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Factors influencing compliance with home-based self-care practices among people affected by leprosy with disability in Shwedaung and Thegone Townships

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A community-based descriptive study was undertaken in Shwedaung and Thegone Townships in Bago West Division in March 2005. The study aimed to investigate the level and factors of compliance with home-based-self-care practices among People Affected by Leprosy (PAL) with disability, and to provide basic information for further development of homes-based self-care package for prevention of disability. A total of 324 PAL were interviewed with a pre-tested questionnaire about the compliance by trained interviewers. Doing exercises of these PAL were observed and assessed by leprosy staff. Sixteen PAL were interviewed in depth. Generally, the study population had high compliance with exercises and low compliance with protection. Knowledge was associated with the level of compliance and the factors influencing compliance were discussed in detail.

INTRODUCTION

Globally, leprosy has been a public health problem for many years. However, with the changing characteristics of leprosy problem after declaration of leprosy, World Health Organization (WHO) more focus on prevention and/or worsening of disabilities (POD/POWD) for Patients Affected by Leprosy (PAL). Because of late treatment, although the disease was cured, some PAL had developed deformity [1]. Similar situation occurred in Myanmar since leprosy was eliminated in 2003. Up to now, in Myanmar, an extent of PAL with disability was one-fifth of the total cumulative released from treatment cases. So as to reduce the patients suffering from disability, a POD pilot project was conducted in Shwedaung and Thegone Townships in Bago West Division during 2002 to assess the relevance and feasibility of POD interventions [2]. This study showed that physical disabilities had improved to some extent, however, compliance with self-care routine was not optimal, which needs to identify the underlying factors of compliance for integration of information obtained into leprosy control programme of Myanmar.

Objectives

The study aimed to investigate level and factors of compliance with home-based self-care practices among PAL with disability in Shwedaung and Thegone Townships.

Specific objectives

(1) To determine level of compliance with home-based self-care practices among PAL with disability
(2) To identify factors influencing compliance with home-based self-care practices among PAL with disability
(3) To provide information input for further development of home-based-self-care package for POD

MATERIALS AND METHODS

A cross-sectional descriptive study was undertaken among PAL with grade I (i.e., anaesthesia present, but no visible deformity or damage) and grade II disability (i.e., visible deformity or damage present) during March 2005 in Shwedaung and Thegone Townships of Bago West Division. This was a continuation of POD pilot project, which was conducted in 2002, involving 395 registered PAL. During which, these PAL were taught by the leprosy vertical staff about home-based-self-care of their anaesthetic eyes, hands and feet [2]. The villages of the pilot project, where all original 395 registered PAL resided, were included in this present study. After getting consents, they were inter-viewed with a pre-tested questionnaire on demographic characteristics, practicing exercises and disability protection practices by trained interviewers. The trained leprosy staff observed disability's type of each PAL according to 1988-WHO disability grade with an impairment summary form, and assessed the correctness of doing eye-, hand- and foot-exercises. To triangulate the quantitative findings, in-depth interviews (IDI) were carried out with 16 PAL, 8 from each township. They were chosen by two dimensions (i) single disability (i.e., having disability on eyes, hands or feet) and multiple disabilities (i.e., having disability on at least eyes, hands and feet), and (ii) improved, worse or same impairment condition. They were asked about mainly on how and why they complied with instructions about home-based-self-care practices and exercises. Research team performed the IDIs. Quantitative data were analysed by SPSS 10 and field notes of IDIs were transcribed and then analysed manually.

RESULTS

Socio-demographic characteristics

Of 395 registered PAL, 324 (82%) were interviewed (Table 1).

Table 1. Distribution of the study population by socio-demographic characteristics of PAL (n = 324)

Characteristics	No. of PAL	%
Sex		
Male	221	68.2
Female	103	31.8
Age group (Years)		
<20	6	1.9
20 – 39	60	18.5
40 – 59	148	45.7
60+	110	34
Marital status		
Married	177	54.6
Single	82	25.3
Widowed	55	17
Separated /Divorced	10	3.1
Household member companionship		
Live with anybody else	302	93.2
Living alone	22	6.8
Level of education		
No formal schooling	98	30.2
Primary school	100	30.9
Middle school	107	33
High school	10	3.1
Collage/University	9	2.8
Type of occupation		
Private	110	34
Odd jobs	90	27.8
Dependant	89	27.5
Others	30	9.3
Government employee	5	1.5
Monthly family income (Kyats)		
2000 – 15000	123	38
15001 - 25000	79	24.4
25001 - 35000	49	15.1
35001 - 45000	15	4.6
45001 - 55000	15	4.6
>55001	6	1.9
No response	37	11.4

Male PAL were over 2 times the females, the majority were over 40 years (79.7%) and lived with family members or other relatives (93.2%), more than half were married, and about 64% had primary or secondary education**.** Nearly one-third was in private business. A little over one-fourth did odd jobs like selling seasonal fruits, working on farm, and driving trishaw. Twenty seven percent were dependants. Only a very few

were government employees. About three-fourths of their families had monthly income less than 35,000 kyats.

Clinical characteristics

Those with multiple disabilities were slightly higher than those with single disability (55.3% and 44.8% respectively). Disability in foot was the commonest- either foot alone or developed together with eyes and/or hands (Table 2).

Table 2. Distribution of the study population by disability pattern

Type of disability (n = 324)	No.	%
Eye only	6	1.9
Hand only	41	12.7
Foot only	98	30.2
Eye and hand only	1	0.3
Eye and foot only	7	2.2
Hand and foot only	142	43.8
Eye, hand and foot	29	8.9
Total	324	100

Level of compliance

Compliance with exercises

Any exercise practised two times a day for 10 days or once a day for 20 days per month was defined as low compliance and the score ranged between 0-20. Any exercise practised more than two times a day for 10 days or once a day for 20 days per month was defined as high compliance and the score ranged between 21 and 60.

Among the total study population, 198 (61%) had lagophthalmos (inability to close eyes fully), claw hands, foot drop or combinations and needed to do regular exercises of eyes, hands or feet. Nearly half (47.5%) of them was high in compliance with exercise for their respective disability condition, of which, a larger number was contributed by the eye exercises.

Compliance with personal protective practices

Compliance score on personal protective practices was developed on answers towards preventive measures of respective eyes, hands and feet (Table 3).

Table 3. Score development for personal protection

Site	Total score	Level	
		Low	High
Eye	0 – 9	0 – 5	6 – 9
Hand	0 – 5	0 – 3	4 – 5
Feet	0 – 9	0 – 5	6 – 9

The majority of them were low in level of compliance with protection practices but level of high compliance increased when it went from eyes through hands to feet.

Factors influencing level of compliance

Generally, while the majority had high compliance with exercises, they had low compliance with the protection of the affected body parts.

Compliance with exercises

Among the study population who needed to do regular exercises, generally, high compliance was found among males, under 40 years, divorcees, those who had no formal education or higher education, government employees, and those with low monthly income less than 15000 kyats. However, the differences between low and high compliance with exercises were not statistically significant for each socio-demographic characteristic.

Regarding knowledge of complications due to lack of care for affected body parts, those with some knowledge had high compliance with eye- and foot-exercises respectively (Table 4). There is highly significant difference between compliance levels for doing foot exercises.

Compliance with protection practices

Low compliance with protection practices was observed for all characteristics of PAL, but none of them were statistically significant. The majority of PAL with low level compliance had no knowledge about possible complications from lack of eye, hand and foot protection (Table 5). Highly statistically significant was found between the differences of levels of compliance.

Table 4. Level of compliance with exercises by knowledge of complications due to lack of eyes, hands and feet care

Knowledge	Level of compliance				Total	Chi square and p value
	Low		High			
	No.	%	No.	%		
Eyes						
No knowledge	7	38.9	11	61.1	18	0.37
Some knowledge	4	28.6	10	71.4	14	(p = 0.54)
Total	11	34.4	21	65.6	32	
Hands						
No knowledge	15	51.7	14	48.3	29	0.017
Some knowledge	67	50.4	66	49.6	133	(p = 0.89)
Total	82	50.6	80	49.4	162	
Feet						
No knowledge	6	100	0	0	6	7.17
Some knowledge	17	41.5	24	58.8	41	(p = 0.007)
Total	23	48.9	24	51.1	47	

Table 5. Level of compliance with protection practices by knowledge of complications due to lack of eyes, hands and feet care

Knowledge	Level of compliance				Total	Chi square and p value
	Low		High			
	No.	%	No.	%		
Eyes						p value for Fisher's Exact test = 0.0001
No knowledge	28	100	0	0	28	
Some knowledge	10	66.7	5	33.3	15	
Total	38	88.4	5	11.6	43	
Hands						
No knowledge	43	95.6	2	4.4	45	6.304
Some knowledge	134	79.8	34	20.2	168	(p = 0.012)
Total	177	83.1	36	16.9	213	
Feet						
No knowledge	47	87	7	13	54	15.314
Some knowledge	130	58.6	92	41.4	222	(p = 0.0001)
Total	177	64.1	99	35.9	276	

Knowledge was a key component for compliance as those who were knowledgeable had high compliance. This could be illustrated by some expressions. As they knew the benefit from doing exercises and were afraid of unpleasant consequences-physically and psychosocially, they performed exercises. They said:

"Doing eye exercises make better seeing. I think it's beneficial. I always do for better seeing"

(56 years, female, dependant, grade 2)

"Before exercise, there was foot drop. Now, if I didn't take care of my deformed feet, my feet would become worse and would be amputated"

(51 years, male, grow crops, grade 2)

"I felt ashamed as being a peculiar [disfigured] *person that unlike others"*

(22 years, female, odd jobs, grade 2)

Time factor played as a dual role for the compliance. While a night watcher who had the opportunity of getting enough time tended to do exercises frequently, one housewife said that she did not have time to do because of working the whole day for her family. Encouragement and assistance from the family also contributed to high compliance. On the contrary, those who did not get the family support were less likely to carry out the protection practices.

Despite the provision of health message on protection and protective devices by the health staff, some PAL pointed out that poor supervision of the staff was one of their reasons for low compliance. A very few said they saw no effect in preventing their affected body parts. One PAL with low compliance had negative feeling of doing exercise and stressed as follows:

"I hadn't done exercise regularly. Because, to say frankly, I don't think it would be better in spite of doing exercise. While the staff were demonstrating, I followed them, and I did it in front of them. Later, I didn't do it because I think there would be no progress"

(54 years, male, dependant, grade 2)

DISCUSSION

More or less, the study population had either single disability of Grade I or II and or multiple disabilities, where disability in foot was the commonest. PAL complied more

with exercises than with protection practices. Knowledge was associated with level of compliance where those who were aware of the benefit and consequences about protection had tended to follow the instructions for protection than those who were not. Time factor, family support and supervision also influenced the compliance. Low economic status, no free time due to daily activities, no interest by their family and poor supervision resulted in low compliance. Only a very few did not believe in preventive measures. However, PAL's characteristics were not associated with the level of compliance. This study reveals that for further implementation, we should consider to reinforce the PAL about the protection of their affected body parts, and to work together with the family, community and health workers for better home-based self-care.

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REFERENCES

1. WHO Srinivasan. H. Prevention of disabilities in patients with leprosy. *A practical guide* 1993.
2. Hugh Cross, Wim H.van Brakel. Prevention of disability pilot project in Myanmar. *Report of the end evaluation* 2004 May; 25-30.