Self Care Group in Leprosy Control Program in Indonesia

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Abbreviations ii
Abstract iii
Introduction v
1. Background of Information 1
1.1. Country profile 1
1.2. Health profile 2
1.3. Organization of health services regarding Leprosy and Yaws Control Program (LYCP) 4
2. Statement of the problems, objectives and methodology 5
2.1. Statement of the problem 5
2.2. Objectives and methodology 7
2.2.1. General objectives of the thesis: 7
2.2.2. Specific objectives: 7
2.2.3. Methodology of the thesis: 8
a. Study location and population. 8
b. Data collection technique. 8
c. Data processing and analysis 9
d. Ethical consideration 9
e. Limitation and biases of inventory study 10
3. Literature review on the self care and Self Care Group 11
3.1. Reduction of physical disabilities and daily activity limitations. 12
3.1.1. SCG for leprosy 12
3.1.2. SCG for diabetes 13
3.2. Reduction of psychological problems 14
3.2.1. SCG for leprosy 14
3.2.2. SCG for diabetes 15
3.3. Reduction of economic problems 16
3.3.1. SCG for leprosy 16
3.3.2. SCG for diabetes 16
3.4. Reduction of social problems 17
3.4.1. SCG for leprosy 17
3.4.2. SCG for diabetes 18
4. Study result on SCG in Indonesia and discussion 19
4.1. Situation of self care group in Indonesia 19
4.2. Steps of establishment of SCG in Indonesia 20
4.3. The role of related stakeholders on SCG program in Indonesia. 20
4.3.1. The role of Ministry of Health: 21
4.3.2. The role of the donor (NLR): 21
4.3.3. The role of the PLS: 21
4.3.4. The role of DLS: 22
4.3.5. The role of LFW: 22
4.3.6. The role of the group leader: 22
4.3.7. The role of the group members: 22

4.3.8. The role of the family members: 23
4.3.9. The role of community: 23
4.4. Self care activities within SCG. 23
According to National Guidelines for SCG the activities during the meeting are respectively as mentioned below: 23
4.5 The result of inventory study of SCG in Indonesia..... 24
In this part a number of issues regarding SCG which were inventoried will be describe and analyzed. These elements are: 24
4.5.3. Inclusion 29
4.5.4. Psychological problems..... 30
4.5.5. Physical disabilities and activity limitation 31
4.5.6. Socio-economic rehabilitation..... 32
4.5.7. Organization issue: Meeting place, frequency, recording and reporting , facilitator, time..... 33
5. Conclusions and recommendations 36

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Abbreviations

BPS: *Biro Pusat Statistik* (National Statistic Bureau)
CBR: Community Based Rehabilitation
DLS: District Leprosy Supervisor
HC: Health Center
ICF: International Classification of Functioning, Disability and Health
ICIDH: International Classification of Impairment, Disability and Handicap
IEC: Information Education and Communication
LFW: Leprosy Field Worker
LYCP: Leprosy and Yaws Control Program
M.Leprae: Mycobacterium Leprae
MB: Multi-Bacillary
MDT: Multi-Drug Therapy
NFI: Nerve Function Impairment
NGO: Non Government Organization
MOH-RI: Ministry of Health of Republic of Indonesia
NLR: Netherlands Leprosy Relief
NLYC: National Leprosy and Yaws Consultant
PAL: People Affected by Leprosy or Person Affected by Leprosy
PB: Pauci-Bacillary
PLS: Provincial Leprosy Supervisor
POD: Prevention Of Disability
PWD: People With Disability
RFT: Release From Treatment
SCG: Self Care Group
SEARO: South East Asia Regional Office
UNDP: United Nations Development Programme
UNESCO: United Nations Educational Scientific and Cultural Organization
WHO: World Health Organization

Abstract

Self care group (SCG) for people affected by leprosy in Indonesia have been started since 2000. One hundred and twenty four (124) SCGs were established within 8 years (2000-2007). It is increasing in quantity but the quality of the SCG program is never assesses properly.

An inventory study of SCG had been done in 2007. Twenty SCG were chosen randomly to be evaluated by the National Leprosy and Yaws Consultants (NLYC) team. The author is one of the team members. A set of questionnaire were used as guidance tool to evaluate some aspects of SCG activities during the SCG meetings.

The major study questions of the thesis were:

1. How is the situation of SCG program in Indonesia?
2. How the SCG establishment process?
3. What is the role of related stakeholders on SCG program in Indonesia?
4. What kinds of activities are done in SCG program?
5. What are the impacts of SCG to its members?
6. What are the challenges of SCG in Indonesia?
7. How to address the challenges to improve SCG program?

Methodologies used are literature study about Self Care Group for people affected by leprosy, Community Based Rehabilitation, report of SCG activities from Indonesia, Nepal, Ethiopia, India and data analysis of secondary data of inventory study of SCG in Indonesia in 2007.

The result of SCG study in Indonesia had shown impacts to its members such as reduction of disabilities, reduction of daily activity limitation, increase the knowledge of leprosy and self care, give better access to referral services, provision of assisting and protective devices, increase awareness of families and community members, Socio-economic rehabilitation (SER) programs, stigma reduction, promote reintegration of people affected by leprosy into community, increase self esteem and financial support from local government. The study also shows challenges and obstacles still remaining such as organizational, financial and technical problems.

SCG is addressing not only physical problem but also psychological, functional, economical and social participation. It would reach the goals only if it prepares promptly and is supported by both health service provider and community.

Therefore the capability of facilitator and SCG is needed to be enhanced. It could be achieved through proper training, sustainable financial support, health policy support, regular technical guidance and material support. More detail study on SCG about determinant factors of failures and supportive agents need to be done in order to get a better insight of the underlying problem for better performance.

The community and the local authorities should be involved to support the program. Finally we need to increase the commitment from all stakeholders to make the SCG a success. These might be achieved by promotion and advocacy of SCG to community and other stakeholders.

Key words: Leprosy, Self Care Group, Community Based Rehabilitation, Socio economic rehabilitation, community participation, people with disability, prevention of disability.

Introduction

I have been working in leprosy control program as National Leprosy and Yaws Consultant (NLYC) since 2001. I have seen many disabilities due to leprosy in the community. It causes many problems, such as drop out of school, loss of job, loss of family, segregation from community and loss of opportunities. It may lead to poor quality of life of the affected people. It affects their family and community as well.

The total number of disability due to leprosy is increasing every year. The national leprosy control program (NLCP) has implemented strategies to reduce disability such as promoting early case detection, free of charge multi-drug therapy (MDT), regular prevention of disability (POD) activities, leprosy reaction management, surveillance after release from treatment (RFT) and rehabilitation services. Unfortunately the effects are limited due poor implementation of these activities.

SCG is one of the effective programs to reduce disability among people affected by leprosy. The implementation of SCG program in other countries had succeeded to reduce disability and improved physical, psychological, functional, economic, and social participation.

The objectives of the thesis are to describe and analyze the Self Care Group program for people affected by leprosy in Indonesia in order to find out the better strategy for the implementation of SCG in the future. It discusses about establishment, organization, activities within SCG, the impact to its members and the challenges to implementation of SCG program. It is based on the result of inventory study of SCG in 2007.

I hope that it will give an insight about the SCG and disability problems in Indonesia and attracts stakeholders such as local government, donors, community leader, health provider and community members; including people affected by leprosy and provide contributions to implement a better SCG program in the future. Hopefully the thesis will also induce operational research in the future to asses the progress and the impact of SCG.

1. Background of Information

1.1. Country profile

Republic of Indonesia is the largest archipelagic country that consists of more than 17.000 islands (only 6000 inhabited). It covers approximately 1.910.000 square kilometers. Administratively Indonesia is divided into 33 provinces, and further sub-divided into 440 districts and 70.460 villages.

Shaikh (undated) cites about Kroeger conceptual framework of Health System which mentioned about physical accessibility factors such as availability of transport, the distance to health service provider and time taken to visit health service or health provider will influence the utilization of health care services or health provider. In Indonesian context, wide areas of the country with sea, straits, and river are gaps thereby constraining the access to health services especially where transport system lacks. Distributions of material and health services such as drugs, vaccine, case holding, reporting and recording material to peripheral area are become costly. Furthermore, the long transport time often makes some drugs and vaccine ineffective.

Indonesia is inhabited by multicultural and multiethnic (300 ethnic) groups of people. Total population as on 2007 was estimated at approximately 228 million people with growth rate of 1,1% (World Bank, 2008). The productive age group (15-64 year) comprises 66% of the population (APCD, 2007). There is unequal distribution of the population due to rapid urbanization where more than 50% (130 million) inhabitants live in Jawa island (Jawa=Java) which has more job opportunities, public facilities and infrastructures. Half of population (48%) lives in urban areas.

Unequal distribution and multicultural population might have led to unequal distribution of health services. Shaikh also mentioned that culture will influence on how people link themselves with health system, how they access health information and promote their lifestyle. Different people with different culture will act differently in health care seeking behavior.

Twenty seven percent of population still lives under poverty line. To reduce this to half in 2015 (MDGs target) is a challenge for the government. Even though, World Bank (2008) mentioned that economic condition of Indonesia especially the public expenditure

situation in 2007 increased significantly with additional fiscal resources USD 15 billion due to reduction of subsidy of fuel in 2005. In combination with a GDP of USD 3500 per capita and an economic growth of around 4.9% in 2004 (APCD, 2007), Indonesia has a chance to achieve the MDGs target. The Investment on education is increasing significantly to 17,2% of National Expenditure in 2007 compared with 2006 which was only 3,8%.

Indonesia has been implementing district autonomy policy and decentralization of power to district level since 2001. Every province and district set their own priorities for development of their region. In terms of budgeting, Central Government still supports the provinces with National Development Budget. World Bank (2008) mentioned that 37% of national expenditure goes to peripheral government. Each province and district themselves have Province or District Development Budget that generate from local trading, natural resources, taxation and public services. This is the opportunity to get financial support form local government since they have more budgets from national expenditure.

1.2. Health profile

Huge population may lead to huge health problems while the ability of the state to provide health service is limited. The investment on health sector is only 1% from national expenditure. It contributes to 50,4% of total expenditure in health sector. Other 49,6% of total health expenditure comes from private sector, with 66% of it coming out of pocket. Social security fund for poor is 20% out of government health expenditure. The health expenditure is increasing since 2002 but it is less when compared with other sector such as education.

National Statistic Bureau (2008) mentioned in 2005 that the Life expectancy rate in Indonesia was 68,1 years. Compared with neighboring country in South-East Asia such as Malaysia and Philippines Indonesia is left behind. Data from World Bank (2007) is reports that the life expectancy Malaysia is 74 years, while that in Philippines is 71 years.

Infectious diseases still is the mainstay for children with 38% of all diseases. For adults, tuberculosis and malaria are the top causes of morbidity and mortality. However, it is expected that the prevalence of non communicable disease like stroke, diabetes and cardio vascular disease will increase, and consequently contribute to an increase in disability.

In Indonesia the National Coordination Committee on Disability is responsible for the implementation of the "The Act of the Republic of Indonesia Number 4 of (1997) concerning disabled people. According to the act, "Disabled person is someone who has physical and/or mental abnormality, which could disturb or be seen as obstacle and constraint in performing normal activities, and consisted of i) physically disabled, ii) mentally disabled, iii) physically and mentally disabled" (cited in APCD, 2007)

The national prevalence of disability is estimated 0.8% or there are 1.8 million people living with the disability in Indonesia. Men seem to be affected more than women (55.7% and 44.3% respectively) (APCD, 2007). The data shown below demonstrate the percentage of different kinds of disabilities.

Table1. Types of disabilities in Indonesia.

Category disability	Percentage (%)
Physical disability	37,0
Visual impairment	13,2
Intellectual disability	12,7
Hearing impairment	10,1
Mute	6,8
Psychiatric disability	6,7
Mute and hearing impairment	2,8%
Overlapping	10,7%
Total	100%

Sources: Statistic Center Bureau (2001) (cited by JICA, 2002)

Physical disability stated in the table is represents the motor impairment of the musculoskeletal system which leads to inability to perform normal activities.

The national survey on disabilities indicated that 65.6% of disability cases live in rural areas. It maybe influenced by the quality of services since most health facilities are located in urban areas.
More than half (53%) of people with disabilities are in the productive age group. This has social and economic consequences for both an individual and the community/nation. Children are particularly for disabilities. Out of all disable cases among school aged children was 21,7% and 44% of them did not attend the school (APCD, 2007). Thus it will impact to the quality of Indonesia human resources.

1.3. Organization of health services regarding Leprosy and Yaws Control Program (LYCP)

Leprosy control program is included in Leprosy and Yaws control program (LYCP) under Sub-directorate Leprosy and Yaws Ministry of Health of Republic of Indonesia. They are responsible for the formulation of national policy, binding corporation with donor agency, logistic (e.g. provision of national guidelines, provision of MDT drugs), training, coordination and monitoring-evaluation of implementation of the program.

The implementation of the program in the province level is managed by a Project Leader and assisted by Provincial Leprosy Supervisor (PLS). Project leaders have a responsibility for the leprosy control program in a province. Their tasks are coordinating, planning, budgeting and evaluation. They directly have link with donor agency and Sub-directorate of leprosy and yaws Ministry of Health.

PLS are responsible directly to Project Leader or their superior in the province health office. The task of PLS are coordination, planning, supervision, training, monitoring and evaluation of the implementation of the program in the districts within their province.

The implementation of LYCP in the district level is managed by District Leprosy Supervisors (DLS). Their tasks are to coordinate and maintain the implementation of LYCP in the Health Center (HC) level.
While the implementation of LYCP in the HC level is managed by Leprosy Field Workers (LFW). They are responsible for case management and other activities that deal directly with the patients such as SCG.

2. Statement of the problems, objectives and methodology

2.1. Statement of the problem

Self Care Group as a concept was considered as strategy was designed and started in 2000 in Indonesia. It was designed to empower PAL to do self care activities by them selves. Since year 2000 there are 124 SCGs have been established in Indonesia. The aim of SCG is to make them less dependent on health facilities to care for their disability.

After almost 8 years since it was established, SCG program still has many challenges. According to MOH (Sub-directorate leprosy and yaws, 2007) these challenges are:

- Stigma in the community; including self stigma and ignorance. Research by Bijleveld (1982) in Sulawesi, Elissen (1991) in South Sulawesi and Idawani et al (2002) in Aceh shows that self stigma is common among the people affected by leprosy in Indonesia. Especially if they have visible disabilities. It happened since they realized about the stigma in their community. It has lead to self retraction from the relation with their families and community.
- It is still an 'additional' or pilot project activity. It is implemented in some districts but not nationwide. In fact the efficacy of this activity in reducing disability has been proven in other countries.
- There was no regular training for the leprosy program manager in all levels (province, district, health center) to establish the SCG. Without proper training it retards the technical capacity of the health staff in managing SCG and undermining the effort to get the best impact.
- Donor dependency in financing SCG is still high. National data on SCG shows about 39/124 SCG were closed after the donor support from the donor had been stopped. The donor only set one year time frame to finance SCG. If they want to continue they have to find out other sources such as a local government budget or other donor.
- There is no reporting system which is implemented nation wide since it is just an additional activity. Therefore the impact of the program could not be properly measured at national level. It has hindered the LYCP to unveil the impact of the program and therefore they could not convince the

donor and other stakeholders to give more and continued support to this activity.

- The SCG program is still mainly focused on physical problems. The other aspect such as psycho-social and socio-economic problem have had never been address optimally.
- The support from local authority and other programs such as community based rehabilitation program to deal with the burden of disability due to leprosy are limited.

Indonesia is the country that was listed in the top 3 countries with the highest number of leprosy after India and Brazil (WHO). The numbers of registered cases in January 2007 were 21.430 (MOH-RI, 2008). The number of disability grade 2 among new cases is 8,6%.

Though the proportion of disability among new cases in Indonesia is less than 10%, the number of disability due to leprosy in Indonesia might be underestimated by several factors such as:

- The number of patients with disability grade 1 was not reported. Recording and reporting system that is available in LYCP of Indonesia mainly focused on disability grade 2. Therefore, it would be difficult to get data of disability grade 1 in national level.
- Under reported patients with disability due to misclassification of disability grading[1] and lack of recording and reporting system.
- Misclassification of disability grading still exist due to lack of skill and lack of experience. In my experience, the number of misclassification of disability cases approximates 5 – 10% it varies from one health center to the other.
- The patients who get disability during treatment are not reported
- The patients who get disability after release from treatment are not reported.
- Existence of backlog cases with disability, but it is difficult to predict since we do not have any information or experiences.

The rough estimation of the number of disable people due to leprosy in a year might include:

(Percentage of Disability Grade 1 + Percentage of Disability Grade 2 + Percentage of additional disability

[1] For instance patient with disability grade 1 classified as patient with disability grade 0 (normal) due to mistake on nerve function examination (POD examination).

during treatment + Percentage of additional disability after RFT) x new cases

The data from ministry of health shows that in 2007:

- New cases= 17.723
- Since there is no data on disability grade 1, we assume that this contribute to 5 % disability (It might be more)
- percentage of disability grade 2 among new cases is 8,6%
- WHO predict 10-20% of patient probably get nerve impairment during treatment and after release from treatment. We assume that this contribute to 5% disability (disability grade 1=2,5% and disability grade 2=2,5%)

So the number of disable people due to leprosy in 2007 might be:
(5% + 8,6% + 2,5% + 2,5%) x 17.723 cases = 3.296 persons.

Based on the data from ministry of health the accumulation of the number of people with disability within 15 years[2] would be almost 50.000 cases.

The significant percentage of disability was mentioned by Depak (cited by Cross, 2007) that based on his study in Myanmar, Indonesia, and India the disabilities after RFT was between 17-50%. If we calculate with this percentage, the number of disabilities in Indonesia will be much more. Therefore SCG is established in respond to disability burden and change of the vision of health services from bio-medical to bio-psycho-social concept (Abera and Lemma, 2003).

2.2. Objectives and methodology

2.2.1. General objectives of the thesis:

The general objective of the thesis is to describe and analyze of SCG in Indonesia in order to find out the better strategy for the implementation of SCG in the future.

2.2.2. Specific objectives:

The specific objectives of the thesis are:

1. To describe and analyze the situation of SCG program in Indonesia and other countries
2. To analyze the steps of establishment of SCG in Indonesia.

[2] With assumption the percentage of people with disability among new cases is the same as above mentioned (18,6%)

3. To analyze the role of related stakeholders on SCG program in Indonesia.
4. To analyze self care activities within SCG.
5. To analyze the impact of SCG on the SCG members.
6. To identify the challenges of SCG.
7. To give input for the strategy that should be done for those challenges.

2.2.3. Methodology of the thesis:

Study type
The thesis is a descriptive study which consists of 2 part: literature review and review of secondary data of inventory study of SCG. Literature review was done by browsing internet using search engine google scholar and Pubmed. Keywords: Indonesia, leprosy, disability, self care, self care group, self help group, and community based rehabilitation, socioeconomic rehabilitation. The common visited websites are Science direct, Picarta, World Bank, UNDP, WHO, and Ministry of Health of Indonesia.

a. Study location and population.

For the inventory study of SCG the study location is mainly Indonesia and 20 Self Care Group in Indonesia. With additional data from report of self care program in other countries like Nepal, India and Ethiopia were also obtained from the literature review.

b. Data collection technique.

The data from literature review was obtained by searching the internet. Secondary data from SCG evaluation in 2007 is used to reflect the SCG situation in Indonesia. Primary data was collected by the author together with National Leprosy and Yaws Consultant team.
The SCG inventory activity was obtained through systematic monitoring visit. The procedure was as follows:

In 2007, NLYCP conducted an inventory of SCG. Twenty of SCGs have been randomly selected to be interviewed by National Leprosy-Yaws Consultants. Six SCGs had been closed but the LFW and group member could still be interviewed. We used a questionnaire with close and open questions during the SCG meeting.

The questionnaire consisted 4 parts:

I. Discussion with responsible health staff
Twenty four questions concerning administrative issue (facts, figures, results) were asked to DSL or LFW before the group meeting started.

II. Observations during the meeting
The interviewer used checklist to observed 18 SCG meeting (14 SCG were still active group, 4 were in-active/stopped but we called them back for this occasion). The checklist contained open question about 12 aspects of SCG activities, group dynamic, role of LFW, group leader and group members.

III. Discussion with the members
Group member of 19 SCG were interviewed (14 active SCG and 5 stopped SCG) with 7 open questions about their opinion regarding membership, benefits of SCG and their expectation in the future.

IV. Personal opinion of the interviewers
The interviewers were asked about positive progress and the aspects which need to be improved.

At the end of data collection process the filled in questionnaires were all sent back in time. The data were processed in Excel database and summarized in a table by Netherlands Leprosy Relief (NLR) rehabilitation team that is supporting Indonesia NLYCP for rehabilitation program.

c. Data processing and analysis

Quantitative data will be analyzed by cross tabulation technique using Excel database program.
Qualitative data was being grouped according to frequently mentioned and was displayed on table of each SCG. The data analysis was discussed within the result and discussion section.

d. Ethical consideration

For the data of SCG permission for interview had been asked to interviewees verbally without written informed consent. Regarding the secondary data being used for the thesis I have asked permission, verbally and by e-mail, to Netherlands Leprosy Relief (NLR) especially to Kerstin Beise who is responsible for Rehabilitation project in Indonesia with whom I collaborated with during SCG evaluation in 2007. They allow me to use the data appropriately. I also asked

permission to use the secondary data about leprosy situation in Indonesia from MOH-RI trough Sub-directorate Leprosy and Yaws.

e. Limitation and biases of inventory study

For the inventory of SCG data, the clarification would hardly be done because this is retrospective study. The data might be incomplete or unavailable for some issues that might be needed to be presented such as on how many people exactly who feel that after have been joined SCG their social relationship improve. In this case I will combine the data with secondary data from Sub-directorate Leprosy and Yaws MOH-RI, the result of interview with the health worker and patients during supervision, other supportive data from other countries experiences obtained through literature review. The interviewer bias, include of the author bias, might have occurred since there were no specific criteria in measuring performance and we also responsible for the successful of SCG program. The situation and condition during observation of the meetings had not been defined.
The questionnaire never pre-tested before used. The interview did not use tape recorders so it has been difficult to get confirmation of the written information.

3. Literature review on the self care and Self Care Group

On this section will be discussed about self care activities and SCG for people affected by leprosy and the impact to the group members. This section also will discuss slightly about SCG for diabetes people as a comparison to SCG for people affected by leprosy.

SCG is a kind of community based rehabilitation program that mainly focus on people affected by leprosy.
According to WHO/ILEP (2007) CBR is a strategy which is involve community (includes NGO, government, health provider, and people with disability them selves) for rehabilitation, equalization of opportunity and social inclusion. It set up to facilitate to better access on basic needs of all people. The principles of CBR are include inclusion, participation, empowerment, equity, raising awareness, self advocacy, facilitation, gender sensitivity and special needs, partnerships, and sustainability. All principles of CBR are related to SCG and will be reviewed also in the findings and discussion section.

WHO/ILEP (2007) mentioned that leprosy is affects negatively to people's lives because it causes physical disability and daily activity limitation, psychological problems, social problems, and economic problems. Therefore the literature review will be set up based on these issues.

Psychological problems are includes self stigma, fear, low self esteem and feeling hopeless. Social problems are includes restriction on social participation, inequity, rejection by family members and community.

SCG is set up to become catalyst of community empowerment. It is try to help the member and the community became their agents of change through capacity building. Health worker will only become an external agent as facilitator to build up their capacity. It was Freire's with his theory of conscientisation (cited by Cross and Choudhury, 2005) who said that "*marginalized people can go through a process which enlightens them to the latent power they have, to address problems. As they become enlightened and start to utilise that power, they become their own change agents*"

The impacts of self care and SCG for the members regarding to those problems are:

3.1. Reduction of physical disabilities and daily activity limitations.

3.1.1. SCG for leprosy

Cross (2007) study in Nepal shows that 2 weeks intensive training has done for a group of people affected by leprosy with plantar ulcer. After 3 month they were evaluated and the result shows that the people who were joined the training are likely get less infected plantar ulcer (with odds ratio of 1: 1,8). Cross (2007) also mentioned that the result of self care training was impact on both their skill and knowledge to solve their limitation due to physical problems and their lives.

A study by Ethiraj and Mathew (cited by Cross, 2007) also mention that knowledge and practical input for people with disability both in group or individually increase positive change in self care behavior. The target people were more aware to do self care and as the result prevalence of simple ulcer reduce by 50%.
But Abera and Lemma (2003) mentioned that level of self concept of the SCG members is better than non-SCG members. They gain a benefit of it so they know how to asses themselves and their ulcer problem. It also increased their ability to manipulate the environment and manage their ulcer.

Kemper (cited by Cross, 2007) mentioned that self care education program reduced the utilization of health care unit since the target group more responsive to symptoms of acute illness and other related ulcer problems.

SCG in Indonesia provide protective device such as footwear. Proper footwear is related to the assumption that occurrence of an ulcer cause by repetition of pressure on insensitive foot, but Cterko (Cited by Cross, 2007) mentioned that ulcer was not mainly due to pressure on foot because the contra lateral feet of subject also got the same pressure. The other factors such as vascular abnormality and infection also contribute to the ulceration.
The study of suitable material of footwear for people with insensitive feet is still pro and contra issue. Micro cellular rubber mentioned to be suitable material but other study mention that commercial sandals or shoes presently are used proper material to reduce pressure on feet. A study by Seboka (cited by Cross, 2007) in Ethiopia shows that 75% of plantar ulcer are heal after 1 year wearing commercial shoes.

Benbow and Tamiru (2001) mentioned that in Ethiopia the SCG members shown better responsibility to manage and monitor of their wound healing. They also provide the materials for self care at home by them selves. They used the group dynamic as encouragement and accountability to support each other in self care such as how to manage the wound at home and get wound healing materials. They are also more responsible to personal hygiene and self performance.

Cross and Choudhury (2005) interviewed 104 SCG members from 5 SCGs in Nepal. He said that all SCG members expressed their satisfaction since they have control over their impairments and they feel more independent of medical service. They got benefits from emotional and practical support from other group members to continue self care activities.

3.1.2. SCG for diabetes

Apelqvist said that diabetic feet tend to be long life disability since the patients are having the chance to get ulcer anytime. The diabetes patients with diabetic feet are often having negative behavior since they were thought that pain is the symptom of foot ulceration. In fact they have insensitive feet and will not realize of ulceration symptoms. That is why they are less to seek foot care and followed advices. It might leads to more severe ulcer and daily activity limitation, leisure activity, and employment. Apelqvist said that the patients need information about their disease and they need long live self care to reduce ulceration and amputation.

Cross (2007) mentioned that ulceration could be prevented protective footwear, but he also said that many studies show that poor fitting and inappropriate footwear causes feet ulcers in diabetic patients. The aberrations from inappropriate footwear contribute to ulceration. Cross said that the patients need to be informed and get access to a program that offers podiatric appliance service such as self care group.

Although some evidence shows the efficacy of self care in preventing ulceration in diabetes patient but the study on self affected impairment control was limited. The healing process needs both self care activity and self esteem of the patients, the feeling that they are able to control the healing process.

The literatures show that the result of SCG in reducing physical disability and activity limitation is better in comparison with the individual self care. The SCG members get positive influence by other members through encouragement and discussion. The SCCG members enhance self esteem better so they get internal power to be more active in practicing self care at home.
Diabetes patients have the similar problems with people affected by leprosy. They experiencing insensitive feet due to neuropathy that tend to be permanent and they have long live chance to get ulcers.

3.2. Reduction of psychological problems

3.2.1. SCG for leprosy

Waxler mentioned (cited by Cross and Newcombe, 2007) that the burden of leprosy is not fully due to the bacteria, but it also influenced by social beliefs and the expectation of the society where people affected by leprosy live. Cross and Newcombe (2007) mentioned that ulcer prevention by the people affected by leprosy is not only reflect the knowledge and skills but also reflect their attitudes and self esteem.

Cross (2007) said that level of self efficacy is also influence their motivation and adherence to positive health behavior. It reacts to the popular beliefs that motivation also could lead to negative health behavior. Therefore the most important role of facilitator is to direct the motivation of the patients become positive health behavior rather than negative behavior. He said that the facilitator should guide the patients to develop their skill in order to gain their internal empowerment.

Cross and Newcombe (2007) mentioned that self care could be implemented in adverse physical environment since the major environmental barrier for implementation of self care are not physical or economical but psychological factors. He said that self potential could be increased if psychological barriers are overcome. Optimisms and encouragement will leads to perceived self efficacy.

Vileikyte (2006) mentioned that specific emotion will influence to specific self care behavior. Worry leads to positive self care behavior while anger leads to negative self care behavior. It shows that

understanding emotional conditions is appropriate to motivate the patients.

Benbow and Tamiru (2001) mentioned that SCG in Ethiopia shows the improvement of the self esteem, sense of belonging within community and dignity of the group members.

3.2.2. SCG for diabetes

Apelqvist (2008) mentioned that psychological factors are important determinant for the outcome of diabetic ulcer. Perception of risk is influence by the symptoms, their expectancy and their beliefs on efficacy of self care It can affect self care practice. If the patients do not realize the risk that might be happened to their selves, they might be taking no actions.

Apelqvist (2008) said that poverty, social isolation and low of education of the diabetes patients are high risk factors for bad quality of health status since they may have less access to health facilities. The diabetes patients with ulcer or amputations are also often suffering from depression. It may leads to poor quality of life. They might need psychological and social support from other people (family members, neighbors, friends and facilitator).

Based on a study in Indonesia, Kanbara (2008) mentioned that the elder patients who are supported by their children have higher level of emotional and behavioral support compared with unsupported group.
Both of emotional and behavioral support will increase the self efficacy and reduce emotional stress that may lead to improve physical conditions. In addition religion is also contributes to positive behavior and reduce psychological stress.

Adolfsson (2007) did comparative study on self care group on diabetic type 2 with individual counseling group. The result shows that compared with individual counseling patients the self esteem and self worth of the group members were highly increased, while the feeling of self blame was decreased. They feel free to discuss their disease with friends and relative.

The literatures show that in both leprosy and diabetes cases the psychological aspects are very important to be addressed. It influence in reduction of disabilities and also to increase self esteem and positive perceptions of their problems. SCG increased self esteem and reduced self blame better than individual self care.

3.3. Reduction of economic problems

3.3.1. SCG for leprosy

Cross (2005) said that in Nepal the SCG members taught to read to avoid unscrupulous loan sharks and they got legitimate banking services to get soft-loans.
The women members change their job to micro-enterprise and generate sufficient income so they do not have to work in agriculture daily wage work. It also will reduce ulcers occurrence.

According to the author experience, in Indonesia some SER program has been proven increase the economic status of the SCG members. The author involved in setting up SER project in 3 SCG in two provinces with revolving goat project. The SCG members had been given 2 goats per person. After 2 years the SCG members should give 2 goats back that will be given to other persons. Within 2 years they succeed to breed the goats and be able to return 2 goats. Some of them even sold something to buy more goats since it was profitable. Within 3 years they have 10-15 goats on average. The market is available within their village. One of their healthy neighbor even asked facilitator to join SCG and to get SER support.

3.3.2. SCG for diabetes

Apelqvist (2008) mentioned that foot care program for diabetes is cost effective if the ulcer and the amputation incidence reduce more than 25%. It will more cost effective if healing process is faster so the patients need less frequent dressing.
It is indirect economic support since the patients do not need to buy material and drugs for wound care. By reducing ulcer and amputation the patient can work and earn money for them selves and their family.

The literature shows that by reducing disability may increase their ability to work and increase their economic status. They also do not need to pay for health care fee. Another benefit of being the SCG members is they have better access to SER support provided by donor or other finance supporter such as bank, local government and CBR project.

3.4. Reduction of social problems

It includes relationship, interaction and participation between SCG members and their family and community.

3.4.1. SCG for leprosy

Valencia (cited by Cross and Newcombe, 2007) strongly suggested that to asses the effects of leprosy it need to consider not only psychological problem but also social problems with all consequences for the affected person, their family and their community

In Ethiopia the SCG increased their confidence to participate in society. They are paid more attention to their environment and sanitation by building latrines and waste disposal sites (Benbow and Tamiru, 2001)

Cross (2005) mentioned that in Nepal the SCG members got their right to access the worship place (temple) by encouraged each other to get their right. They feel better community acceptance after being the SCG member.

The SCG also encouraged to be participated in village survey to explore the priority needs of community. Then they take initiative to set up the projects. All negotiation and bureaucratic demands were handled by the SCG members. They contribute to finance the project together with local government and NGO. The projects are:

- Early Child Development.
- Non formal adult literacy.
- Building community and domestic toilets.
- "Care Haven" for abandoned elderly people.
- Leprosy awareness campaigns (mobilizing schools to conduct village parades).
- Defaulter tracing and case detection (for many local people, SHGs are the first consultation point when leprosy is suspected. Over 238 people suspected to have leprosy were referred by SHGs to Health Posts, where 215 cases were confirmed. 54 treatment defaulters were restarted after being traced and counseled by group members).

- Installation of wells and hand pumps.
- Small scale environmental hygiene projects
- Creating access to public areas (pathways) for underprivileged groups.
- The groups combined efforts and resources to establish a stall at a major Hindu festival. From the stall, they offered free snacks to a considerable crowd of devotees. (A banner identifying them as leprosy affected people was prominently displayed).

Cross (2005) followed up the participation of SCG members within their community in Nepal. He found that only 7% of SCG members still suffered significant participation restriction. It is better compared with the non- SCG members that 40% among them have suffered participation restriction.

3.4.2. SCG for diabetes

Adolfsson (2007) mentioned that compared with individual counseling patients the self care group members have better relationship with facilitator and other group members. They gain mutual communication and supporting each other. They did not shy to ask questions and sometime they got the answer of subconscious questions from other members.

Their self control was also increase. They change their lifestyle habits because they understood the importance of diet control, regular exercise, taking care of their feet, controlling blood sugar and reduce body weight and it impacts to their body.

The patients know when they could allow themselves to eat food that they knew it is bad for them without feeling guilty because they understand the limit when they should stop and back to their healthy diet. It keeps their relationship with relatives and friends indirectly, since they do not have to be afraid to go to invitation from their relatives or friends.

The literature shows that SCG member gain encouragement, empowerment and support from facilitator and other members. It made them get back their rights to actively participate and interact with their community. Their confidence and active participations will gain better acceptance from their family members and community members.

4. Study result on SCG in Indonesia and discussion

4.1. Situation of self care group in Indonesia

Indonesia have been established the first SCG in year 2000. They learn the concept of self-care groups in leprosy from ALERT, Ethiopia, in 1999.

MOH-RI (2006), mentioned that the objectives of SCG in Indonesia are not only addressing the impairment and disability but it also promoting reintegration of it members into community. The objectives are as follows:

1. To prevent or reduce disabilities.
2. To solve leprosy related problems among group members by support each other.
3. To promote using simply-applicable material (cheap, available at their home).
4. To be more efficient and effective in evaluate and monitor the disease, impairment and disability among group members.
5. To ease referral process for the members if they need to be referred for specialized health care.
6. To increase self dignity and active participation in social life.
7. To eliminate leprophobia in community and self stigma.

It also mentioned that hopefully by joining the SCG PAL will get benefit such as:

1. They get information and education to do self care by discussion and direct practice by them selves. Increasing their knowledge, attitude, and practice about leprosy and related issue.
2. They can see the improvement of other members so they are more motivated get better condition of their disability, reducing limitation and morbidity.
3. They can share their experienced among themselves without shy or afraid because they have similar problem. It would increase their self esteem.

Other benefit of SCG is they are examined regularly. It would detect NFI early. SCG activity also will increase awareness among the group member and the community surrounds them. They also could get benefit of socio-economic support since some SCG also provide socio-economic rehabilitation (SER).

Compared with CBR, SCG program in Indonesia mainly focused on physical disabilities and activity limitation. It also supports few SER program, raising awareness and psychological problem in small part through group discussion.
Unfortunately the other CBR principles such as inclusion, participation, empowerment, equity, self advocacy, facilitation, partnerships and sustainability have never been done properly.

4.2. Steps of establishment of SCG in Indonesia

In the national guidelines of SCG the steps to establish SCGs are as follows:

- Proposing process: the health center proposes to the district Health Office (DLS) at the district and he/she will propose to PLS at the provincial level who then puts it on their annual budget proposal to the donor (Netherlands Leprosy Relief) for the ensuing year. Sometimes the proposal comes from the DLS PLS directly.
- The budget approval process: usually every SCG proposal will be approved by NLR, but it is only for the first year. After that if the district intends to continue the activities they have to find other financial resources.
- Preparation process: This is usually done by LFW and DLS and involves selection of members, preparation of venue, tools and materials.
- Facilitation process: the initial meeting is usually held at the HC. The LFW and DLS facilitate the meeting; explaining the objectives and benefit of SCG that might be achieved together. The member will be asked to come every 2 weeks in the first three months and after that meet monthly.
- Organizing process: after 2 or 3 times meetings, the LFW will guide the group to choose the group leader who will be responsible for counting attendance and discussion process. The task-shifting process from the LFW to the group leader is done step by step. At the end, all activities will be done by the members and group leader. LFW will then become the passive facilitator and observer.

4.3. The role of related stakeholders on SCG program in Indonesia.

4.3.1. The role of Ministry of Health:

- The MOH roles are to make policy and national guidelines for SCG program.
- To promote implementation of SCG
- To maintain financial support from donor.
- The MOH also promote integration of SCG program with existing CBR program and cooperation with other sector, and other department. Unfortunately there is no significant support from other sector or CBR program to SCG for people affected by leprosy.

4.3.2. The role of the donor (NLR):

- NLR contributes to financial support. They give the initial budget for one year frame time. The aim is to stimulate the local authority to find out other source of fund to support SCG program to sustain.
- NLR also hire National Consultants for rehabilitation and NCLY to give technical guidance to increase technical capacity of facilitator, DLS and PLS to manage SCG.
- NLR provide material of SCG such as SCG tools kit, protective footwear and IEC material. Rehabilitation consultants also provide and distribute bulletin as IEC material for all SCG in Indonesia.
- NLR also support Socio-economic rehabilitation (SER) scheme in few provinces but it is not the priority program. It applied only in 10-15% of total SCG. The kinds of the SER activities are "revolving goat" scheme, micro-credit loan to provide jobs for the members such as motorcycle-taxi driver (Indonesian language = *ojek)*, farming and fishery credit, and scholarships for people affected by leprosy children.

4.3.3. The role of the PLS:

- To initiate the SCG establishment and help district to get financial support from the donor.
- To promote of SCG program to district Health Manager during supervision.
- To supervise the DLS in assist SCG in health centers.
- To monitor and evaluate of SCG programs within the province.

4.3.4. The role of DLS:

- To select the HC that appropriate for establishment of SCG
- To promote to the HC manager about SCG
- To supervise leprosy health worker in manage the SCG.

4.3.5. The role of LFW:

- To select the SCG members.
- To prepare the meetings.
- To explain SCG to the members.
- To lead the discussions.
- To explain how to do POD and self-care in practice.
- To motivate the members to be actively involved in the activities.
- To guide and empower the group leader to be able to do his/her tasks.
- To monitor and evaluate the group.

4.3.6. The role of the group leader:

- To inspire the members to attend the meetings.
- To Support group members to solve problems in self care, to recognize any improvements.
- To encourage group members to be more active during the meetings, asking questions, answering the questions, express their feelings, tell their problems, and explain how they did self care at home.
- To take over administrative activity such as filling recording or examination forms, if he/she is willing and able to do so. (Ideally LFW should empower and guide the group leader to be able to do this task in order to make the group independent from LFW and HC)

4.3.7. The role of the group members:

- To join the meeting and learn self care activities.
- To do self care at home regularly
- To support each other
- To give feedback to facilitator about difficulties, failures and achievements for better planning
- To support case finding

4.3.8. The role of the family members:

- To remind and help the group member to do self care at home
- To give psychological support
- To allow the group member to join the meeting

4.3.9. The role of community:

- To give space and support the group members to access the SCG

The role of the health provider (PLS, DLS and LFW) is mainly too focus on technical and organizational to achieve physical well being. Involvement of the community and empowerment of the SCG members are left behind. The role of SCG members still become the objects rather then agent of change for them selves and community. Networking with other local resources (local government, local industry, community leader, religion leader, teachers and local donor) is still abandon. There is no role to assess the needs of SCG members to guide them to fulfill their needs.

4.4. Self care activities within SCG.

According to National Guidelines for SCG the activities during the meeting are respectively as mentioned below:

- **Opening:** A meeting is opened officially by the facilitator (health center staff who are responsible for SCG) or by one of the members to increase group ownership. The group members and the facilitator should sit together in a circle.
- **Attendance check:** the group leader checks the attendance of the group members. The reason of irregular attendance should be known and facilitator has to motivate them to attend the meetings regularly.
- **Examinations:** All members should be examined regularly at each meeting, because only then is it possible to monitor the *development* of disabilities. It is also important to motivate the members by pointing out and praising improvements, to correct

self-care practices in case of worsening, and to evaluate the results of the group in order to decide continuation of the SCG.

- **Basic self-care program:** Soaking the wound in clean regular water, trimming the dead part of wounds and thick skin and oiling the dry skin are the basic self care to be done at home.
- **Special self-care program:** They are also taught how to dress wounds and other special self care for any kind of disability. It is practiced by everybody. The facilitator only gives supports only when it is really necessary.
- **Discussions:** During discussions the members are given opportunity to ask questions, talk about their problems, and share their experiences on how to do self care at home and how they overcome other problems such as social life problems. They also will be directed to understand their own problem, how it happened, and how to solve their own problems.

4.5 The result of inventory study of SCG in Indonesia.

In this part a number of issues regarding SCG which were inventoried will be describe and analyzed. These elements are:

4.5.1. Empowerment

- Eight out of twenty (8/20) SCGs have a specific name while the other 12/20 used the name of HC where the meeting was conducted. Maybe the facilitator did not offer the opportunity to choose specific name. Naming the group with specific name selected by group members appears to increase the ownership of the group. Ownership is important to maintain the responsibility of the group members. Naming the SCG with the name of the HC encourages dependency on health facilities and may delay the process of making SCG more independent.
- In 16/22 of SCG the health worker had the role as the facilitator, in 2/22 of SCG the facilitator was the group members, in 1/22 of SCG facilitator is the group leader and in 1/22 the facilitator is the village worker, and in 1/22 the DLS were mentioned as additional facilitators. It showed that the role of the health workers in most cases was still dominant. It might hinder the empowerment process for SCG members. But

the involvement of SCG members as facilitator gives a new sign of empowerment of the SCG members.

- Distribution of medicine was still a part of the routine in 13/20 of SCG such as symptomatic drugs, reaction treatment and MDT. Only one group used medicine for wound care. SCG should have a more non-medical character in order to become independent. Dependency on medical treatment is still high, mostly because of the characteristic of the disease itself and perception of the group members.
- Asked for the preferred meeting place, 14/19 groups preferred the health centre or a clinic, 5/19 preferred the village. The reasons for the health centre were that the treatment can be obtained at the same time was 8/14, that the staff is friendly and familiar was 2/14, and that they fear stigma in the village was 2/14. The members prefer to have meetings in the village because it is close to their homes were 19/19. It shows that the SCG is still a clinical base rehabilitation when the aim of SCG is community rehabilitation. More efforts and support are necessary to bring SCG into community. We should realized the needs of the members and bring the service to community. It would not be easy to be achieved only by HC staff. Promotion and advocacy is very important to get supports from village leaders, family members, community and the members themselves.
- All of SCG preferred health workers to be facilitators. The group leader only acts as an additional facilitator if the facilitator could not attend the meeting (2/20) (The role of health worker is still dominant so the members are dependent. This condition should be analyzed to find out the main determinant factors. The failure of transferring knowledge and skills, lack of encouragement and empowerment are few of the possibilities. On the other hand the SCG need the leader figure that could help them to solve their health problems, and the most reliable person that has close to the community members and understood of the situation and condition of SCG members is the health worker.
- According to the interviewers, the important determinant factor to make a SCG functioning well were the maximum support from the district government, the HC doctor and head of the HC, the health workers, hospital staff, cadres or village staff. The appropriate monitoring system and a good relationship between members and health staff are very important.
- According to the interviewer more support by HC doctor in medical treatment was needed for medical problems including

reactions. Furthermore there is the need to provide better referral system and guidelines for referring patient to more comprehensive institutions such as hospitals.

- Supervision has been conducted in 18/20 SCGs, usually by the district staff. Supervision from province or national level was rare. A checklist was only used in 2 cases. Reports were written to the district and only in 4 cases to the province. This question was incomplete since it did not reflect the frequency, regularity, and the quality of the supervision.
- Interviewer mentioned that more supervision was needed from district and province at the beginning and in the course of performing a SCG. Recording and reporting needed to be improved, including evaluation of results after a certain time.
- According to interviewers regular training and On Job Training (OJT) for health workers and group leaders in self care is necessary.
- According to interviewer facilitation skill needs to be improved by having better training and OJT for health workers and group leaders in order to achieve the empowerment of SCG members.
- Discussions developed during most of the meetings 16/18. Reasons for wounds were discussed in 13/18 of meetings, footwear was inspected and discussed in 7/18 of groups, and non self-care related topics were discussed in 9/18 of groups such as social life, their job and SER activity. Discussion would give better insight about their disease and disability, how to prevent the occurrence of the ulcer, what they need to do at home, when they need to go back as soon as possible to HC and how to find out solutions for their social problem.
- Health education material was available in 14/20 of groups. This is important material so the group member can read again when they back to their home.
- The participation of members in these discussions varied from good to fair. Most of the members however were involved in conversation with other group members who sat next to them, and most of the members had been interested in the activities. The comfortable and relaxing atmosphere was described by 17/18 of the group but 1/18 mentioned that the atmosphere is too formal. The atmosphere of the meeting place is important for the group dynamics and interaction between the group members. Free and comfortable atmosphere might induce free discussion and attract the members to come regularly.
- According to the discussions, physical and medical problems seemed to be the main problem for the members: Ulcers, clawing fingers, lagophtalmos, reactions, hard work and low

self esteem. Medical problem is the most challenging part to make the SCG independent from the HC. In fact most of the medical problem could be prevented by doing self care routinely. Ability of the members to do self care is influenced by the quality of health education and discussion during SCG meeting.

- Problems concerning doing self-care at home were as follows: working 6/16, slow progression of wound healing 3/16,boring to do self care alone 3/16, having little problem so they neglected self care 2/16, inadequate information 1/16, complication such as reaction 1/16. Working was prevented wound healing due to lack of times to rest the wound and limited time to do SC. Wound healing therefore often progressed slowly.
- According to the interviewer home visits should be considered as an alternative approach to teach self care for those unable to come.
- Mc Murray, Brannon, and Feist (cited by Abera and Lemma, 2003) mentioned that the patients or clients, on this case are SCG members, are biologically, socially functional, and primarily responsible for their health. He said that participation and contribution of individuals to maintain overall well being is need to be encouraged.

4.5.2. Sustainability

- Fourteen out of twenty (14/20) of SCG were still active at the time of the visit while 6/20 was closed. Of those active groups 8/14 were still within the 1 year frame, while 6/14 groups were active for longer than 1 year (only 2/6 of them were financed by NLR with 4/6 financed by local budgets). The sustained groups were the SCG that got finance support from local government after 1 year frame. It shows the importance of the role of local authority to sustain SCGs after the donor stopped their support. Even the local authority has more budgets for health since decentralization law unfortunately the local government support is still difficult to get since SCG is not health priority. It depends on bargaining power and commitment of the local health authority to support SCG program.
- Based on the personal discussion (it did not written in the questionnaire question) the reason for closing the 6 groups were the problems of organization and facilitation (3/6), the

great distances (2/6), and budget support from donor was stopped (1/6).

- The organization and facilitation problem could be rise from both facilitators[3] and the group members[4]. The long distance of the meeting place hinders the SCGs members to come to the meeting. It caused by lack of transportation, expensive transportation fee, it take long time journey while they need to do domestic work or take care of young children. The activity stopped after the budget was stopped since there is no local budget available to support SCG program
- In 14/20 of the groups, some people left the group mainly because they were too busy 4/12, died 3/12, moved 3/12, too old 1/12, they were disappointed since they feel they do not get sufficient information about self care activities that can read at home such as hand out 1/12. Others thought they did not need the group anymore after they could heal their wounds. Some group members could not afford the transportation fees.
- According to the SCG members the main problems that hinder efficacy of self care activities was the occupation of the members which needs more physical activities, such as with farmers and laborers, which was mentioned in 16/32 of the groups. Ignorance 4/32 and inconsistency of members was another reason 6/32, and reactions 2/32 and complications 4/32 was often a hindrance to wound healing. Dilemmatic problem of wound healing or other disability prevention is when it is hindered by their job which earns them their living.
- Snack was provided in 14/20% of the groups. Transportation fees were reimbursed in 13/20% of SCG. In 3/20 cases (settlement, hospital, village), no transportation was needed. Fifteen percent 3/20 SCG did not reimburse transportation costs. Of those groups where members were reimbursed, in 7/13 the same amount was given to all members, in the other 6/13 they paid according to the real costs. The average was Rp 8,000 ($ 0,9). The cost for transportation and snack is included in the SCG budget. It will decrease greatly if the meeting place was located in their village but the problems were limited number of PAL who lives in the same village mostly in the low endemic area and sometimes the group members do not want

[3] such as uncertain meeting schedule or keep changing because facilitator was busy, meeting place in the health center used for health staff meeting and there is no planning for activity during SCGs

[4] such as the SCG members did not come regularly, decide to stopped early as soon as their ulcer healed and the group leader being inactive.

their neighbors to know about their disease in areas where the stigma is still high.

- It was in only 7/18 of groups that most of the members wore proper footwear. The groups in which about 50% of the members wore proper footwear were 22%. The group which few of the members wore proper footwear was 7/18. Proper footwear is the indicator of the understanding of the member of feet protection and the ability of the program and the patients to provide it. Sometimes facilitator had given the footwear to the group member but they were not used everyday. Fifteen out of twenty (15/20) of the members would like to continue the SCG, 2/20 would like to stop after a certain time, 2/20 had no idea and 1/20 want to continue with other activities. There is no ideal time to stop SCG in national guide lines for SCG. Usually it would be stopped after 1 year time frame due to disruption of the financial support from the donor. In fact it depend on the need and ability of the district and provincial leprosy manager to provide support for continuation of the program

4.5.3. Inclusion

- The average number of members was 10, and the ratio of female: male was 41:59. One hundred and eight out of two hundreds and forty three (108/228) of members were in the age group 16-40, 84/228 were older than 40 years, and only 36/228 were children (<15 years). The data about this fact are a bit shifted because one of the visited groups (an "association" in East Java) had 32 leprosy affected school children as members for the purpose of treatment. The general situation in Indonesia shows that percentage of children in SCG is small, the author predict less than 10%. It shows that the majority of SCG members are in the productive age. Disability may reduce their capability and productivity for income generation. At the end it will affect their economic status.
- Two hundreds and fifteen out of two hundreds and forty five (215/242) of the members were released from treatment (RFT), while 27/242 were still on treatment. The people affected by leprosy still have the chance to get reaction and nerve damage after RFT. SCG could help in monitoring people affected by leprosy after RFT since they will not get POD examination after RFT. This role is very important since the surveillance system was not practiced in most of the HC in Indonesia.

- A hundred and thirty one out of two hundreds forty one (131/241) of the members had disability grade 2, while 33/241 had grade 1 and the members with no disability was 77/241. The proportion of disability grade 0 is high since the members of the associations of leprosy in East Java were not mainly looking at physical rehabilitation but on socio-economic rehabilitation, and who have a large number of members, many of them without disabilities. The real proportion of disability grade 0 among SCG members is predicted less than 10%. People with disability grade 2 are main target of SCG in Indonesia but people with disability grade 1 or 0 allowed to join SCG if they intend to.

4.5.4. Psychological problems

- Family members or neighbors were joining in the group meeting (9/20 SCGs). The family members who joined the SCG meeting were parent or children of the SCG members, and their spouse. The other 11/20 has neither family member nor neighbors. This condition could promote integration to their family and community, reducing stigma in community and promoting awareness of leprosy and its disability burden. It also reflects that stigma in community and family is reduced.
- No people with disabilities due to other causes than leprosy were group members. Integration or combination with other group of PWD has not become the agenda of SCG program.
- According to the interviewer counseling and the involvement of family members to support SCG at home should be paid attention.
- Asked about their feeling about the SCG, most (41/43) members had positive comments as follows: that they were happy or proud was 10/41 SCG members, became more self-confident and reducing stigma was 8/41, could reduce their impairments was 7/41, it is useful 7/41, had an opportunity to meet and share 5/41, gained more knowledge was 2/41, may have the chance for income generation was 1/41, and could get a free examination was 1/41. Those who gave negative comments (2/43) concerned the failure of wounds healing 1/2 and 1/2 mentioned of pain during exercises; probably due to reaction.

4.5.5. Physical disabilities and activity limitation

- Eleven out of twenty (11/20) SCG has the new members who joined the meetings later on. Either they heard about it and joined voluntarily or they had been encouraged by the health worker) SCG could promote awareness its members to reduce their disability, and the active facilitator had done a great job in promoting SCG. It means facilitators need to motivated to actively promote SCG.
- The interviewers also saw SCG as a good exercise for health workers to get more accustomed with self care, and as a strategy to increase new case detection.
- In order to practice self care during the meetings, basic equipment (basins, rubbing stones, oil) was available in 95% of the groups, but other extensive equipment, like trimming gear, sunglasses, finger splints, cloth for dressing and gloves could only be found in 30% of all groups.
- Footwear was distributed in 16/20 groups, but in sufficient number only in 8/16 of the groups. Eleven out of twenty (11/20) of the groups have no plan for the distribution of footwear. Only 9/20 had thought about this, and they had give different solutions: they provided 1 pair per year or 5 pairs as a maximum, or as long as sources are available. The sources of footwear were in most cases came from the LCP, or the nearest leprosy hospital with a workshop. One out of twenty (1/20) SCG mentioned health insurance scheme for poor people as the solution. Ten out of twenty (10/20) of the groups had contact to a workshop in a leprosy hospital, where special footwear can be produced. The benefit of SCG members are better access to HE, assisting and protective devices such as footwear and self care material.
- Only in 6/18 groups were members in need of referral It does not determine whether people in the other groups were not in need of referral, or whether referral was not possible.
- Examinations were usually done in 18/20 of SCG; 15/18 done by the health worker, 2/18 done by DLS and only 1/18 by the group leader. Most members had no problem showing their hand or feet in front of other people. In half of the groups the members were encouraged to watch the examinations and encouraged to do it by them selves. Examination should also teach to SCG members mostly the group leader if they are able to do so. It is the preparation step to release the SCG done completely by the group members.

- The positive impacts of SCG are healing the ulcer and preventing the new ulcer because the SCG members have better understanding of self care. It makes them being able to work again. Friendships and group support also increase their self confidence and social interaction.

4.5.6. Socio-economic rehabilitation

- Activities in most groups were mainly self care and related issue discussions. In 15% SCG *arisan* (regular social gathering whose members contribute to and take turns at winning an aggregate sum of money) and income generating activities were done, and in another 15% groups these additional activities were in planning. Other activities should be planed carefully in order to keep them focused on self care and to keeping the dynamic of the group.
- The members would like to have additional activities in 18/25 of SCG such as vocational training 3/18, micro credits 10/18, *arisan 3/18* and religious meetings 1/18, and 1/18 extend on going project (SER). While in the other 7/25, groups had no obvious interest for additional activities. The additional activities usually started when the disability problem had reduced. It may be increase togetherness and possibility for income generation. Financial dependency may reduce their self esteem and keep them restricted and isolated by their families and the community. Income generation program within SCG is easier to be monitored and more transparent than giving the aid personally.
- Obstacles that might be facing to establish SER program are:

  Funding: SER activities need the big amount of money. To find out the party to finance SER is the most challenging matter. The fund is actually available in some CBR project but as Van Brakel mentioned that stigma caused leprosy patients are excluded from general CBR program. In Indonesian context the donor supported some SER projects. Other parties need to be approached to give contribution to sustain and extend the SER program such as other donors, CBR projects and local government.

  Management: the beneficiaries of the SER program are disables with different characteristic and limitation. They need different guidance and support to gain optimum result for each condition otherwise the project will be failed and they gain nothing.

In term of limitation of the budget it might needed to choose who will get SER support, but it might create jealousy and distract the interaction among the group members.

Monitoring: to monitor the SER process to ensure the progression of the project is not LFW expertise. It might need other expertise.

- According to the interviewer SER, vocational training, and scholarships for children should be worked at in collaboration with other sectors. Unfortunately the supports from other sector are lack.Cross (2007) mentioned that poverty, marginalization and discrimination should be considered as constraints in constructing self care and POD program. However he mentioned that the internal empowerment should be done first before setting economic intervention. Orr and Patient (cited by Cross, 2007) mentioned that it is needed to prepare positive identity, aspiration, self confident and beliefs that their life is important and valuable before set up economical support activities.

4.5.7. Organization issue: Meeting place, frequency, recording and reporting , facilitator, time

- All groups have the meeting monthly for 2-3 hours. (Activities during the meeting had been explained in separate sub-topic). This is very crucial moment for the SCG members where they lean from facilitator knowledge and skill of self care. They also support each other through encouragement, suggestion and show their success or failure to motivate each other.
- Twelve out of twenty (12/20) of the groups had their meetings in a health centre, most of them in a rural environment, 2/20 were established in the hospital, and 1/20 were established in the settlement. Five out of twenty 5/20 of the groups were met in their own village outside a settlement and a health centre. In general the village-based SCG in Indonesia is only 8% while 92% had their meeting place in HC or hospital or settlement or leprosy hospital. In this inventory study HC is still where the majority use as their meeting place. The role of HC and facilitator is still dominant. It shows the dependency of SCG on health facilities and facilitator is still high.
- Based on direct observation during inventory study 11/17 of the meeting places were in the HC, 6/17 in the village either in the village hall or the house of the members and 1/17 in the hospital. The meetings places, both in health centers and

villages were adequate except one which was too small. Using HC for the meeting place have positive points such as health promotion to increase awareness for other patients who come to HC, the other health staff in HC could learn about SC as well, and the group members who are afraid to be known by their neighbors would like to join the group. It also has negative points, such as the long distance, need for transportation fee, opportunity costs and it tend to keep the members depending on HC. The other important issue is by setting SCG in the village may increase awareness of the community and reduce stigma in the community.

- Attendance was however very good, 19/20 SCGs has regular attendance, only 1/20 SCG which the members come irregularly. The reasons like being busy, being confused with the meeting schedule, and for various problems with transportation. In 5/20 of the SCG the members needed to be reminded or even to be picked up for the meetings. It might be caused by two factors, either the facilitator is too active and wanted everything under his control or the members them selves had no motivation to come.
- The ratio of female: male for the facilitator was 10:10. They all had some knowledge about POD, but only 8/20 had some kind of training or on-the job training for facilitation of a group. 12/20 of the facilitators never had any training, 8/20 of them had "informal training" since there was no regular training for SCG
- All of the group leaders were male. Most of them had POD training and some even training in facilitation, but this could not be cross checked, and is slightly doubted by the interviewer of this inventory.
- Recording was a problematic issue. 2/20 of the group had no register of its members. Examinations were conducted in almost all groups, but good recording had been done in 15/20 of the groups only, 3/20 did it irregularly. Remarks about the individual examination book, which were provided as an example in the SCG manual were positive, but it was still only used in 12/18 groups, and irregularly filled in. Recording of the nerve examination and disability is very important to compare the result of self care activities. Without proper recording it would be difficult to assess the SCG program
- The results of the SCG were difficult to assess completely, due to the lack of recording. The available data showed that in 14/20 groups most people were successful, in 5/20 groups

some people were successful, and in 1/20 group few people were successful. In 10/20 of the groups new ulcers appeared. It might determine the benefit of SCG program but it was not strong enough, until the real figures of the success rate among the members in the large number are known

- In only 9/18 of the meetings people sat in a circle together, 8/18 sat where ever they like but still in the room, 1/18 sometimes they sat in a circle. In most of the meetings (16/18) self care was practiced in form of soaking, but exercises and dressing of wounds were rarely seen. Sitting in the circle would create better environment. Every member could see each other during exercise, examination, and discussion. It also offers extra education; for example the member who has no plantar ulcer would know how to dressing the wound if it happened to them. Exercises for the muscle and dressing wound needed to be more practical rather than theory; unfortunately an untrained facilitator can not teach how to do those activities
- Results of examinations were recorded in 10/16 of groups while 6/10 SCG have no examination record. Recording system for SCG is to help follow up the progress of the disability and it would motivate the members to do self care better at their home
- The facilitator in 14/16 meetings had aspects of a good facilitator, i.e. he guided, encouraged and facilitated instead of instructing, but only 9/14 of them did this in a sufficient manner.
- The group leader was skilled in 9/11 cases, but this data did not reflect the real situation since many group leaders were not attending the meetings on that special occasion.
- According to interviewer the information should be given to members at the beginning to identify their needs and expectations.
- According to the interviewer Meeting places should best be close to the SCG member's houses to reduce transportation problem.
- According to the interviewer in general the SCG should be extended to increase the coverage of people affected by leprosy, and the groups should be continued until all members are well.

5. Conclusions and recommendations

The literature and the SCG inventory study shows that many aspects of SCG have give benefits to its members. But it is need so much efforts, encouragement and supports to gain its benefits. This part will Discuss conclusion and recommendation.

1. Physical disabilities and activity limitations

   SCGs have been proven as effective measure to reduce physical disabilities and activity limitations of people with disabilities compared with individual self care. It gives more benefits due to facilitators and other group members' supports. Therefore we need to sustain and enhance SCG program in general and particularly in Indonesia. The good attendance might reflect self control is increased among the group member. It also indicates that patient get benefits from self care activities which have been taught in SCGs meetings. Even SCG has demonstrated its efficacy as a valid approach to reduce impairment and disability among its members but it need more than transfer of knowledge and skill from the facilitator. The supportive condition from local authority, community and the family of the group members should be promoted.
   There is no reporting system to asses efficacy of SCG in Indonesia, therefore MOH need to include SCG report into national report system.

2. Reduction of psychological problems

   The study shows that psychological aspect is influence greatly for self care activities. It will affect to the reduction of disabilities but also their quality of life since disability is also influence by beliefs and environmental factors. SCG has proven to be effective in increasing self esteem and self control of its members. The role of facilitator and other group members is very important. The facilitator should create open atmosphere and encourage the members to get back their self confidence. Therefore facilitator is needs to be trained to facilitate the SCG better and more supportive. SCG has demonstrated that encouragement and increase self esteem of the members will empower them to unveil their latent potency. It is not only will affect positively to their selves but also will transform them become change agent in community development process.

3. Reduction of economic problems.
   By reduction of disabilities we indirectly reduce economic problems. The members do not need to pay for medication and loss opportunity cost due to their disabilities and activity limitation. Furthermore some SCGs provide socio economic rehabilitation program that offer micro credit. It will allow the members to change their job that less harmful for themselves. So the new disabilities could be prevented.
   The study also shows that donor dependency in supporting SER program is still high. Therefore health service manager should be more creative to find out as many as possible financial resources. We need to involve of local authority, other local NGO, community leader and other stakeholders.
   Most of the group members are in productive age. They may be responsible for family income generation. Therefore SER is needs to be promoted to reduce economic burden due to disability. But we need to prepare supportive condition for the SCGs members. The activity limitation due to disability should be address first and their self esteem and confidence should be increased. If they are ready and become able to work than we can start to give them SER project. The SER budget should be set at the beginning and implemented equally. It is unwise to give charitable support while other members should pay for micro-credit loan. It will create jealousy among the SCG members and the goals may not be achieved.
   The community also should be prepared to accept their product or services otherwise these product and services will not have the market.

4. Reduction of social problems.

   Through encouragement and support from facilitator and other members the SCG member gains their self confidence and their rights to be respected and accepted by their family members and the community members.
   The study shows that family members and neighbor involve during the meeting. It might reflect awareness among the community and support from them to SCG members.
   The SCG members gain their right to the worship place so they can interact with other people.
   SCG need to create a better environment such as sharing, love, companionship and emotional relationship, through collective

action with the similar problems. It may leads to better achievement to reduce disabilities and increase their quality of life.

The actions taken by SCG members for their environment and community in Nepal are reflect both social responsibility and ability to control over their disadvantages of impairment. It is shows of better self respect of SCG members.

The SCG members show their improvement on community participation. It also reflects the efficacy of SCG in enhancing their self esteem, self confidence, dignity and acceptance from the community.

5. Empowerment.

   The important role of facilitator of SCG is to empower the SCG members to be more independent from health services, from their family and their community. Knowledge and skill have to be improved together with their internal power. We need to encourage them to get their right through collective movement. The study shows that by empowering the SCG members they will be able to be agent of change for themselves and for their community. The SCG members should be supported as a subject and not as object of rehabilitation program. Good relationships and open atmosphere to talk and discuss their problems therefore need to be prepared. We need to find their needs and their capability and guide them to achieve positive actions. The facilitator should have consultation and facilitation skill. Therefore we need to provide proper training for facilitator on consultation and facilitation skills. Training for facilitator is crucial since they will transfer their knowledge and skill to the group members. Wrong instructions may lead to worsening of disability or failure to reach successful achievement. The facilitators also need to be trained of facilitation process so the open discussion and free atmosphere could be achieved. It is important for SCG to absorb all information from the facilitator and other group members so they gain better knowledge and skill.

   The involvement of SCG members as facilitator gives a new sign of empowerment of the SCG members. They need training for facilitation and enhance their knowledge and skill.

6. Sustainability

   Self care for people affected leprosy sometime became an obligatory activity if they were having permanent disabilities. Therefore sustainability of the self care activities is very

important. By giving them knowledge, skill and build up their self esteem and self control they will be able to do self care by them selves at home for the rest of their live.

Support from donor and local government has been proven to be important factor to sustain SCG. Therefore involvement of other parties such as local NGO, community leader and religious leader, local workshop and other fund resources should be promoted.

7. Inclusion

   SCG provide better access for its member to get health services and self care services. The members also get access to assisting and protective devices such as proper footwear. The SCG also increase awareness of the family and the community to support the SCG members to achieve complete participations within their community.

   Women and children give the same opportunity to join the SCG.

   The inclusion of the SCG members to CBR project has to be encouraged because the SCG members also have the same right with other disable people, and they have the right to gain such the benefits of CBR program.

8. Organizational issue

   The great distances and the organizational problems have contributed significantly to failure of SCG. The meeting place should be close to the SCGs member's house to reduce absentee and the number of irregular visit. The reasons of leaving the group are varied such as too busy, died, moved, too old, unsatisfied with the services and expensive transportation fee. We need to find out the most common reason of defaulter for better planning by survey to defaulter SCG members. Health centers are the most common meetings place. Even it has benefits but it also detriment integration of SCG members into community. It also keeps SCG demanding to health facilities and the ownership of the group may be slowly progress.

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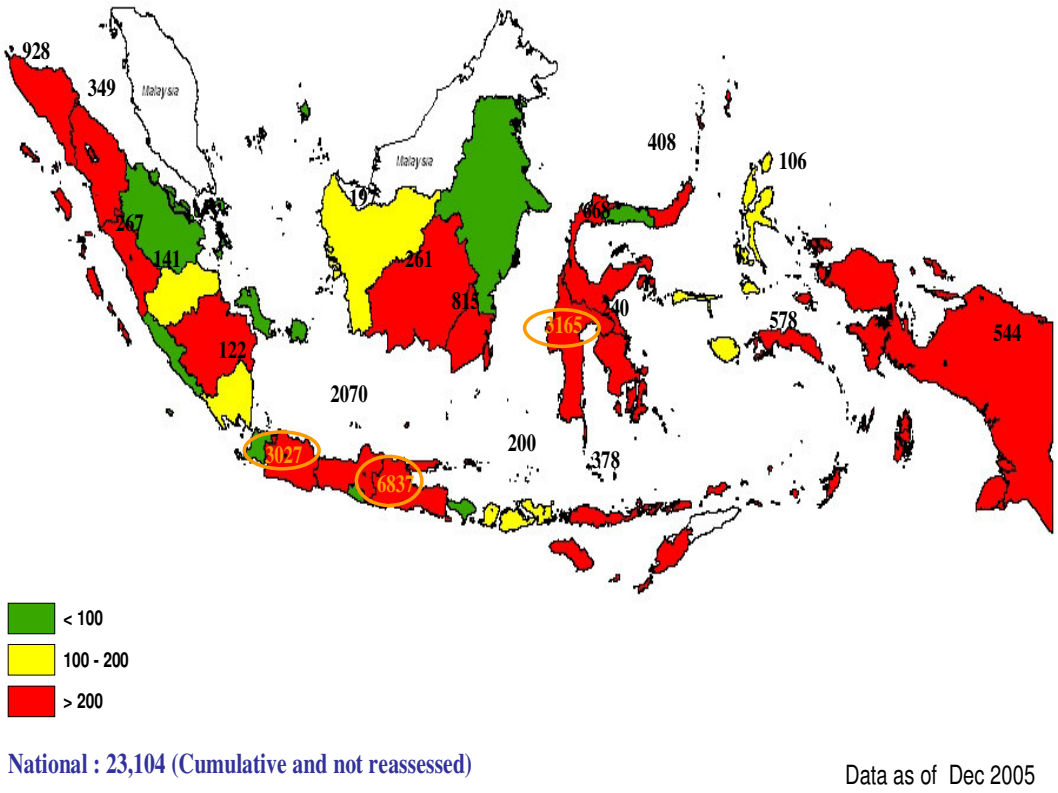
Annex 1. Map of disability grade 2 rate year 2005.

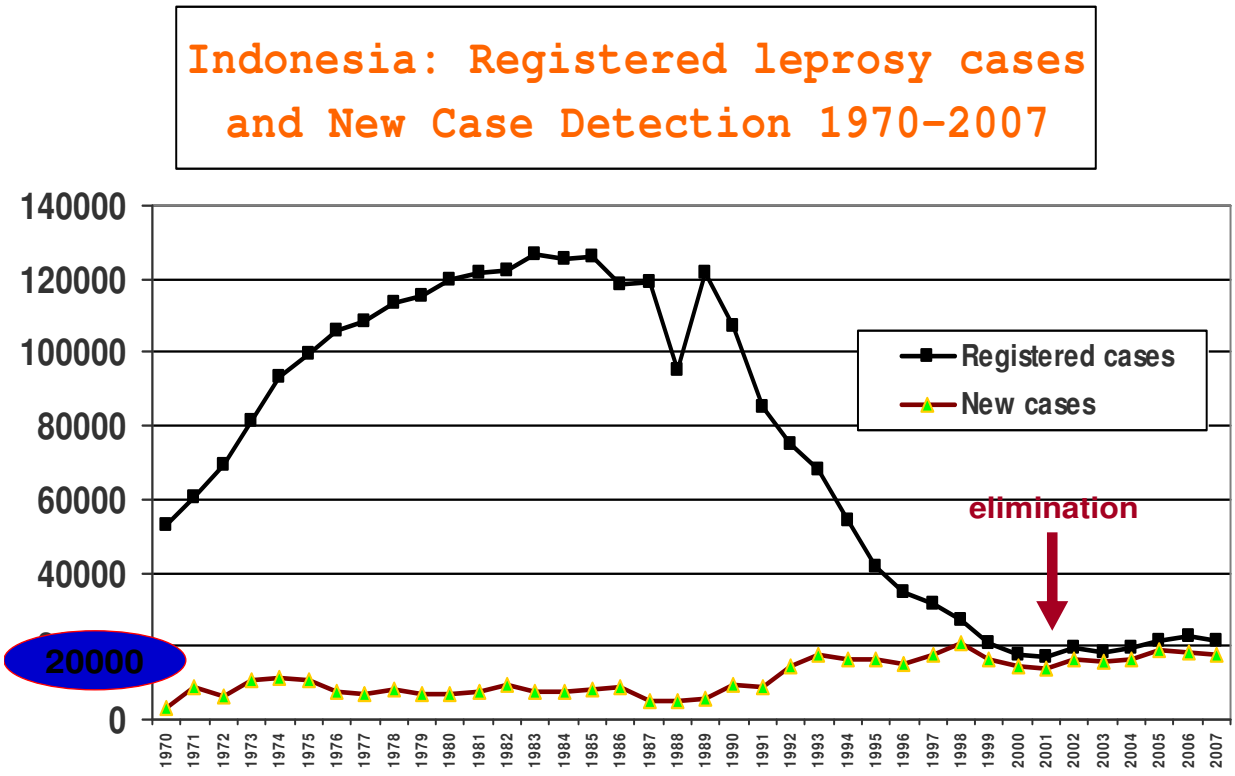
Source: Ministry of Health of Indonesia (2007).

Annex 2. Maps of distribution of cumulative disability grade 2



Source: Ministry of Health of Indonesia (2007).

Annex 3. Trend of registered leprosy cases and new case detection 1970-2007

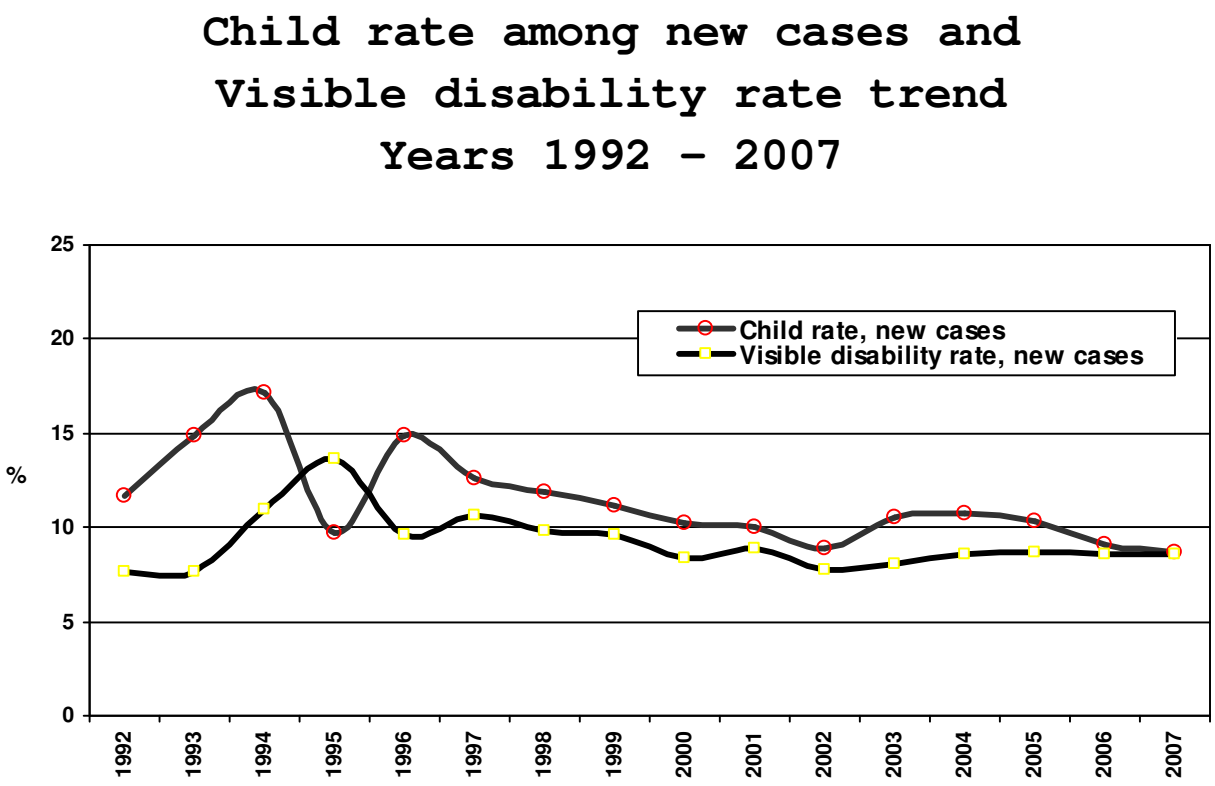


Source: Ministry of Health of Indonesia (2008)

Annex 4. Picture of SCG activity: Reading the IEC material

Source: *Buletin* SCG (2007)

Annex 5. Trend of child rate and disability grade 2 rate in Indonesia 1992 - 2007.



Source: Ministry of Health of Indonesia (2007).

Annex 6. SCG inventory questionnaire

SCG Inventory: Guide

I. Discussion with responsible health staff (e.g. wasor and facilitator)
II. Observations during the meeting
III. Discussion with the members
IV. Personal opinion

PLEASE TAKE A DIGITAL PICTURE OF THE GROUP

Date of visit:
Name of interviewer:

I. Discussion with responsible health staff (e.g. wasor and facilitator)

Please fill this part in beforehand, not during the group meeting, as this would disturb the group dynamics

1	Province:	
1a	Person responsible for SCG:	
1b	How many SCG have been introduced in the province:	Ongoing: Closed:
2	District:	
2a	Person responsible for SCG:	
2b	How many SCG have been introduced in the district	Ongoing: Closed:
3	Puskesmas / hospital / settlement:	
3a	Person responsible for SCG:	

4	Name of the SCG:	

5	Is the SCG in a	rural setting?	
		urban setting?	
		hospital?	
		settlement?	

6	When did the SCG start?	
6a	When will the SCG end?	
7	How is the SCG funded?	
7a	Is other than NLR funding available and which?	

8	Frequency of meetings:	

9	Number of members:		
		Female:	

		Male:	
9a	Age:	< 15:	
		16-40:	
		> 40:	
9b	How many members have	disability grade 2?	
		disability grade 1?	
		disability grade 0?	
9c	How many members	are RFT?	
		are on MDT?	
9d	Are family members joining?		
9e	Are people joining who have disabilities due to other reasons than leprosy?		

10	Did new members join later?	
10a	Why did they join? (e.g. they heard about the group / new detected cases, etc)	
11	Did members leave the group?	
11a	Why did they leave?	

12	Is a member register kept?		
12a	Do (most / half / few of) the members attend regular?		
12b	If not: why not?		
12c	Do (most / half / few of) the members	come on their own?	
		have to be reminded beforehand?	
		have to be picked up?	

13	Facilitator:	Name:	
13a		Function:	
13b		Male / female:	
13c	Has he/she been trained?	POD refreshing:	
		Facilitation of a group:	

14	Group leader:	Name:	
14a		Male / female:	
14b	Has he/she been trained?	Self care	
		Facilitation of a group:	

15	Is self care equipment available?	Enough basins or buckets:	
		Oil:	
		Rubbing stones:	
		Trimming gear:	
		Fingersplints:	
		Glasses:	
		Cloth for dressings:	

		Gloves:	
15a	Is health education material (e.g. disability leaflet) available?		
15b	Is any medicine handed out or used during the meetings?		

16	Is footwear distributed for those in need?	
16a	Is there a plan on how often to provide footwear for free?	
16b	Are orders for orthopaedic footwear possible?	

17	Are examinations conducted during the meetings?	
17a	Are the results recorded?	
17b	Are examination books for each member used?	
17c	Do you have any remarks about these examination books?	

18	Are other activities conducted (e.g. SER/ arisan)?	

19	Are transportation costs repaid?	
19a	If yes: According to expenses or the same amount for all?	
19b	If yes: Average costs per person for transport:	
20	Is a snack provided?	
21	Are members expecting financial benefits?	

22	Has supervision been conducted to the SCG?	
22a	If yes: When and by whom?	
22b	If yes: Is a checklist used?	

23	Are reports written about the SCG?	
23a	If yes: By whom / When / To whom?	

24	RESULTS: How many members	in need of referral have been referred?	
24a		could heal an ulcer?	
24b		could not heal their ulcer(s)?	
24c		how many new ulcers appeared?	
24d	What are the main problems for the members, that slow down wound healing? (e.g. work, not consistent with self care at home, not understanding, surgery needed, etc)		

II. Observations during the meeting

1	Meeting No:	
2	Number of members present:	

3	Where is the meeting place?	
3a	Is it adequate?	

4	Are the members sitting in circle?	

5	Are members	soaking together?	
5a		do other self care activities (e.g. exercises)?	
5c		dressing their wounds (with cloth) afterwards?	

6	Are examinations done?		
6a		By whom?	
6b		Are all members encouraged to watch and participate when another member is examined?	
6c		Are results recorded?	
6d		Are reasons for wounds discussed?	
6e	What is the major problem of the members?		

7	Is footwear inspected and discussed?	
7a	Do most / half / few members wear adequate footwear?	

8	Are discussions held about self care?	
8a	Are discussions help about other topics (e.g. social life, work, etc)	
8b	If yes: do (most / half / few of) the members participate?	

9	How is the atmosphere? (e.g. relaxed / uncomfortable, etc)	

	Do (most / half / few of) the members:		
10		seem interested in the activities?	
10a		discuss with each other or help each other?	
10b		are willing to show and discuss their hands, feet, eyes?	

	Does the facilitator:		
11		act as facilitator (e.g. guides, encourages members to participate, facilitates discussions, etc)	

		act as instructor (e.g. leaves members in passiveness, dominates, talks instead asks, etc)	
11b		supports the group leader?	

	Is the group leader:		
12		actively helping members, demonstrating, discussing etc?	
		rather shy?	
		too dominant?	

III. Discussions with the members:

Please ask open questions. The following points are only guidelines.

1. What do members feel about being a member of this group?

---

2. What do members do at home regarding self care? Where are problems?

---

3. Where according to the members is the best meeting place for the group? (village, puskesmas, others)

---

4. Who should be the facilitator of the group? (health worker, group leader, others)

---

5. How does being a member of this group influence their dealings with other people? (family, community, self confidence, etc)

---

6. Would members like to add other activities, and which? (SER, arisan, others)?

---

7. What do members think about closing the group after 1 year?

IV. Personal opinion

What in your opinion are positive aspects of this SCG?

Where in your opinion is room for improvement?

