful if a complication of leprosy occurs.
Besides these main activities other activities of the SCG such as income generating programme and saving groups (‘arisan’) can be considered. However, in general there is no budget from the leprosy control program for these kinds of activities. Therefore the SCGs, with the help of the local health provider, needs to search for the resources independently.

In the following two sections I will describe the reality in the two SCGs respectively Tambak Dahan SCG and Compreng SCG. The descriptions are based on the in-depth interviews with the fifteen members of the two SCGs, the two facilitators, and some family members of the twelve members; the informal conversations with a village leader, two religious leaders, and some villagers; and my observations during the SCGs meetings and during ‘my stay’ with the SCGs members.

6.1 Tambak Dahan: the power of being together

Bojong Keding and Bojonegara are two villages that are so close to one another, that people commonly refer to them as Bojong village. They are in the working area of Tambak Dahan health centre and are located approximately three kilometres from the health centre and also from the main road to the district capital. In these two green villages that are surrounded by paddy fields and mango plantations, members of the Tambak Dahan SCG, i.e. the PALs, live side by side with other villagers. The SCG was started in 2000 by the Tambak Dahan health centre, and Salwa and Sulaiman, who became members of the SCG in the beginning of the group, recount their experiences in the following stories. Their experiences serve as illustrations for the analysis in this section.

When Salwa was offered to join the SCG, she was suffering from leprosy reaction that happened one year after she had been declared RFT in 1999, and she had developed lagophtalmus and insensitive feet. She is about 50 year-old now.

“I joined the SCG because I wanted to be cured, to be healthy, just like normal people... [At the group meeting] I was given these pictures that have the instructions on how to take care of my feet, soaking them in the water for 30 minutes, 40 minutes, scraping the dead skin using the stone when the skin had become soft, getting thinner day by day, rubbing them with oil..., three times a day,
everyday... Then my eyes, when I went to bed, I covered them with a piece of clean cloth, first I made the cloth wet, then I covered my eyes. During the day, I exercised the eyes twenty times each exercise [demonstrating the exercise by closing the eyes and stretching the tip of the eyes], three times a day. I had never stopped exercising...

Every second-Thursday of the month we met together, for seven years we've been doing this... In the beginning we met in the health post but then, I could not remember when exactly, we moved to the village hall... Oh, the meeting was always really fun. We had been always asking each other how we had been practicing the exercise back home... there [in the meeting] we soaked, scraped, and oiled together, we also demonstrated our achievements... I really enjoyed all the meetings... I think all of us [the members] did... we chatted together while soaking our feet... we ate some snacks together... we became very close to one another, just like a family, and also with Mr. Amran [mentioning the facilitator’s name]... we were sometimes visited by the doctors, from the health centre, from Subang, from Bandung, [mentioning all the doctors’ names], they all were so kind, they kept on motivating us.... Our neighbours [the ‘villagers’] sometimes watched our meeting and they were fine.

I felt the improvement; my eyes... my feet... I felt happy because of that... but it did not happen immediately, I needed to follow the guide that was given in the group... I think it was almost a year when I really felt that I was back to normal... I could close my eyes properly... well the feet were still not back to normal... but they were much better, no more cracks, no more ‘sandals left behind’ and no more ‘chicken pecking on them’... Ooh, how could I not be so grateful to my group...? I felt more confident now and my heart is so happy that I did not become totally impaired and losing my toes... I could still remember how I used to stay at home, avoiding my friends and feeling so sad... I was embarrassed then, I was afraid that I would become a cripple...

After I felt better I went out to the paddy field again during the harvest season and the planting season to earn some money... I didn't feel embarrassed whenever my friends picked me up; I have always joined them. However doctor, I could feel that I was not that strong anymore to work in paddy field.... I sometimes worried about my insensitive feet when I was in paddy field, but I needed to earn money, so just be careful... [During my field work, she had just finished working at the paddy fields during the harvest season]. Last year, doctor Ahmad [the national leprosy consultant for West Java] offered us some working capital... at the beginning he suggested us
[the female members] to join a sewing course, but we had told him that we would not be able to learn, it would take time to learn such skill... [Finally,] all of us [the ten members] decided to start goat farming. Each of us received two goats, and the agreement was that we would have to return two goats after two years [during the fieldwork, she already has thirteen goats]. I may sell the goats in the future, they are still small now, [and their price is] still cheap; I still have two sons that need to continue their education [during my fieldwork, the sons are still in junior high school]...

Our group was invited once by the regent [in a ceremony at the regent’s office]. Irwan the group leader, my self and Sulaiman went there on behalf of our group, so I've met and shaken hands with him [looked proud and happy]. It was amazing that an important person like him wanted to meet with us....

We [the members] were asked once by our doctor at the health centre whether we wanted to stop or to continue our group, and we all said continue!!”

Sulaiman had suffered from several episodes of leprosy reaction, and the last one happened after he had been declared RFT in 1997. He had developed insensitive feet and hands and slight clawed fingers, when he was asked to join the group. He is about 50 year-old now

“My friend [Irwan, the group leader] encouraged me to join the group, I was not sure at the beginning, I was still feeling not so well and uncertain of my health condition, but I told my self ‘just give it a try... I might be cured, it [leprosy] will not relapse anymore’... so my motivation [to join the group] was nothing else but hoping to be cured... to be healthy...

We met once a month on the second-Thursday, we soaked our hands and feet, for half-an-hour, together, scraped and oiled the hands and feet using coconut oil while they were still wet [demonstrating the gestures]... we asked each other about our health condition, also about our lives in general... we had been always watching the progress of our [physical] conditions, exchanging experiences... We would find out if someone had not been practising the self-care at home, we had been always asking what the problems were; we tried to help and encourage one another...

I felt happy being in the group, especially when I could see that my feet and my [clawed] fingers were getting better and better [showing me his slight-straight fingers]... I felt that I’ve cured my self!!!
Besides meeting with friends, I could also meet with the health workers, the nurses, the doctors... we had been very supported by every one of them... Mr. Amran had always been our motivator, we [the members] all have close relationships with him, and for me personally, he's like a family to me. I was still feeling uncertain every now and then at the first year, but Mr. Amran would always listen to my complaints and he has been helping me with his attention and advises. The people here in our village had been also very open and kind to us. We had our meeting in the village hall without any complaints from them [the villagers]... and the ten of us [the members] had made a deal that we would always support each other, we had been living in the same place anyway, [so it would be] easy to meet each other...

After I felt better I accepted the task as the treasurer of our village's mosque committee that I did not feel embarrassed anymore...

I was not always in my best condition, I felt really sick in 2003 after the wedding of my eldest daughter, but at that time I knew that it wasn't kusta... I was sure because I kept taking care my hands and feet and I could see that there were not any swollen reddish patches then, I was just too exhausted. I felt more confident in recognizing my health condition, it was a big bless for me.... As you could see doctor, that I have been busy with goats [the project that Salwa has mentioned], that is my main activity in day time [during my fieldwork one of his nanny goats gave birth to a kid, and he has seventeen goats then]... I did not expect to receive the goats when I joined the group, I just wanted to be healthy; they were an unexpected blessing that I got of being in my group

Besides the goats, I also look after my first grandson [the toddler grandson stays with his grandparents in the village while his parents live and work in Jakarta]; I am sure and happy that I will not infect him [with leprosy].”

**SCG: reason, motivation, and expectation**

Salwa, Sulaiman and all their other friends joined the SCG because they were hoping to be cured, regardless the fact that all of them except Ani had completed their treatment course. What they meant of hoping to be cured, as previously mentioned, is not to have visible signs and symptoms of leprosy such as suffering from leprosy reactions and having wounds and other physical impairments. They want to be healthy and 'normal'. Despite in the beginning most of them were not sure of what a SCG exactly was,
Sulaiman and his five other colleagues said that they just gave it a try with a hope that SCG might help them to be back to normal.

Besides the facilitator’s invitation, there was a role of Irwan (the group leader) as a reason of some members to join the SCG. Three of them said that they were encouraged by Irwan to join the SCG. Irwan was their source of motivation and information, because he was the one among them who had suffered from leprosy before the others, and he was the one who ‘referred’ some of his friends to seek for leprosy treatment.

Besides the hope of being healthy, the location of the meeting was one reason for the members to join the SCG. Fifty per-cent of the members (three males and 2 females) said that having the meeting in their own village had made them willing to join the group that they did not have to travel to reach the place. I think this reason was also supported by the fact that they had not been experiencing enacted-stigma in their community. On the contrary, in places where PALs are facing enacted stigma in their community, they would prefer to travel instead of having the meeting at their own place in an attempt to avoid friends/relatives’ recognitions and discriminations, as what I also found in this study in Compreng SCG which I will discuss later.

The process: activity, relationships, support from inside and outside

The experiences of Salwa and Sulaiman, that were supported by the other members’ experiences too, describe the philosophy of self-care/help groups in which people who share the same problem come together to support and help one another in trying to overcome their common problems. Furthermore, the concept of ‘peers as role models’ was also happening in this SCG, in which a strong personal motivation of one member might influence the other’s motivation, as Sangaji, 50 year-old now, states

I had been admiring Salwa’s great diligence in taking care of her impairments. She could hardly close her eyes when we started the group... and there were many cracks and wounds at her soles which were horrible... but she had never stopped exercising until they were all back to normal... [by looking at her hard work] I was encouraged not to neglect my insensitive palms; I sometimes did not protect them
when I worked in the yard [sweeping the leaves, making fires] nor soaking and cleaning them regularly

From the members’ stories and from what I have witnessed in terms of their physical impairments, I was convinced that all this time the group had been practising the principle of self-care activity regularly and in a proper way. All members seemed to be very committed to the aims of the group, and they seemed to enjoy their togetherness. The relationships among themselves seem to be strong, which is not surprising since they have been together in the group for seven years. Furthermore, according to them, they also have good relationship with their facilitator, i.e. the leprosy health worker. He had been a good motivator to them, and none of the members felt that he or she was being left behind.

Before discussing the process that took place until the group was established as they are now, the facilitator of this group recounts his experience. Amran had become the leprosy health worker of Tambak Dahan health centre about two years before they started the SCG. Recently, his other task at the health centre is the head of the emergency ward and he is also the co-wasor at district level. His experience provides more illustrations for further analysis of this section.

"I had become the facilitator [of Tambak Dahan SCG] since the time when the group started in 2000. I was trained how to facilitate the group, together with the group leader. [I was trained] how to do the 'POD' examination [this was the second time for him to be trained regarding POD] and we had role plays... the trainer was from the province [mentioning the name of the doctor who, then, had just visited and learned from ALERT, Ethiopia regarding SCG]...
The training subjects were regarding the concept of SCG, the aims, and the advantages that can be achieved through SCG, the activities that should be regularly done such as the basic soaking, scraping, oiling together, etc. that members of SCG would be the main actors and led by a group leader.
From the beginning, I as a [leprosy] health worker and a group facilitator have been told that in SCG, we would not only treat the physical aspect of the members, but also we needed to pay attention, and if possible do something, about the psychosocial aspects which usually were affected even worse...
We [a team from Tambak Dahan health centre that was often led by the doctor] had been always approaching the community of different villages in our working area; we gave them information regarding leprosy over and over again: the early symptoms, how it can be transmitted, etc... We did that because we wanted to increase their awareness of leprosy and to make sure that [enacted] stigma would disappear...

Before we started the SCG, we had socialized the SCG programme to the villagers; we tried to prepare the community so they would not see SCG and its member as 'alien'... Actually, we had introduced the SCG concept in all [five] villages of our working area, not only in the two villages where the SCG exists now, and I was quite sure that they were all quite accepting the idea. In the beginning when I invited all candidates, a PAL from village X and a PAL from village Y [two other villages] seemed to be interested in joining the group, but due to long distance they withdrew from the beginning... only those two villages [in our working area] that are very close to one another, they were just like two hamlets, so it was easy for us to coordinate a group of the PALs from those two villages...

I could see that in the first year, even though I had been explaining the aims of SCG and we had been doing the activity for quite a while, some members were still not so sure how they would benefit from the group, some of them were afraid that the group was just an undercover of a political campaign and they would be asked to give money in return... so it was not a quick process doctor... This group was also helped by the fact that the members had been knowing one another before the group was started and that the group leader had been able to encourage every member in maintaining the 'quality' of the group... But still, in the beginning some members were still shy, and needed extra encouragement.

As I told you before doctor, it wasn't a quick process that we could be like we are now. Some members were just quiet in the meetings, I thought that then, they had not felt 'the change' and of course that was also probably their personality... and also old-aged members were more difficult in following the 'self-care routines' so I needed to give extra attention to them [mentioning two members’ names]... But I could see that as time passed by, these quiet members started to enjoy being in the group, a new 'family' has been produced... they have been always encouraging each other.

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7 After the national economic crisis that had resulted the fall of Soeharto’s regime in 1998, many new political parties were formed during the transition era, in which many of them were not qualified.
I had my own advantages also as the facilitator, personally and professionally... I [personally] felt happy being able to do *silaturahmi* [meeting each other with an aim to support each other] with the members regularly once a month, more than that being able to meet their families and other villagers as well... we became like family... [looked happy]. [Professionally] I could easily detect members who were suffering from leprosy reactions, during the meeting, and since we had been meeting each other regularly, I could be sure that the symptoms [of leprosy reaction] had just appeared... [in some meetings] some villagers were not hesitant to come and consulting their ‘suspicious patches’... [However] I also had faced some difficulties sometimes [in time management], for instance when I have so many tasks to do at the same time. [Though] I still have been always trying as much as possible to stick with the schedule of the meeting; it’s a commitment that we [he and the members] had made together... I agreed that the members are the main actors, and that they have their group leader, and I am proud to see that our group is quite successful; that the members in general have shown good results in terms of their techniques and willingness in practising daily self-care, and also their improved self-confidence and self-esteem... [However,] I think that we [the health worker] had better not leave them alone... we still need to motivate and to encourage them... They still need our attention every now and then.”

From the facilitator’s explanation, it can be said that this SCG was not established without preparation. The decision to start up this SCG at one place was based on careful calculations. Firstly, the health centre, as a full team, has been providing the communities with information regarding leprosy, which had resulted in no enacted stigma in the community, a long time before the SCG concept was started. Furthermore, they had introduced the concept of SCG to their communities, and that has made the community aware about the activity that was going to be implemented in their area. These circumstances in a community might be conducive for a SCG to develop, in which the members would feel comfortable to be in the group because they would feel that their group is accepted by the community. Secondly, geographical feasibility, i.e. focusing on a group of PALs who live close to one another, has been considered also. There are several advantages to this consideration. First, facilitator and group leader can

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8 It is very crucial to detect and treat a person who suffer from severe leprosy reaction immediately because then, the inflamed nerves can still be treated, thus preventing the nerves damage.
do their tasks, i.e. visiting the members, relatively easily because the members live in the same area. Second, the PALs have known each other quite well and they have shared common norms by living in the same community. This situation might increase the possibility of the members’ homogeneity, which is an important variable of a group to succeed (Adamsen 2002). Thirdly, the facilitator and the group leader were well prepared because they were trained before taking their responsibility. Besides that, their personal commitments in doing their tasks were also of vital importance. In my opinion which is based on the members’ acknowledgement, strong and continuing personal commitments of the facilitator and the group leader in encouraging them have created trust of the members toward them, and the trust creates a feeling of attachment by the members to the group.

As described in the illustrations, it took quite a while for this group to become as they are now. Similar reasons, motivations and hopes of joining the group, as previously mentioned, have gathered the PALs to form a group. However, in the beginning, some members were still uncertain whether the SCG could benefit them; e.g. Rahman and Ani found it difficult to do the self-care alone at home, which they thought was due to their advanced-age. However, all members said that they were continuously encouraged by each other and also by the facilitator, and that was how they gradually became connected to the group, and also to a routine ‘home based self-care’. Furthermore their family members were very supportive. All members said that they had never been discouraged to participate in SCG by their family members. On the contrary, family members including their [young] children had been encouraging them, as what Rohim, about 55 year-old now, experienced:

“One day before our group meeting, Irwan usually came to my house and remind me to attend the meeting. When he visited me, we would usually talk about our friends who needed more encouragement. I didn’t realize that my daughter had been noticing this [started smiling]... one [meeting] day I went to paddy field and thinking of being absent from that day meeting... suddenly I saw my daughter [at that time she had just finished primary school] approaching me while crying, and she said ‘father... why are you here, you are supposed to be with your group now, don’t you feel sorry for your friends that need your help?’... I was really touched and encouraged by my daughter’s concern.”
Besides acceptance by the community, the SCG and its members are also appreciated by them. In my conversations with some villagers, some positive comments on the SCG members came out:

"The members give a good example [to me] of not being hopeless.... They also made me aware of leprosy... better check [your skin patches] than being not sure and late..." (Dede 23 years, bachelor graduate)

"They [the members] have been gathering here [at the village hall] for how many years I can not remember. They were all hard workers: soaking together, etc... I enjoy talking with them... last year they received some goats, aren't they lucky... they are blessed because of their patience...” (Amir, 40s, the village hall keeper)

"Our village has many leprosy patients, but we have been told over and over again [by the leprosy health worker and the village midwife] that leprosy is not so infectious... so don't be afraid... now we have this group [SCG] in our village, they [SCG members] show us [the villagers] that leprosy does not stop them from living a common life...” (Laila, 34 years, house wife)

The group’s efforts in maintaining their unity and in taking care of their physical impairments have led the way for them to receive extra support from the 'outside'. Their one step achievement has produced a 'reward', in which all members have received two goats as their working capital [see Salwa’s story]. According to all members, the working capital has made them feel more attached to their group, and they appreciate their togetherness even more. Furthermore, the working capital has added more meaning to the members’ experience of being in the SCG, as what I will discuss in the following sub section.

The change: physical results, personal feelings, daily lives

Leprosy is notoriously known as causing severe permanent impairments such as clawed hands, ulcers, and mutilations of fingers and toes, which may create fear and disgust. What is not really known is that the severe impairments may be prevented from getting worse, that they may be reduced, and that they are not the source of germs. As
previously mentioned, those severe impairments occur as secondary consequences of untreated nerve damage that causes insensitive hands and feet and weakness or paralysis of muscles. Thus, a regular daily self-care is the main way to prevent the permanent impairments of getting worse or to reduce them. This message was heard over and over by the SCG members, and they have been practising the method which proved to give good results.

The fact that the members have been able to control their impairments has increased their self-confidence and self-esteem. All members said that they feel happy and confident that they could reduce their impairments. Despite the persisting impairments that the members have now, they perceive those impairments differently. They are convinced that they will not become a source of infection anymore. They became more aware not only of their vulnerability of getting wounds, but also on how to prevent them. Being aware of their ability to support one another in the group has restored their dignity. Furthermore, the SCG members do not experience enacted stigma in their community, and thus this situation enhance their confidence to participate in their community. For example, Sulaiman, Irwan, Rahman and Soleh participate actively in religious activities now, whereas before they had avoided these activities when they were ‘sick’ due to feeling of shame.

Working capital, i.e. the goats, that was loaned to the members may help the members to have a secure way of earning a living. Most members’ occupation is mainly [temporary] agricultural labour who works in paddy field. Furthermore, when I asked those particular members how they had been protecting their hands and feet while working in paddy field, none of them said that they protected their hands and feet properly. Their reasons were: rubber boots are too heavy to be worn in paddy field that they might be stuck in the mud and hand gloves would make them work inconveniently. Thus, they had only been using the conventional method of checking their hands and feet every now and then while they were in the paddy field, besides the regular home-based-self-care. These members have been thinking to stop working in paddy field because they also have thought about the risk. However, it will take some time before they can earn money from the goats.
The meeting: Tambak Dahan SCG in reality

It was on Wednesday afternoon, one day before the meeting day, when the group leader visited me at my host-parents’ house. He came to invite me to their group meeting that would be held the next day at nine o’clock in the morning, at the village hall of Bojonegara. According to him, they had always preferred to meet in the morning, so afterwards they could do their other activities. He also ‘reported’ to me that he had contacted all his members, and that one member, Rosinah, would not be able to attend the meeting because her husband was not feeling well and she had to look after him.

My host-parents’ house is just approximately fifty metres a way from the village office and hall, and I was having my breakfast at around eight when I saw two SCG members passing in front of my house, walking to the village hall. Then, I could hear our next-door neighbour calling them to stop by at her house, because it was too early for them to go to the village hall. I observed the situation from my house, in which I could also listen to some parts of their conversation. I saw my neighbour preparing some tea and fried cassava, then my host father and his grand-son went there and joined them, and also three other ‘common’ villagers joined them later on. They chatted about the up-coming rice-planting season, and other kinds of daily-lives topic. I was not surprised but still impressed by the situation in the village in terms of how PALs and other villagers live side by side without any discrimination against the PALs.

Amran the facilitator arrived on time and so did the other members, and the meeting was about to start. Nine basins had been filled with water by the male members, and the other self-care kit such as stone, coconut oil, etc had been prepared too. The group leader started with greetings and they proceeded with the soaking-scraping-oiling activity, in a relaxed and friendly atmosphere. They interacted among each other naturally, which made me become ‘invisible’. I could see that all the members were used to ‘the soaking rituals’, meaning that they had been practising it regularly. During the ‘demonstration’ of every members ‘physical condition’, the group leader asked a member to lead the discussion, and they discussed their condition among themselves. According to the members they had always taken turns among themselves in leading their discussion; and when somebody who was leading the discussion had not
been doing his/her task ‘correctly’, they would ‘correct’ each other without anybody feeling offended.

Nevertheless, the group had not been recording the members’ condition in members’ files/books in the way as how it is suggested in the guidelines. Irwan, the group leader at about 55 year-old, explained his reason of not recording their conditions in members’ files:

“It was too time-consuming to make the records, a little bit difficult also... But we have seen the [physical] progress of every one of us, and we would be able to recognize if new impairments have occurred... no one of us has ever kept a new impairment secret from the group, we talk about it, and we encourage each other [to take care of the impairment regularly]”

They reminded each other to watch and take care of their hands and feet when they are going to work at paddy field, by checking their bare hands and feet every now and then, in the up-coming planting season and they talked about their goats too. During the meeting, Amran the facilitator answered the members’ questions whenever he was asked such as what is the facilitator’s suggestions about going to paddy field when somebody has a small wound’, and his answer was ‘it will be much better if they don’t go, but if they have to go, they must wrap the wound with a piece of clean cloth, as thick as possible, check their feet from time to time in the paddy field, and clean the feet right away when they finish their work. Sometimes he asked questions too, but in general, he did not have to guide the meeting because the members had guided it themselves. After one-and-a-half hours of gathering, the meeting ended and the members continued their daily activities, in which many of them are either going to cut some grass to feed their goats or taking their goats to the grass-field and let them eat there.
6.2 Compreng: the never ending struggle of being alone

Compreng health centre is one of two health centres in Compreng sub district. It is located in a village which is also called Compreng. The village is located at one of the main roads leading to the district’s capital. The village is divided into three hamlets that are close to one another. All hamlets are relatively close to the health centre, and also to the village hall. Most of the SCG members live in the same hamlet, and they have known each other well. However, the group has been struggling in maintaining its existence since the start in 2003. In the following stories, a member, the group leader and the group facilitator recount their experiences of being in the SCG, which will serve as illustrations for the analysis in this section. Jamal had developed severe physical impairments, a recurrent ulcer at his sole and clawed hands, when he joined the SCG in 2003. He is 35 year-old now.

"[I joined the SCG] because I was hoping that, well, maybe I could be cured [looked doubtful].

I was taught how to exercise my hands everyday for several times, soaking them and scraping them using a stone.... well, my hands were worse in the past, much stiffer... I also had an ulcer at the sole, it was healed finally. Mr. Iskandar [mentioning the leprosy health worker’s name] treated the ulcer ‘till it was cured. He visited my house quite often, and I was grateful... If he had not helped me, I might have lost my leg... My father was taking care of me too.

[Regarding] our group, well we mostly had the meetings at the health centre, sometimes in the village [hall], oh, I didn’t feel comfortable when we had the meeting in the village, I just went there to be examined by Mr. Iskandar, and then I went home... [I did that] because the villagers were afraid of us, of me, because of my illness... I often felt offended because of the way people looked at me, avoiding me...

I knew many of the group members because most of us live in the same hamlet, including our group leader; you better ask him how our group was... I think that our group was okay, because I could meet with people who had similar problem like me, it helped me to know that I was not alone [looked sad]... But, we had never really met as a whole group in the previous meetings, we had hardly waited for one

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9 In general, a village’s name that is the same as the sub district’s name is the capital of the sub district, but it is not like that in the case of Compreng.
another or soaked [the hands and feet] together, just let Mr. Iskandar examine us then we went home, sometimes but very rare our group leader accompanied him during the examination.

I am thankful that my ulcer had been healed, but regarding my feeling, I feel the same as when I was really ill [looked really sad].... There has not been much progress in my life. Long time ago when my hands were not like they are now [showing his clawed hands] I used to be an agricultural labourer at the paddy field, but how could I be like that now..?... I have this motorbike [his wife bought it for him], I have been trying to earn some money by *ngojek* [private motorbike that is used as 'taxi' by the owner], but I couldn’t get many customers in this area, they are afraid of me because they know my condition. I couldn’t go to another area to get some customers who don’t know me, because I am not strong enough to ride the motorbike in long distance, so I just stayed home most of the time... I live with my two children and my parents-in-law at a house that was built using the money that my wife has earned in Middle East, but I sometimes feel embarrassed that I don’t have a proper job, so every now and then I go back and stay for a while at my parents’ house.”

At the time the SCG was started, Johan the group leader had an ulcer at his sole and 2 clawed fingers of his right hand. He is 46 year-old now.

"I decided to join the group because Mr. Iskandar asked me [started laughing]. He came to my house. I tried my luck to be cured, by joining the group.... I was appointed as the group leader [of one hamlet] when we started the group in 2003. I was trained by Mr. Iskandar and a lady from Subang [the district wasor] on how to examine my members [the SCG members]... Each of us was given a bucket, some stone and a bottle of oil, and we were taught how to soak, scrape and oil our hands and feet. In the very beginning we were shown how to do the soaking, etc... But, how would I know if my members had been practising it at their home or not... I sometimes did the exercise, not so regular; I didn’t have time doctor... [seems trying to change the topic]. Actually my task as a group leader was to coordinate my members [laughing], but what could I do if they had been always having all their reasons [to be absent from the meeting]... [They said that they] felt embarrassed, busy working at home, etc.... To be honest, I also had many excuses to tell to Mr. Iskandar whenever I felt that I didn’t want to go to our regular meeting..."
Hmmm..., I guessed there were ten of us at the beginning, I couldn’t really remember, the members had been changing from time to time... As a group leader, I was always puzzled; it was so difficult to gather all the members. I told this problem to Mr. Iskandar, that I was fed up, and it would be much better for me to take care of my warung than to get tired with the group members... Poor Mr. Iskandar, but I could not do more... Actually I thought that some of us were embarrassed to be in the group.... we didn’t feel comfortable when we had the meeting in the village... people in the village were not so nice to us, the group of people with kusta... [laughing] well it’s up to them.

But Mr. Iskandar had been so nice to all of us, he treated us kindly... and he took me once to meet with the regent at the regent’s office...

Last year we finally stopped the regular meetings, but last April Mr. Iskandar contacted me again, and we [the group] met once at the health centre and I think the health centre is a better place for us to meet, than in the village... There were some new faces in the group, we just wait and see...

I was better sometimes ago, but as you can see, I have a new wound [showing his sole, the wound is covered with bandage and antiseptic liquid had been applied to the wound]... I admitted that I have not been taking care of my hands and feet, I hardly have time, I am busy with my warung...”

Iskandar had become leprosy worker of Compreng health centre more than two years before they started a SCG. Recently, his other task at the health centre is as tuberculosis health worker.

“I was very confident in 2003... I started with a big group [that consisted of twenty people] at that time, and I divided the group into two sub groups based on hamlets... I was partly ‘forcing’ the PALs to join the group, I picked them up... I was intending to motivate them, but it had not worked very well, and I needed to remind the members to come to the meeting... Then, the group leader of one hamlet died in a traffic accident, and it had made it more difficult for me to coordinate the members in two sub-groups... I consulted district [level] about the problem, they had advised me to concentrate only on members who were really willing to participate, and I then started to focus on one smaller group [that exists now]... [Still] I have been struggling all this time to keep the group existing... The group leader has not been very active to coordinate the other members, he told me that he was fed up with the difficulties [to gather the members]... I have been giving the
members vitamins to stimulate their willingness and motivation; sometimes the group meeting looked more like a ‘mobile clinic’ than a SCG meeting... [Furthermore] we hardly had a real self-care group meeting except the ones at the beginning of the group... it had been always very difficult to gather all members so that they would be able to soak together and so forth. They had hardly waited for one another, they would just come to be examined and they would go home, and I had been doing the examination alone most of the time... Some members said that they felt uncomfortable to be seen in the group meeting by the villagers. So, in many group meetings, it was only me with one or two members who would come and go one after the other... Generally, the people in our [health centre] working area are still afraid of leprosy... They still perceive leprosy as a highly infectious disease... I think that is the main reason that stigma in the community is still existing... All this time, my focus [for health education] was limited to the village leaders only, because I was hoping that they would help me to spread the health messages, but apparently it had not been succeeded... It had been difficult for me to make the community aware that ‘white patches’ on people’s skin can be the early signs of leprosy, probably they have just been denying the fact [looked desperate]... I had introduced the SCG concept to the village leaders but I haven’t approached the community, so the community in general were not yet informed about SCG...

Regarding the members’ home based self-care, most members including the group leader had not been practising it regularly [he looked puzzled]... Some members said that they could not see a real progress of their impairments, which made them fed up... Some said that they just didn’t have time... I had been visiting them at home one by one to encourage them; I just don’t know what else I could do... [looked disappointed]... I think, all this time, there were only two members, who have suffered from leprosy reaction that have become better... Because of too many constraints, our group stopped in 2006, but last April, I have started the group again [I thought that he probably did this because he was ‘forced’ and ‘challenged’ by the success of Tambak Dahan SCG], and I’ve motivated Johan the group leader to be active again... This time, two new members were willing to join, but actually all this time the members had been changing from time to time. I hope that the group will work better from now on...”
SCG: reason, motivation, & expectation

Of the five members that I interviewed, two members were still on their treatment when they became members of SCG and both were suffering from leprosy reaction too, while the other three were already RFT. They joined the SCG because they all were having visible impairments due to leprosy. In general, they were mainly accepting the offer by the facilitator, and just had a try. Erna said that she knew nothing about SCG but she just followed the health worker’s invitation. None of the members were invited to join the group by other members or other PALs. Through SCG, they all were hoping that they would be cured.

The process: unity and sustainability of the group

When we go back to the definition of SCG, we could see that one important value of SCG is that people who have common problems, which are leprosy-related problems in this case, would come together to support and help one another in overcoming the situation. This value of SCG was hardly seen in Compreng SCG. All members and also the facilitator acknowledge that they hardly had any proper group meeting. The members did share a common problem, which was a good beginning to start a group, but then they failed to maintain the unity and sustainability of their group.

Based on the information that I received, I identify some mutually related causes, for the group’s failure. First, despite the leprosy health worker’s big enthusiasm and motivation in setting up the SCG and his good relationship with the PALs, the leprosy health worker was less capable as a facilitator. Members were not well-informed regarding the principles and the aims of SCG. Two members thought that SCG is the way for them to receive treatment from the health centre; they were not well informed that they needed to practise the daily home-based self-care, nor to practise it together in a group meeting. The other three members knew, but they were not used to being independent in taking care of themselves. The leprosy health worker kept being their ‘care-giver’ by picking them up, taking care of their wounds, etc. I understand that the leprosy health worker might have been ‘forced’ to set up a SCG due to the high burden of leprosy in his working area. Thus he wanted to keep the group alive, and he kept it
alive by replacing a member that has left the group by a new member, and by providing the members with ‘unnecessary’ vitamins. He identified the constraints that were hampering the development of the SCG, but he had not being able to solve everything. He has been working on his own, and there was hardly any support from the health centre’s doctor.

Secondly, this SCG did not have a reliable source of encouragement and support among the members. The group leader has not being able to create the ‘group spirit’. He has not shown a good example to his peers in terms of practising daily self-care, and thus he was not tough enough in encouraging his group members either. Furthermore, the fact that the members have been hardly meeting up as a whole group, practising together, and discussing their problem together has hampered the development of their connectedness into the group. In short, this group had never reached the stage of ‘performing’, i.e. the stage in where a group has become a unity in trying to achieve its goals (Handy 1985 in Benbow & Tamiru 2001: 312).

The source of the problem was not only within the struggling group but also from their larger societal environment, i.e. their community. Regardless the SCG had not been functioning well, a person like Jamal who was lonely and feeling inferior still saw the SCG as a place where he hoped to meet his ‘fellow sufferers’. However, enacted stigma of their community has hampered the willingness of SCG members to participate actively in the group. I have tried to ask the five members what kind of difficulties the members had faced in practising home-based daily self-care, because I thought that there might have been difficulties that are related to enacted stigma in their community. However, none of the members had linked their difficulties in doing home based self-care directly with the enacted stigma.

*The challenge: persisting [enacted and self] stigma, restrictions in members’ daily lives*

There are many causes that are mutually related, which are impeding the success of the SCG in achieving the aims of SCG, i.e. enabling its members to solve the problems due to leprosy independently. As I have discussed previously, this SCG has never performed as a real group due to several hindrances, and one hindrance was the enacted stigma in
the community. The following illustration will describe enacted stigma in that village. It is based on my conversation with a religious leader that lives there.

"I think that [people in] our village are still afraid of leprosy... this village had been always full of leprosy patients since long time ago... many of them [the PAL] were severely impaired, and people were afraid that they might get infected by those people... yes, leprosy is feared to due its infectiousness... sometimes the \textit{mantri} [health worker] would come and tell the villager that leprosy is not that dangerous, but people are still afraid... too many villagers had been infected with leprosy in the past... it is not easy to convince [the villagers] that leprosy is not easily transmitted” (Jaya 58 years)

Enacted stigma that is existing in the community has caused a persisting self-stigma by some members. It affects a member’s self-stigma through several mechanisms. We could see the example in the case of Jamal. Firstly, his membership in SCG has failed in restoring his self-confidence and self-esteem. He hoped to meet his peers in their meetings, but the members’ willingness – besides other causes – was hampered by the enacted stigma. If Jamal had been able to be encouraged and supported by his peers, there has been a possibility that he would have felt better. Secondly, rejection of his community has made him unable to earn a living for his family, in his own community. While at the same time, due to his physical limitations he does not have much choice either. This situation creates a feeling of shame and inferiority of him towards his children and in-laws. Of the five members, Erna has never been bothered by the enacted stigma, while Tauhid [who was felt offended when he was almost fired from his job] was not bothered anymore. They both are in their sixties during my study and they thought that they were too old to get bothered by people’s bad conducts towards them, and they would just put their lives in God’s hands. However, they also hoped that those people would stop showing the disrespectful attitudes.

\textit{The meeting: Compreng SCG in reality}

When I arrived at Compreng health centre, where the group meeting was going to be held on that Saturday morning, the five members that I have had met and three other
members were already waiting in one of the rooms in the health centre. For the three members that I had not met, that day was the first time for them coming to the meeting, but they had not decided yet whether they wanted to become a member or not. The members were sitting in circle, quietly and not talking to each other. However, I was quite happy to see that Jamal and Tauhid, from their looks, seemed better than the day when I met them for the first time.

Iskandar, the facilitator opened the meeting, and then Tauhid started with a short prayer. In his prayer Tauhid encouraged his friends not to be embarrassed or offended when they had to face discrimination from people. He was much calmer than the time when I interviewed him, probably because he was doing his role as a religious figure. The meeting then continued, with the facilitator as the meeting leader, but the members did not do the soaking-scraping-oiling activity together.

Johan the group leader assisted by the facilitator, started to ‘examine’ one member while the other members were just sitting and waiting. Johan seemed not used to his task as a group leader, and he looked a bit nervous. Therefore, Iskandar took over the task from Johan, and he did the inspection. Not all members had been doing the ‘basic self-care’ regularly, as was shown by the thick dead skin of the members’ palms and soles and by the wounds of three members. Therefore, Iskandar started explaining the importance of doing daily self-care. He tried to explain everything, but I could see that the members were not really listening. Then, Amran the facilitator from Tambak Dahan who also attended the meeting started to assist Iskandar. Together, they demonstrated how to exercise the weak dropped feet. Iskandar also dressed the wounds of three members. At the end of the meeting, the group members were encouraged to take care of themselves, by the head of district health service of Subang, who came to the health centre especially for them. At that time, all members have agreed that they would take care of their impairments and that they want to continue with their group. They have all preferred to meet at the health centre at the following month.
Chapter 6
Conclusion and Recommendation

The objective of my study was to explore the experiences of the people affected by leprosy (PALs) who are members of Self-care groups (SCGs), to know their perceptions on their 'leprosy-affected life' before and after joining the SCGs. By exploring their experiences and also experiences of the health workers who are involved in this activity, I tried to identify the limitations and the strengths of SCG as a stigma reduction programme. I can not generalize the result of my study; however it may provide relevant insight into the programme.

From the narrative experiences of the PALs, I learned that suffering from leprosy had been a long lasting experience for them. This was due to medical consequences and social consequences of leprosy that were intertwined. Medical consequences that were raised by the PALs varied, ranging from simple to serious ones from the viewpoint of biomedicine. The simple ones were lengthy treatment course, discoloration of skin patches due to side effect of leprosy drug, while the serious ones were leprosy reaction with painful nerves and terrifying visible signs that may appear at skin and extremities, and the permanent physical impairments as the result of untreated leprosy reaction. However, they all were perceived serious from the viewpoints of the PALs. Furthermore, there was also a notion of high infectiousness of leprosy among the PALs. The aforementioned medical consequences of leprosy are intertwined with the social consequence of leprosy that became the central focus of my study, i.e. self-stigma of leprosy. Self-stigma had been prominent among the PALs in the two SCGs i.e. Tambak Dahan and Compreng, who reduced their activities or withdrew from their relationships with people after knowing that they were suffering from leprosy. The major cause of self-stigma was the feeling of shame due to the perceived infectiousness of leprosy [they feared that they might infect other people], the fear of being stigmatized and the fear of not being able to earn a living [particularly the PALs who were the breadwinner of their family]. Self-stigma led the PALs into low self-esteem and low self-confidence. Furthermore, higher self-stigma was also intertwined with enacted stigma, as what had been experienced by the PALs in Compreng SCG where the community still perceives leprosy as a highly infectious disease, thus they stigmatize the leprosy sufferers.
The PALs’ experiences of affliction were not limited to the time when they were taking medical treatment. Even though they had been declared cured by the health provider after they completed their medication most of them had persisting physical impairments and/or had been experiencing episodes of leprosy reaction. In the PALs’ understanding, ‘being cured’ means not having leprosy signs. These concepts and experiences created the feeling of uncertainty regarding their status as ‘being cured’, and furthermore their feeling of uncertainty deteriorated their self-confidence and self-esteem that were not restored completely. With regard to this different understanding, I came up with suggestions on how to minimize the gap, which I will discuss in the recommendation section.

The presence of the SCG was seen by the PALs as an opportunity to get over their long lasting illness experience. The results of my study indicate that SCG can be a promising activity to fulfill the PALs’ hope. However, contrasting experiences of the two SCGs show that there are certain conditions that are influencing the SCG’s chance to be able in achieving its aims, and thus, in fulfilling the PALs’ hope.

At the beginning of a SCG formation, many PALs could not see or feel the aim and principle of this activity which according to the leprosy control programme, is enabling the PALs, i.e. the SCG members, to be the main actors by supporting one another in overcoming their problems due to leprosy, mainly in the prevention and reduction of disability through practising the daily self-care. This is the situation in which a competent facilitator and group leader are needed to continuously deliver the right message regarding the aim of SCG to the members, while at the same time to guide and to motivate the members in practising self-care. The facilitator and group leader have a major role in creating the ‘group spirit’. As I have argued in the previous chapter, the facilitator or the leprosy health worker, and the group leader of Tambak Dahan SCG were capable of their tasks whereas the ones of Compreng SCG were not. Furthermore, personal commitment to do their tasks was also of vital importance, which was lacking in the group leader of Compreng SCG. In Tambak Dahan SCG, the capabilities and continuing personal commitments of the facilitator and the group leader in encouraging the group members, produces the ‘group spirit’. Once a SCG has produced its ‘group spirit’, it becomes a social structure that may start ‘performing’ to achieve its aims, and many advantages can be achieved by its members, as happened in Tambak Dahan SCG.
A SCG which failed to produce its ‘group spirit’ will not be able to perform, and thus will not give any advantages to its members as was the case in Compreng SCG (Handy 1985 in Benbow & Tamiru 2001).

With regard to Tambak Dahan SCG, i.e. a successful group, by encouraging one another through continuously exchanging experiences and by seeing a peer as a role model (Borkman 1976 in Steward 1990:1061), the members got used to practising self-care, and by doing so, they were able to control and to reduce their impairments. Furthermore, being aware of their ability increases the members’ self-esteem, and thus diminishes their self-stigma. In other words, the members of Tambak Dahan SCG have been experiencing the advantage of ‘bonding social capital’, by being connected to their group. In Compreng SCG that has never been able to perform, some group members were still ‘able’ to reduce their impairments, but it was the group facilitator, i.e. the leprosy health worker who had been their ‘care-giver’.

As previously argued, stigma in the community was one of the hindrances that impeded the ability of Compreng SCG to develop. Members were hesitant to participate actively in the group activity because they were protecting themselves from being stigmatized by the community. Whereas in Tambak Dahan SCG, members were not affected by enacted stigma, since the health provider had provided the community with information regarding leprosy. Furthermore, the community had been informed about the concept of SCG, and thus the community was aware about the activity. In short, Tambak Dahan SCG was accepted by the community, because of the ‘bridging’ that was performed by the health provider. Furthermore, the health provider has made a ‘link’ between Tambak Dahan SCG and an aid donor, which has resulted in the form of working capital [the goats] for its members.

Because of the community’s acceptance, Tambak Dahan SCG has been freely and openly conducting the group meeting in their own living environment. Support of and connectedness to their family and community helped the SCG members in maintaining their positive results that had been achieved in the SCG. At the same time, the community also received some advantages through the SCG, such as increased awareness and knowledge of leprosy (see Kawachi, et al. 1999: 1190-1191). This norm of reciprocity may enhance the connectedness between the SCG and the community, and thus it may create the community’s sense of belonging of the SCG.
In Compreng SCG, a male member was badly affected by his leprosy-related disability. He could not earn a living in his own living environment due to the community’s rejection, but due to his physical limitation he didn’t have much choice either. In Tambak Dahan SCG, despite the members’ ability to control and reduce their impairments, to a certain extent they do have physical limitations that inhibit them from performing certain manual occupations. Self-stigma might occur due to the [fear of] inability of earning a living. Therefore, working capital that was loaned to the members of Tambak Dahan SCG helped the members to have a secure way of earning a living.

The following recommendations for enhancing the success of SCG are based upon the findings of my study in the two SCGs in Subang district West Java Indonesia. Some practical recommendations are directed to the health centres as the provider of leprosy services and to the leprosy supervisor/manager at the district or provincial level.

**Information Education Communication (IEC) in the community**

Starting up a SCG based on high burden of PALs with disability, availability of motivated staff and support from the local health service are not sufficient without looking at the condition of the larger community in general, for instance the level of stigma in the community. The result of this study indicates that stigma may hamper the success of a SCG; therefore it is advisable not to impose the programme without careful calculation. Before a SCG is being started, community needs to be sensitized about leprosy [and the SCG concept]. IEC activity is definitely needed given the fact that many communities are not well informed with regard to the [early] signs and symptoms of leprosy, means of transmission and places to seek for treatment. This activity may increase awareness of leprosy and thus, may reduce [enacted] stigma. It is important that the health educator emphasizes that leprosy is treatable, the sooner the better; and that leprosy is not highly infectious, by for example using a statement such as ‘leprosy can not be transmitted as easily as a common cold’, in order to reduce the fear of leprosy. Creativity is needed to develop an IEC kit which is appropriate in a certain context.
Community-based SCG

The principle of SCG is that members play the most important role in the prevention of disabilities, and members are supposed to practice daily self-care at home by using local materials. Therefore, it would be more suitable if SCG meetings are based in the community in order to develop the connectedness between SCG and the community, so that the SCG will belong to the community. Thus, SCG [members] may benefit from the social capital of their community and vice versa. Health provider may act as the motivator and the linker between SCG / the community and different leprosy stakeholders, such as the donor. This study indicates that community-based SCG is possible and can be successful.

SCG: a holistic approach to a PAL

The result of this study indicates that a ‘successful’ SCG gives many advantages to the PALs [and also to their community]. SCG touches not only the physical [biomedical] aspect of the PALs but also the psychosocial aspects of them. One crucial figure is the group facilitator. The group facilitator, i.e. the leprosy health worker is [well] trained merely in the physical [biomedical] aspect of leprosy, and not [much] in the psychosocial aspect of the PALs. Therefore it is preferable if he/she is provided with more skills, such as the skill to counsel a member that needs more psychological support and skill to ‘advocate the SCG to NGOs’. Furthermore, in relation to the concept of peers as a role model and the high value of experiential knowledge (Borkman 1976 in Steward 1990: 1061) I would like to suggest a member of a successful SCG to be given a chance of being a [guest] co-facilitator in a ‘learning’ SCG to encourage his/her fellows.

Income generating activities

It is ideal if a SCG is followed by ‘solutions for life’, by taking into consideration that the SCG members are, to a certain extent, disabled; and that being disabled and not having the ability to earn a living may cause self-stigma. The health provider or the community may try to make a link between the SCG and an aid donor for a suitable income generating project.
**IEC to PALs regarding their affliction**

IEC should be given to a PAL at any phase of his/her treatment [and after RFT] with different emphasis in each phase and different emphasis depending on the PAL’s condition. For instance: if a PAL who has just been diagnosed had already developed a permanent impairment, it is crucial that he/she is informed that MDT would not cure the impairment, that the impairment can be reduced or prevented of getting worse by practising daily self care; that MDT will only destroy the bacteria, meaning that he/she would not infect other people within a month of his/her treatment course. There was a tendency that a health worker would not give complete information to his/her patient, by only saying that the patient would not infect other people and would be cured once they take their medication regularly and completely.\(^\text{10}\) With regard to the PALs’ perception of being cured, incomplete information might raise expectation and confusion of the PALs. If a PAL is about to complete his/her treatment meaning that they will be RFT, it is crucial that they are provided with information regarding the remaining risks of leprosy reaction and what action should be taken afterwards, and how to take care of their impairment back home. Giving complete information is important, rather than simply saying that they are cured already. There are still many IEC messages that have to be informed to the PALs, and it is understandable that a leprosy health worker is not capable to do everything on his/her own. Thus, guidance from the medical doctor is needed occasionally.

During my study, I have been reflecting over and over again regarding the different perceptions of 'being cured' between the leprosy sufferers and the health care provider. I realize now, how it must have been confusing or even depressing for the PALs to be declared cured with the persisting impairments, moreover with the [potential] experience of getting the leprosy reactions. Nevertheless, I also understand that encouraging the PALs that they can be cured is a way that is used by the health worker, to decrease the stigma of leprosy as an incurable disease. That is one cleft that should be bridged (as I have stated in the recommendation). There might be many more 'clefts', worth investigating, that have been hampering the success of leprosy control.

---

\(^{10}\) My participants were mostly diagnosed in the 1990s. Nowadays, there is a possibility that leprosy health workers provide complete information to the PALs.
Through my small study, I learned much from the experiences of some PALs regarding their 'leprosy-affected' lives, i.e. their 'never ending affliction'. I am more convinced now, that, the PALs should not be 'released' from the attention and support of health care services, even if they are already 'released' from [medical] treatment. Therefore, I personally think, that a ‘well-prepared’ SCG for PALs is a good holistic way to keep on supporting them.
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Glossary of Sundanese and Indonesian terms

Arisan  Saving groups
Bidan  Midwife
Dinas Kesehatan Kabupaten  District Health Service
Dukun  Traditional healer
Es mambo  Local ice cream, in which milk is substitute by coconut milk
Kambuh  Relapse
Kumat  Relapse
Kelompok Perawatan Diri (KPD)  Self-care Group
Kusta  Leprosy
Malu  Embarrassed
Mantri  Male health worker
Minggon desa  Weekly village gathering
Muslimah  Female Muslims
(Ng)ojek  Private motorbike that is used as ‘taxi’ by the owner
Panu  Skin patches due to fungal infection
Puskesmas  Health centre
Puskesmas Pembantu  Sub-health centre
Rotinan  Female Muslims’ prayers and worship
Silaturahmi  Meeting with people, with an aim to support one another
Ustadz  Islamic priest
Warung  Small shops
Wasor  Supervisor
Wasor kusta kabupaten  District leprosy supervisor
Wasor kusta propinsi  Provincial leprosy supervisor
Annex 1

Table.1 WHO Disability Grading of Leprosy (WHO 2005)

<table>
<thead>
<tr>
<th>Grade 0</th>
<th>No disability found.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 1</td>
<td>Loss of sensation has been noted in the hand or foot (the eyes are not given a grade of 1). Loss of sensation in the hand or foot means that one of the main peripheral nerve trunks has been damaged by leprosy and this is more common later in the disease than at diagnosis. It should not be confused with the loss of sensation in a skin patch, which is caused by local damage to the small nerves in the skin, and not to the main peripheral nerve trunks. People with loss of sensation (grade 1 disability) on the soles of their feet, but no other abnormality, are at significant risk for developing plantar ulcers. People with grade 1 disability who routinely use appropriate shoes are protected from ulceration and have far fewer long-term problems with their feet. Therefore, measuring and recording grade 1 disability is an essential step in preventing damage to the feet of people affected by leprosy – it is therefore a key component of quality leprosy services.</td>
</tr>
<tr>
<td>Grade 2</td>
<td>Visible damage or disability is noted. For the eyes, this includes the inability to close the eye fully (<em>lagophtalmos</em>) or obvious redness of the eye (in leprosy, this is typically caused by either a corneal ulcer or by <em>uveitis</em>). Visual impairment or blindness also gives a disability grade of 2.</td>
</tr>
</tbody>
</table>
Annex 2

Problem analysis diagram

Health services

- Human resources limitation
  - Insufficient IEC
  - Insufficient counseling

Community

- Enacted stigma
- Self stigma
- Negative perception on leprosy & the sufferers

- Visible leprosy symptoms / disability

- Lack of efficacy of SCG intervention in diminishing self-stigma
- Lack of skill of SCG facilitator
- Dynamics of group don't run well
- Daily self care less priority
- Disability no improvement

- Unemployment
- Health services
- Community

- Positive life style
Annex 3

Map of Leprosy Newly Detected Case Rate 2005
(per 100,000 population)

(source of data: Ministry of health of Indonesia)
Annex 4

INDONESIA, LEPROSY DISABILITY GRADE 2
2005

Distribution of LEPROSY G 2 Disabilities 1990 – 2005

National: 23,104 (Cumulative and not reassessed), data as of Dec. 2005
(Ministry of Health of Indonesia)
Annex 5

Map of Subang district and West Java
Annex 6

Map of leprosy situation in Subang district per health centre
(Number of registered cases per 10,000 populations at the end of 2006)
(Source of data: District health service of Subang)
Table.2 Characteristics of the participants

<table>
<thead>
<tr>
<th>SCG</th>
<th>Participant (Pseudonyms)</th>
<th>Sex</th>
<th>Age</th>
<th>Education</th>
<th>Occupation</th>
<th>Marital status</th>
<th>Existing symptoms and or physical impairments</th>
</tr>
</thead>
<tbody>
<tr>
<td>TD</td>
<td>Sulaiman</td>
<td>M</td>
<td>50</td>
<td>Primary</td>
<td>Agricultural labour*</td>
<td>Married</td>
<td>Anaesthetic palms</td>
</tr>
<tr>
<td>TD</td>
<td>Irwan</td>
<td>M</td>
<td>55</td>
<td>Primary</td>
<td>Driver*</td>
<td>Married</td>
<td>Anaesthetic palms</td>
</tr>
<tr>
<td>TD</td>
<td>Rahman</td>
<td>M</td>
<td>65</td>
<td>Primary, not finished</td>
<td>Agricultural labour*</td>
<td>Married</td>
<td>Clawed toes</td>
</tr>
<tr>
<td>TD</td>
<td>Widya</td>
<td>F</td>
<td>55</td>
<td>-</td>
<td>Agricultural labour*</td>
<td>Married</td>
<td>Anaesthetic palms</td>
</tr>
<tr>
<td>TD</td>
<td>Salwa</td>
<td>F</td>
<td>50</td>
<td>Primary, not finished</td>
<td>Agricultural labour*</td>
<td>Married</td>
<td>Anaesthetic soles</td>
</tr>
<tr>
<td>TD</td>
<td>Ani</td>
<td>F</td>
<td>70</td>
<td>-</td>
<td>Agricultural labour*</td>
<td>Widowed</td>
<td>Anaesthetic palms</td>
</tr>
<tr>
<td>TD</td>
<td>Rosinah</td>
<td>F</td>
<td>60</td>
<td>-</td>
<td>Agricultural labour*</td>
<td>Married</td>
<td>Anaesthetic palms and soles</td>
</tr>
<tr>
<td>TD</td>
<td>Soleh</td>
<td>M</td>
<td>55</td>
<td>Primary</td>
<td>Vendor*</td>
<td>Maried</td>
<td>Anaesthetic left palm</td>
</tr>
<tr>
<td>TD</td>
<td>Sangaji</td>
<td>M</td>
<td>50</td>
<td>Primary</td>
<td>Agricultural labour*</td>
<td>Married</td>
<td>Anaesthetic palms</td>
</tr>
<tr>
<td>TD</td>
<td>Rohim</td>
<td>M</td>
<td>55</td>
<td>Primary, not finished</td>
<td>Agricultural labour*</td>
<td>Married</td>
<td>Anaesthetic palms</td>
</tr>
<tr>
<td>C</td>
<td>Erna</td>
<td>F</td>
<td>65</td>
<td>-</td>
<td>-</td>
<td>Widowed</td>
<td>Anaesthetic soles</td>
</tr>
<tr>
<td>C</td>
<td>Jamal</td>
<td>M</td>
<td>35</td>
<td>Primary</td>
<td>Ojek rider</td>
<td>Married</td>
<td>Clawed hands, dropped feet</td>
</tr>
<tr>
<td>C</td>
<td>Johan</td>
<td>M</td>
<td>46</td>
<td>Primary, not finished</td>
<td>Vendor</td>
<td>Married</td>
<td>Clawed finger, sole ulcer</td>
</tr>
<tr>
<td>C</td>
<td>Tauhid</td>
<td>M</td>
<td>65</td>
<td>Primary, not finished</td>
<td>Retiree</td>
<td>Married</td>
<td>Anaesthetic palms</td>
</tr>
<tr>
<td>C</td>
<td>Eni</td>
<td>F</td>
<td>45</td>
<td>Primary, not finished</td>
<td>Agricultural labour</td>
<td>Married</td>
<td>Ongoing severe reaction</td>
</tr>
</tbody>
</table>

TD = Tambak Dahan; C = compreng
* (small scale) goat farmers beginners, received capital loan from donor a year ago.
Annex 8

**Data Collection Tools**
Questionnaire-guided interview, for all members of SCG

<table>
<thead>
<tr>
<th>General</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Residency</td>
</tr>
<tr>
<td>Religion</td>
</tr>
<tr>
<td>Highest formal education</td>
</tr>
<tr>
<td>Occupation</td>
</tr>
<tr>
<td>Marital status</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>'Leprosy-affected' life</th>
</tr>
</thead>
<tbody>
<tr>
<td>When was the first time that you were diagnosed as suffering leprosy?</td>
</tr>
<tr>
<td>Who made the diagnosis and where?</td>
</tr>
<tr>
<td>What physical symptoms did you have then?</td>
</tr>
<tr>
<td>What was your reaction? How did you feel? How did you manage?</td>
</tr>
<tr>
<td>Did you get treatment? If you did, for how long? How did you experience the treatment?</td>
</tr>
<tr>
<td>Were you being taught how to take care of your impairment at home?</td>
</tr>
<tr>
<td>Did you change your daily activity after being diagnosed? If you did, what made you change your activity? What kind of changes did you make?</td>
</tr>
<tr>
<td>Did you disclose your condition? If you did, to whom? What were their reactions? How were your relationships with them afterwards?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Membership SCG</th>
</tr>
</thead>
<tbody>
<tr>
<td>When did you become member of SCG?</td>
</tr>
<tr>
<td>What were your reasons? What motivated you to do so?</td>
</tr>
<tr>
<td>What were your expectations?</td>
</tr>
<tr>
<td>What are the activities in SCG?</td>
</tr>
<tr>
<td>How do you experience the SCG? How are your relationships with other members and facilitators? Do they support you? If yes, what kind of support?</td>
</tr>
<tr>
<td>Do you feel any changes in your life? What are the changes?</td>
</tr>
<tr>
<td>How do you experience your life now?</td>
</tr>
</tbody>
</table>
In-depth interview topic list with selected participants (for case studies)

<table>
<thead>
<tr>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principally, questions for in-depth interview will be based on the</td>
</tr>
<tr>
<td>results of the questionnaire-guided interview. The topics are:</td>
</tr>
<tr>
<td>Self-stigma: shame, self-worthlessness</td>
</tr>
<tr>
<td>Experience in SCG: what kinds of supports they get (from facilitators,</td>
</tr>
<tr>
<td>other members), what they like and what they don’t like in the activity.</td>
</tr>
<tr>
<td>Relationships between participants and families</td>
</tr>
<tr>
<td>Relationships between participants and community</td>
</tr>
<tr>
<td>Participants’ daily – personal and social – activities</td>
</tr>
<tr>
<td>Participants’ position in the community</td>
</tr>
</tbody>
</table>

In-depth interview with selected participants’ families

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>When he/she found out for the first time that he/she was suffering</td>
</tr>
<tr>
<td>leprosy, were you with him/her? If yes, how did you think he/she</td>
</tr>
<tr>
<td>reacted upon it? As families, how did you react?</td>
</tr>
<tr>
<td>Did you notice any changes in his/her activity, his/her relationships</td>
</tr>
<tr>
<td>with you and others? If yes, can you explain the changes?</td>
</tr>
<tr>
<td>Do you know that he/she joins the SCG? If yes, do you see any changes</td>
</tr>
<tr>
<td>in his/her life after joining the SCG?</td>
</tr>
<tr>
<td>What do you think are the impacts of SCG for him/her?</td>
</tr>
</tbody>
</table>
In-depth interview topic list with health workers / facilitators of SCG

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>When have you become SCG facilitator?</td>
</tr>
<tr>
<td>Do you have any other duties in the health centre? If yes, what are they?</td>
</tr>
<tr>
<td>How do you experience being a facilitator?</td>
</tr>
<tr>
<td>In your opinion, how is the interaction within the group?</td>
</tr>
<tr>
<td>Has any member left the group? If yes, what made them leave the group?</td>
</tr>
<tr>
<td>In your opinion, how does community treat the PALs?</td>
</tr>
<tr>
<td>Do you think the community treats the PALs who are members of SCG and who are not members of SCG in different ways? If yes, can you explain the differences?</td>
</tr>
<tr>
<td>Has any member of SCG needed more attention or help from you than the others? If yes, what were the reasons? How do you deal with such situation?</td>
</tr>
</tbody>
</table>

Observation topic list, living in the village

<table>
<thead>
<tr>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geography</td>
</tr>
<tr>
<td>Natural resources, economic condition</td>
</tr>
<tr>
<td>Relationships within community, social hierarchy</td>
</tr>
<tr>
<td>Role of health-care provider</td>
</tr>
<tr>
<td>Attitudes toward leprosy and the sufferers</td>
</tr>
<tr>
<td>Presence of PALs beggars</td>
</tr>
</tbody>
</table>
Observation topic list, SCG meeting

<table>
<thead>
<tr>
<th>Location of the meeting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atmosphere of the meeting</td>
</tr>
<tr>
<td>Interactions among members</td>
</tr>
<tr>
<td>Interactions between member and facilitator</td>
</tr>
<tr>
<td>Physical condition (the impairments) of members</td>
</tr>
<tr>
<td>Body language of members</td>
</tr>
<tr>
<td>Topics in their conversation</td>
</tr>
<tr>
<td>Availability of ‘self-care’ kit</td>
</tr>
</tbody>
</table>

Observation topic list, selected participants’ daily lives

<table>
<thead>
<tr>
<th>Personal care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships and interactions with family, friends</td>
</tr>
<tr>
<td>Social lives (attendance at social activity, religious activity)</td>
</tr>
<tr>
<td>Employment</td>
</tr>
</tbody>
</table>