Measurement of Quality of Life and Social Participation of Persons Affected by Leprosy in the Rehabilitation-in-the-Community Programme in Thailand

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ABSTRACT :

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The objectives of this study was to measure the quality of life and social participation of ex-leprosy patients (persons affected by leprosy, PAL) who receive socio-economic rehabilitation (SER) in general community in Thailand. A combination of a cross-sectional descriptive study and a qualitative study was performed. The first batch of 120 PAL with severe disability who were approved to receive the new SER-in-the-community programme, were purposively selected and interviewed with the Leprosy Disability and Socio-economic Scale, WHOQOL-BREF-THAI and the Participation Scale. Data were analyzed using unpaired t-test, one way ANOVA and stepwise multiple regression. Qualitative interviews of 12 PAL and 40 key informants were also conducted. The results showed that 94 PAL were interviewed between May-August 2009. Fifty-six percent of PAL had moderate quality of life. Factors predicting quality of life were migration, absence of limitations in social participation and accessibility to health care, and disabilities (R^2 = 0.401). About a quarter of PAL (25.5%) had severe participation restriction, 24.5% moderate restriction, and 22.3% mild restriction. Predictive factors in limitation of social participation were illiteracy, unemployment and disability (R^2 = 0.223).

In conclusion, we propose that SER in-the-community programme for PAL improved self-esteem, financial contribution, and more out-going of PAL. SER in-the-community programme should be integrated into the social welfare programme for people with disability in order to increase the coverage for all PAL and eliminate the discrimination against leprosy.

Key words: Leprosy, Quality of Life, Socio-economic rehabilitation

บทคัดย่อ :

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การศึกษาคุณภาพชีวิตและการมีส่วนร่วมทางสังคมของผู้ประสบปัญหาจากโรคเรื้อนในประเทศไทย วารสารโรคผิวหนัง 2557; 30: 265-275.

**สถาบันโรคผิวหนัง กรมการแพทย์*

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การศึกษาครั้งนี้เป็นการศึกษาเชิงพรรณนาแบบตัดขวาง ร่วมกับการศึกษาเชิงคุณภาพ วัตถุประสงค์เพื่อวัดคุณภาพชีวิต และข้อจำกัดในการมีส่วนร่วมทางสังคม และปัจจัยที่เกี่ยวข้องในผู้ประสบปัญหาจากโรคเรื้อนที่รักษาหายแล้ว ที่ยังคงมีความพิการและได้รับการฟื้นฟูทางสังคม - เศรษฐกิจในชุมชนทั่วไป

จำนวน 120 ราย การฟื้นฟูสภาพในชุมชนเป็นโครงการใหม่ที่มาแทนระบบเก่าที่ให้การฟื้นฟูสภาพในนิคมโรคเรื้อน เครื่องมือที่ใช้ในการวิจัยประกอบด้วย แบบสอบถามข้อมูลทั่วไป ข้อมูลด้านโรคและสุขภาพ ข้อมูลด้านความพิการและ

ข้อมูลการรับการสงเคราะห์ แบบวัดอุปสรรค/ข้อจำกัดในการมีส่วนร่วมทางสังคม (participation scale) และแบบวัดคุณภาพชีวิต (WHOQOL-BREF-TH) ข้อมูลวิเคราะห์ด้วย Unpaired t-test, one way ANOVA, และ stepwise multiple regression ผู้ประสบปัญหาจากโรคเรื้อน 12 ราย และผู้มีส่วนเกี่ยวข้องอีก 40 ราย ถูกสัมภาษณ์เชิงคุณภาพ ผลการศึกษาพบว่า ผู้ประสบปัญหาจากโรคเรื้อน 94 ราย ได้รับการสัมภาษณ์ ร้อยละ 56 ของผู้ถูกสัมภาษณ์มีคุณภาพชีวิตระดับปานกลาง ปัจจัยทำนายคุณภาพชีวิตคือ การอพยพย้ายถิ่น การไม่มีข้อจำกัดในการมีส่วนรวมทางสังคม และการเข้าถึงบริการทางสาธารณสุข และความพิการทางร่างกาย (R^2 = 0.401) ด้านอุปสรรค/ข้อจำกัดในการมีส่วนร่วมทางสังคมพบว่า ร้อยละ 25.5 ของผู้ถูกสัมภาษณ์มีข้อจำกัดอย่างรุนแรงในการมีส่วนร่วมทางสังคม ร้อยละ 24.5 มีข้อจำกัดปานกลาง และร้อยละ 22.3 มีข้อจำกัดเล็กน้อย ปัจจัยทำนายข้อจำกัดในการมีส่วนร่วมทางสังคม ได้แก่ การไร้การศึกษา ภาวะว่างงาน ความพิการทางร่างกาย (R^2 =0.223) สรุปโครงการฟื้นฟูทางสังคม – เศรษฐกิจ สำหรับผู้ประสบปัญหาจากโรคเรื้อนในชุมชนทั่วไป ช่วยให้มีความรู้สึกภาคภูมิในตนเองดีขึ้น ฐานะทางเศรษฐกิจดีขึ้น และการออกสู่สังคมมากขึ้น โครงการฟื้นฟูสำหรับผู้ประสบปัญหาจากโรคเรื้อนในชุมชนทั่วไป ควรได้รับการยกระดับเป็นส่วนหนึ่งของระบบการฟื้นฟูผู้พิการต่อไป เพื่อให้มีการฟื้นฟูครอบคลุมผู้ประสบปัญหาจากโรคเรื้อนทุกราย และช่วยลดตีตราทางสังคมของโรคเรื้อน

คำสำคัญ : โรคเรื้อน, คุณภาพชีวิต, ผู้ประสบปัญหาจากโรคเรื้อน, การมีส่วนร่วมทางสังคม

Introduction

The prevalence of Thai leprosy patients could reach the elimination goal (PR < 1/10,000 population) since 1994.[1] The trend of leprosy is drastically decreasing, thus one of the leprosy control strategies in the future is to provide care and rehabilitation of PAL who are treated, aged and disabled in order to improve their quality of life. As in the 8th Plan of the National Economic and Social Development (PNESD), which focused on the holistic development with "human as the centre of development" and the 10th PNESD which had the aim for "the sustainable happy society", these plans target all Thai population including people with disability and PAL.

About 14 % of Thai leprosy patients already had visible (grade 2) disability at the time of diagnosis[2], and this proportion increased to 18% when patients completed treatment. Since the establishment of the first leprosarium in Chiangmai in 1908, leprosy patients had been segregated in one of the 13 leprosy colonies[1]. Ex-patients who needed physical rehabilitation and SER, would be assessed with the Leprosy Disability and Socio-economic Scale. Those whose scores passed the criteria would be allocated in a leprosarium, where PAL were provided care, meals, accommodation, temporary access to farm land, vocational training, social welfare and monthly allowance.

At present, 2 small leprosy colonies have been shut down because of absence of dwellers. Other larger colonies are always fully occupied because of the long

waiting list of PAL who have severe disability and socio-economic deficiency that pass the criteria of admittance to leprosy colonies. In order to establish a new method of providing SER for PAL outside leprosy colonies, since January 2005, the Department of Disease Control, Ministry of Public health has approved the novel programme of providing SER interventions, e.g., meal expense and monthly allowance, for the qualified PAL in their normal community including PAL who are willing to move out of leprosy colonies to re-settle in the community. The objectives of this programme were to integrate leprosy health care and SER into local administrative authorities, to decrease discrimination, and to improve quality of life and social participation of PAL residing in general community.

The aim of our study was to measure quality of life and social participation of PAL receiving SER in-the-community programme, and to examine the association factors of quality of life and social participation, in order to assess the effectiveness of this novel rehabilitation intervention.

Matherials and Methods

The present study is a combination of a cross-sectional descriptive study and a qualitative study.

A purposive sampling was used to access all 120 PAL who were among the first batch of PAL approved for SER in-the-community programme between January 2007 and June 2008. The research setting were in Disease Control Centres 2, 6, 8, 9 and 10, in northern, northeastern, and central parts of Thailand.

Data collection methods were interviews based on the following instruments: the Leprosy Disability and Socio-economic Scale, the Participation scale (P-scale)[3] and the Thai abbreviated version of World Health Organization Quality of Life (WHOQOL-BREF-THAI)[4]. Demographic and rehabilitation-associated information were also assessed.

Demographic and rehabilitation-associated informations consist of 33 items including sex, age, marital status, education, occupation, accommodation, family member, family history of leprosy, past history of chronic disease, health seeking behaviour, access to health care and social welfare, use of aids and appliance, method of receiving allowance, and the influence of the SER on their ability to perform their social role. Descriptive statistics were used to summarize demographic information. Unpaired t-test, one way ANOVA and stepwise multiple regression analysis were used in analyzing process.

The Leprosy Disability and Socio-economic Scale is a questionnaire, designed by the Department of Disease Control, used to assess the physical disabilities of hands, feet, eyes and face and socio-economic status of leprosy patients and PAL who apply for SER in-the-community programme as well as rehabilitation in the leprosarium.

The WHOQOL-BREF-THAI is the Thai version of the brief form of the WHO Quality of Life assessment instrument (WHOQOL-BREF).[5] After pre-tested in 33 PAL, the WHOQOL-BREF-THAI was slightly

modified. The modified WHOQOL-BREF-THAI consists of 25 items, each with 4-point Likert responses. The instrument assesses four broad domains, namely physical health (7 items), psychological well-being (6 items), social relationships (2 items), and satisfaction with the environment (8 items). The score in each domain (subscale) is calculated by adding up the scores of the corresponding items. The overall QOL score is the summation of all four subscale scores plus another two global item scores. The QOL score is then used to classify the quality of life as bad, fair or good (Table 1).

Table 1 Subscale and overall QOL scoring criteria.

Subscales	Bad	Fair	Good
Physical health	7-13	14-20	21-28
Psychological health	6-11	12-17	18-24
Social relationship	2-3	4-5	6-8
Satisfaction with the environment	8-15	16-23	24-32
Overall	25-50	51-75	76-100

The Participation Scale is an 18-item interview-based instrument to measure perceived problems in major, mainly socio-economic areas of life. It will allow quantification of participation restrictions (psycho-social and economic problems) experienced by PAL, disability or other stigmatized conditions. The generic English version of the P-scale was translated into Thai language by the principal investigator (K. Kampirapap). The Thai version, after pre-tested in 33 PAL, had quite high reliability (alpha = 0.86). The scale was pre-coded and the scores to each response were assigned in the response boxes, each between 0-5, the sum score would be between 0-90. People's participation would be classified according to the sum score as follows : 0-12 = no significant restriction,13-22 = mild restriction, 23-32 = moderate restriction, 33-52 = severe restriction, 53-90 = extreme restriction.

In order to further explore the socio-economic condition, QOL (quality of life), and the social participation, an in

-depth interview was also included in the study methodology. The data resulting from the semi-structured interview was analyzed qualitatively. A semi-structured interview is a face-to-face interview using a standard list of open questions. Twelve PAL who could respond verbally would be purposefully selected , one from each community, to be interviewed through semi-structured questionnaires. In order to further validate the information through triangulation, 1 family member,

1 community leader and 1 health care provider related to each of the 12 PAL have to be also interviewed.

The in-depth interview questions of the PAL, the family members, the community leaders and the health care providers were the quality aspects of the following domains ;

1. Treatment of leprosy (when, where)
2. Marital status, family member
3. Occupation, economic status
4. Condition of accommodation
5. Health seeking behaviour
6. Access to health care
7. Stigma
8. Availability of prosthesis, orthosis, facilities
9. QOL
10. Social participation

Five quality aspects were presented to each interviewee before ending the interview. He/she would choose 3 aspects which might be the most beneficial to improve QOL.

Table 2 Demographic and rehabilitation-associated information.

	No.	Percent
Sex		
-Male	64	68.1
-Female	30	31.9
Age		
≤ 55 y.	16	17.0
56-70 y.	45	47.9
≥71 y.	33	35.1
Marital status		
-Married	54	57.4
-Single	15	16.0
-Divorced/widowed/separated	25	26.6
Education		
-Illiterate	34	36.2
-Primary/secondary school	60	63.8
Occupation		
-Unemployed	56	59.6
-Unsecured job	8	8.5
-Full-time job	30	31.9
Location of community		
-North	41	43.6
-Northeastern	44	46.8
-Central	9	9.6

	No.	Percent
Housing		
-Owner	79	84.0
-Tenant	15	16.0
Number of family member		
-Alone	22	23.4
-2-5	65	69.1
-> 5	7	7.4
Family history of leprosy		
-Yes	46	48.9
Past history of chronic disease		
-Yes	45	47.9
Use of aids/appliance		
-Yes	22	23.4
Dependency		
-Dependent	7	7.4
-Independent	87	92.6
Health seeking behaviour		
-Never	7	7.4
-Governmental hospital	73	77.7
-Drug store/private clinic	14	14.9
Obstacle of access to health care		
-No obstacle	56	59.6
-Travel cost/distance	27	28.7
-Dissatisfied with health care quality	11	11.7
Method of receiving allowance		
-Receiving cash in a nearby colony		
-Bank transfer	55	58.5
-Money order by post		
Influence of SER on their social role	28	29.8
	11	11.7
-Improved	76	80.9
-No difference	18	19.1

Results

A total of 94 out of 120 PAL were interviewed between May and August 2009. Twenty-six PAL were missed because of death or migration happening before the study. The demographic and rehabilitation-associated information of the respondents were summarized in Table 2. Most of them (68.1%) were male, 45 PAL (47.9%) aged between 56-70 years (mean 66 years). Most of them (57.4%) were married, 36.2% illiterate, 59.6% unemployed. A quarter of PAL moved out of the colonies to receive SER in-the-community programme instead. The majority (80.9%) said that their daily life and acceptability in community improved after receiving the SER in-the-community programme.

The majority of the PAL had WHO disability grade-2 of the right hand (68.1%), left hand (63.8%), right foot (58.5%), and left foot (55.3%). Visual aquity worse than 6/60 was detected on the right eye (57.4%) and left eye (59.6%). About half of them (52.1%) had facial disfigurement.

The majority of PAL (44.7%) had physical disability score range 16-27/40, 55.3% socio-economic score range 13-16/20, and 48.9% total score range 24-35 from 60.

More than half (56.4%) of the PAL in this study had a fair QOL level ; 40.4% and 3.2% had good and bad QOL level respectively. The overall QOL scores varied 46-93, mean = 71.60, SD = 10.95. Most PAL had a total subscale score on social relationships, psychological health and satisfaction with the environment at the good level, only a fair level of physical health (63.8%).

The stepwise multiple regression analysis showed that occupation, migration, access to health care, activity limitation, discrimination and participation restriction were significant predictors of QOL.

The P-scale score had a mean = 29.20, median =26, SD = 17.13, range 0-86. About a quarter (25.5%) of the PAL had severe participation restriction, 24.5% moderate restriction, 22.3% mild restriction, 18.1% no significant restriction and 9.6% extreme restriction.

Education, occupation, family history of leprosy, access to health care, disability of left foot, and facial disfigurement had statistically significant difference ($p < 0.05$) of the average P scale scores.

Illiteracy, unemployment, foot deformity and facial disfigurement were significant predictors of participation restriction.

A total of 12 PAL (8 males, 4 females), 13 family members (5 spouses, 8 relatives), 16 community leaders and 11 health care providers (3 leprosy coordinators of district hospital, 8 primary care unit nurses) were interviewed. The in-depth interviews showed that all PAL completed leprosy treatment more than 20 years before. Most PAL were treated at a leprosy colony or a leprosy hospital, only 2 PAL treated at district hospitals. A half of the PAL stayed in their house alone, including 3 female PAL who were abandoned by their spouse. Female PAL had the higher risk to be abandoned. It is a tradition for Thais in rural areas who are likely to build

his house nearby his parents' or relatives', establishing a cluster of relatives. This is an advantage for any disabled PAL, that relatives can pay a visit, help, or show sympathy for their illness or troubles. This is the way PAL can survive under grief and poverty.

All PAL except one said they were not able to earn enough money. They could earn less than 20,000 baht (about £400) per year by doing weaving, dying silk. This low income resulted in poor living condition and housing, that were partially supported by their children or close relatives. One PAL had to get a loan from a provincial social welfare office but could not pay back regularly.

Four PAL received a prosthesis after a below-knee amputation treatment of chronic foot ulcer, and all had to give up using them because prostheses are not suitable for walking in the rice field or going to toilet. Two PAL asked for a wheelchair because they used to see it in a leprosy colony. They were not sure they could use it effectively on bad road condition and in the rice field.

All PAL felt self-stigmatized. One female PAL had extreme participation restriction. She never went out of her house except to neighbors who were close relatives. All family members insisted that they had no prejudice or discrimination against PAL. They are willing to help PAL.

All PAL said that their QOL improved because of the monthly allowance received. Four PAL mentioned that the money were granted from His Majesty because leprosy patients had been under the royal patronage. The allowance let them buy nutritious foods, travel to see a doctor, join religious ceremony and make a donation. They saw a change in their status in the family. Four PAL even though receiving allowance, still felt inferior to non-leprosy disabled people.

When PAL were asked to list their priorities of quality aspects most beneficial to improve their QOL, they considered social welfare, as their top of the list, followed by adequate income and good health.

All health care providers knew that their responsibility was to provide treatment, health promotion and rehabilitation for all persons in catchment area including PAL. All 8 health care providers working in PCU did not know PAL because they were very old ex-patients and never registered for leprosy treatment at PCU. All those providers admitted that they did not have knowledge and experience to perform physical rehabilitation for PAL.

All PAL were told of SER in-the-community programme by their community leaders, who were also their relatives. All community leaders said that it was their duty to help all disabled people by providing social welfare, setting up self help group, and vocational training.

Discussion

Leprosy affects peripheral cutaneous nerves and, if not treated in time, leads to irreversible neuropathy in a substantial proportion.[6-10] This in turn leads to secondary impairments. These impairments lead to limitation in

activities of daily life[11], restriction in social participation[12], and/or QOL.[13]

Data on determinants of disability, impact and response to interventions is very scarce. The paucity of data hampers planning service for prevention of disability (POD) and rehabilitation, and hinders advocacy efforts for the right of PAL.

Leprosy-related disability has five components. QOL may be considered the fifth component requiring data. Although not conceptualised within the ICF, QOL is strongly influenced by stigma and discrimination, as well as by other aspects of disability, such as visible impairment and poverty, but data specifically related to leprosy is scarce.[13-16] QOL is a client-relevant concept that has been shown to be important as an outcome measure in various treatment and rehabilitation programmes other than leprosy. Although a large number of QOL instruments have been developed, very few are suitable for use in leprosy-endemic countries. The most widely used instrument is WHO Quality of Life (WHOQOL) scale, sometimes in the abbreviated version (WHOQOL-BREF).[4,14,16] Tsutsumi found good psychometric properties using the WHOQOL-BREF among people in Bangladesh.[16] Further studies are needed to explore the utility of QOL measures in rehabilitation and to study the relationship between QOL and participation.

The Participation Scale, was developed specifically to measure participation in developing countries.[3] The scale is generic and is particularly suitable for use with people affected by stigmatized conditions, such as leprosy and HIV/AIDS. It has been used to evaluate the impact of a stigma reduction project and to study risk factors for participation restrictions.[12,17]

The present study shows that the QOL level of PAL receiving SER in-the-community programme was fair to good. This finding is not congruent with similar research. The study of QOL of leprosy patients attending leprosy clinic in district hospital in northeastern Thailand showed only fair level.[18] The same fair level was also found among PAL residing in a leprosy colony near Bangkok.[19] The different results can be because of the community-based rehabilitation (CBR) instead of institutional rehabilitation used in the past. Most PAL had a total subscale score on social relationships, psychological health, and satisfaction with the environment at the good level, only a fair level of physical health. This was in contrast to the study in leprosy patients attending leprosy clinics which showed that the lowest level was found in the social domain.[18] The PAL tend to have more severe disability than general leprosy patients, thus it is logical that they deserve to receive SER in-the-community programme, and this resulted in improved overall QOL.

Most PAL had grade 2 disability which therefore could result in unemployment, activity limitation, participation restriction and then fair QOL. Other significant predictions of QOL were migration of PAL, access to health care and discrimination.

The PAL studied had moderate participation restriction. That meant obstacle/limitation of participation had occurred in less than 50% for duration more than 1 month and the severity had interfered with the daily life for some time. There was a statistically significant correlation between participation restriction and education level, occupation, family history of leprosy, access to health care, disability of left foot and facial disfigurement. Illiteracy is closely related and probably the cause of unemployment /low income. Both factors are major causes of social unacceptability and then the participation restriction.

Conclusions

SER in-the-community programme for PAL seems to contribute to a reduction of stigma and increase self-reliance and self-esteem. SER in-the-community programme should be integrated into the social welfare programme for people with disability in order to increase the coverage for all PAL and eliminate the discrimination against leprosy. The evidence also demonstrates that local health care providers did not know how to work with PAL. Thus, more effort should be put into improving their rehabilitation skills.

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