Original Article

Development of Skin Disease Disability Index to Assess the Dermatologic Burden in Nepal

Shrestha DP[1], **Shrestha R**[2], **Gurung D**[3], **Lama L**[2], **Rosdahl I**[4]

[1]Institute of Medicine, Kathmandu, Nepal; [2]National Academy of Medical Sciences, Kathmandu, Nepal; [3]Di Skin Hospital, Kathmandu, Nepal; [4]Kathmandu Medical College, Kathmandu, Nepal and Department of Clinical and Experimental Medicine, Linköping University, Sweden.

Corresponding author: DP Shrestha, MD, Institute of Medicine, Maharajgunj, Kathmandu, Nepal

e-mail: drdpshrestha@gmail.com

Abstract

Introduction: Skin disease is one of the leading cause of morbidity worldwide. Most instruments measuring the impact of skin disease on quality of life are developed in the west and not applicable to the socio-cultural situation in Nepal. The aim of the study was to develop and validate a questionnaire to measure quality of life impairment due to skin disease in Nepal.

Methods: Different aspects of quality of life impairment were identified from 35 in-depth interviews and two focus group discussions, with villagers with various skin diseases. Based on this information, 10 questions scoring the influence of skin diseases on quality of life – Skin Disease Disability Index (SDDI) – was developed. This instrument was tested and validated in 212 villagers with skin disease and in 100 healthy villagers.

Results: The maximum total Skin Disease Disability Index score was 36. There was a wide variation in total Skin Disease Disability Index score between individuals with skin disease (range 1-33) with a mean score of 13.2, while in controls the mean total score was 1 ($p<0.001$). Thus, the Skin Disease Disability Index clearly discriminates between these two groups. The difference in mean score for single questions between patients and controls was also highly significant ($p<0.001$).

Conclusions: The questionnaire clearly covered all aspects of quality of life related to skin disease and was, simple, robust, easy to use and well accepted by the selected population. The Skin Disease Disability Index was reliable in the overall score as well as in individual questions.

Key words: Skin disease; Disability index; Health burden; Nepal

Introduction

Skin conditions are common problems in most countries, but the highest prevalence has been reported from developing countries and poor areas[1, 2, 3]. According to the annual reports from the Ministry of Health, skin diseases (SD) are one of the leading cause of morbidity in Nepal. In 2010, SDs constituted the 5th and in 2011 the 4th most common reason for visits to outpatient clinics in the entire Nepal, with approximately 2 680 000 and 2 660 000 visits respectively [4].

It is well documented that SDs have a significant impact on quality of life (QoL)[5, 6, 7, 8, 9, 10]. Most accepted instruments to assess QoL, are based on questionnaires. The most commonly used is Dermatology Life Quality Index (DLQI) [11, 12,] which was developed in United Kingdom and primarily intended for the use in western societies. The socio-economic and cultural situation in Nepal is completely different, and several questions in DLQI are not relevant in the rural Nepalese areas where the majority of the population lives. In Nepal, in particular in rural communities, people have limited number of clothes, they usually do not have leisure activities or hobbies, and most of them do not practice sport. Further, the DLQI question on sexual difficulties is too direct for the norms of the Nepali society and indirect questions about these aspects have to be formulated, but, there are also similar worries in Nepal as in western societies that their SD is contagious or might become cancer. Other aspects and beliefs might be more significant in the Nepalese situation, such as social discrimination, suspicion of leprosy, association with blood impurities and financial burdens.

Due to shortage of doctors in the countryside in Nepal, the inhabitants have generally suffered for a long time without treatment. Consequently, the impact on QoL has to be measured for a longer period of time than one week. Further, in Nepal, particularly in the rural areas, most patients are not literate or education level is low, hence it is not possible to use a self-administered questionnaire. With this background we have now developed and validated an interview questionnaire to appropriately measure QoL impairment due to SDs in Nepal.

Materials and Methods

The study was conducted in Talku – Dudhechaur, a rural village 25 kms south of Kathmandu. This village has all the characteristics of a rural Nepalese village with around 3200 inhabitants (1700 m, 1500 f). It is a poor village with mainly an agriculture based economy. The study was conducted in 3 steps.

Step I - In-depth interviews and focus group discussions

Fifty villagers with common and recurrent skin disease diagnosed by a dermatologist were identified, and a total of 35 in-depth interviews were performed (12 m, 23 f; age 9 - 89 years, mean 41±18). All interviews were performed at their homes, by the same two doctors, following a structured checklist. The interviews were recorded and subsequently transcribed. Next, two focus group discussions were organized with 9 (2 m, 7 f) and 12 (6 m, 6 f) individuals randomly selected from this group of villagers. The transcriptions were analyzed and important symptoms, problems and disabilities affecting the QoL were identified.

Step II - Development of questionnaire

From the above information, the problems due to the SDs reported to have an effect on the general well-being, work/school/play, daily activities, psychological well-being and social relations, along with local beliefs were registered and a first version of the questionnaire – Skin Disease Disability Index (SDDI) - was developed. This version was pre-tested in 10 other villagers with skin problems (5 m, 5 f) and 5 controls (2 m, 3 f). After pre-testing the questionnaire was edited.

Step III - Validation of the questionnaire

Expert panel meeting - Feedback from an expert panel of 8 dermatologists was processed and modification in the questionnaire done.

Translation - Subsequently, three of the Nepalese authors independently translated the questionnaire from English to Nepali. Variations were discussed and a consensus reached. One external person, who masters both English and Nepali and is familiar with both cultures scrutinized and compared the original English version and the translated version. Thereafter, a back translation from Nepali to English was made by an independent reviewer. In the end the Nepali version was considered to have the same meaning and weight as the original English version.

Testing SDDI in villagers with and without SDs –Two, health camps (dermatologic examination in designated area) were conducted. Skin problems were diagnosed and treated by two dermatologists in 359 villagers. All villagers with skin problem of more than one month duration, of age more than 14 years, and those of age 14 or less accompanied by a family member were interviewed. Altogether, 212/359 villagers (59%) were interviewed using the SDDI questionnaire (98 m, 114 f; age 3 - 80 years (mean 28 ±16). A total of 100 randomly chosen healthy villagers present at the camp (55 m, 45 f; age 15 – 80 years (mean 30±17)), were interviewed in the same manner. These control subjects and the patients were not exactly matched, but the age range and sex distribution was similar. (Figure 1).

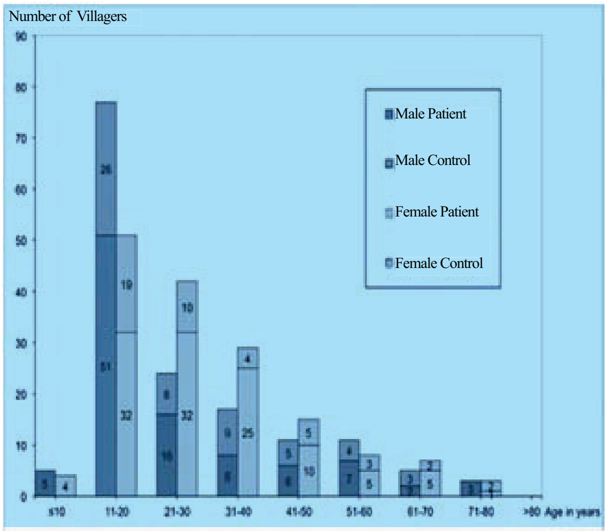

Figure 1: Gender and age distribution of patients (n=212) and controls (n=100)

The data were analyzed in SPSS 16 programme. A conceptual validity was established, by comparing villagers with and without SD. T-test was used for statistical significance. To verify internal consistency of the questionnaire, Cronbach's alpha was calculated.

Ethical consideration: The study was performed according to the ethical principles of the Helsinki declaration and approved by the Institutional Review Board of the Institute of Medicine, Tribhuvan University, Kathmandu.

Results

In-depth interviews and focus group discussions

Pruritus was the most common symptom in the 35 villagers interviewed in Step I, followed by pain and burning sensation. Among the psycho-social problems many thought that their SD was due to bad blood, god or evil spirit, snake, curse or might be leprosy (Table 1). These aspects were reiterated during the focus group discussions.

Table 1. Symptoms, problems and beliefs due to SDs reported in 35 in-depth interviews with villagers (12 m, 23 f). Seven individuals had more than one skin condition. n = number of villagers.

Diagnosis	No.	Symptoms, Problems, Beliefs	No.	Life aspects affected	No.
Chronic foot eczema	6	Pruritus	16	General well-being	23
Urticaria	6	Blood impurities	7	Work/school/play	3
Chronic hand eczema	5	Believes that it is due to God,		Daily activities	2
Vitiligo	4	evil spirit, snake, curse	5	Psychological and social aspects	30
Acne	4	Pain	4	Treatment	4
Warts	3	Contagious	4		
Fungal infections	3	Worry	4		
Melasma	2	Burning	3		
Others	10	Difficulty in doing house work	3		
		Discrimination	3		
		Costly	3		
		Difficulty to walk	2		
		Embarrassment	2		
		Thinks it can become cancer	1		
		Frustration	1		
		Low self esteem	1		
		Scar	1		
		Pigmentation	1		
		Time consuming	1		

Questionnaire development- SDDI:

All symptoms, problems, beliefs and feelings related to SDs that the patients rose during the in-depth interviews and group discussions were considered, when developing the questionnaire. The questionnaire comprises 10 simple questions (Q), which all together addresses 6 aspects of life, General well-being – Q 1, Work/school/play – Q 2, Daily activities – Q 3, Psychological well-being – Qs 4, 5, 6 and 9, Social relations – Qs 7 and 8, and Treatment – Q 10. This tool was designed to be used by a doctor for a questionnaire interview. As in other QoL questionnaires the scoring is approximate and not exact. The score for a single question ranges from 0 to 3. For questions 1 to 9 the scoring scale is, 0 – for not at all, 1 – for a little, 2 – for a lot and 3 – for very much. Q 10 concerning consultation and treatment has a different design, in which availability and type of health care, time and money has been taken into account. If the villager has consulted a dermatologist; the score is 0, a general doctor 1, any other health worker 2 and a witch doctor gives 3 score. A villager who has not consulted anybody, because he/she thinks that it is not necessary the impact is 0, if due to lack of time 1, lack of access to health-worker 2, and if due to lack of money the impact is considered high and scores 3.

General well-being and work/ school/play have very significant overall impact on the QoL, therefore Q 1 and 2 are multiplied by a given weight factor of 2. Hence, the maximum score is 6 for each of these two questions., while for all other questions the maximum score is 3. The psychological well-being also has a strong influence on QoL. There are 4 questions within this field, which gives a maximum total score of 12. The total SDDI ranges from 0 – 36 and the score has been estimated to have the following influence on QoL: 0- no effect, 1-5 little effect, 6-12, moderate effect, 13-24 significant effect, and >24 severe effect.

Testing SDDI in villagers with and without SDs

A total of 212 villagers with SDs and 100 healthy villagers were interviewed using SDDI questionnaire. In both groups, most were students, followed by housewives also working in the fields, and farmers. Age and gender is presented in Fig 1. A total of 272 skin conditions were diagnosed. The most common SD was various types of eczemas, followed by acne, pigment disorders, urticaria and fungal infections (Figure 2).

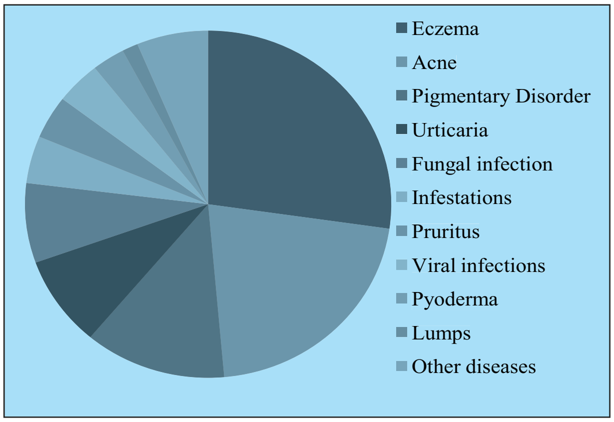

Figure 2: Groups of SDs and percentage of all skin diagnoses patients.

There was a wide variation in SDDI between the various groups of SDs and also between patients with the same skin diagnosis. Among the group of SDs the total score was highest for urticaria (17.3), followed by pruritus (16.7), pyodermas (16.5), infestations (15.3) and pigment disorders (14.7). The variation in total SDDI between patients ranged from 1 - 33 with a mean score of 13.2. This was significantly different from the control group with a mean total score of 1, ($p<0.001$). The difference between the mean scores of each single question in patients and controls was also highly significant ($p<0.001$), (Table 2). Considering the 6 aspects of life, the scores were highest for psychological aspect 4.2 (Q 4, 5, 6, 9) and general well-being 3.9 (Q1), (Table 3). Likewise, the difference between the mean scores of the 6 aspects of life addressed by the 10 questions in patients with SDs and controls were all highly significant ($p<0.001$). Thus, this SDDI questionnaire successfully differentiated between QoL in these two groups of individuals. There was no statistically significant difference between the total mean SDDI between males (12.6) and females (13.7; $p=0.26$).

To verify the internal consistency of the questionnaire, Cronbach's alpha was calculated. Based on 312 subjects (both patients and controls), its value was 0.77, demonstrating acceptable internal consistency.

Table 2: The SDDI instrument clearly differentiated between QoL in individuals with and without SD. The difference between SDDI score of each single question between patients and controls was highly significant for all questions ($p<0.001$).

Question number	**SDDI score Mean ±SEM**	
	Patients n = 212	**Controls n = 100**
1. General well-being	3.9 ± 0.2	0.7 ± 0.1
2. Work/school/play	1.9 ± 0.2	0.1 ± 0.1
3. Daily activities	0.7 ± 0.1	0.0 ± 0.0
4. Psychological-worry	0.9 ± 0.1	0.0 ± 0.0
5. Psychological-local belief	1. 6 ±0.1	0.2 ± 0.1
6. Psychological-feeling	1.0 ± 0.1	0.0 ± 0.0
7. Social relation	0.5 ± 0.1	0.0 ± 0.0
8. Social relation	0.9± 0.1	0.0 ± 0.0
9. Psychological-feeling	0.6 ± 0.1	0.0 ± 0.0
10. Treatment	1.2 ± 0.1	0.1 ± 0.0

Table 3. The difference in mean SDDI scores between patients and controls concerning the 6 life aspects affected were all highly significant ($p<0.001$).

Life aspects	**SDDI score Mean ± SEM**	
	Patients n = 212	**Controls n = 100**
General well-being	3.9±0.2	0.7±0.1
Work/ school,/play	1.9±0.2	0.1±0.1
Daily activities	0.7±0.1	0.0±0.0
Psychological aspect	4.2±0.2	0.2±0.1
Social aspect	1.4±0.1	0.0±0.0
Treatment	1.2±0.1	0.1±0.0

Discussion

It is not only the prevalence of a disease that has to be taken in account when allocating health resources in a broader perspective, but also the QoL for each affected citizen. Therefore, an accurate QoL evaluation should not be based only on the physician's routine assessment, but include also the patient's opinion. It is obvious that a severe chronic and disabling SD significantly reduces QoL and is a great distress for an individual and for his family, but there are many skin diseases, as vitiligo, moles, birthmarks, which also have profound psycho-social impact. An accurate perception and comparable information of QoL in these patients can only be obtained by a structured situation- and disease-driven QoL questionnaire describing the patient's own view.

Most methods estimating disability due to SDs have been developed in the west[11, 12] and not applicable in the social and traditional situation in Nepal. We have developed the first dermatology specific tool to measure QoL in Nepal. This instrument addresses the most common skin problems and aspects of life, economy, socio-cultural norms and beliefs in the context of Nepal, more specifically in rural areas, where the majority of the population in Nepal is living, often in remote and difficult terrain, with limited access to health-care and deprived of specialist care in dermatology. A realistic understanding of the health burden due to SDs is fundamental for each country with the ambition to plan and validate intervention programs to meet the needs and suffering of the population.

In contrast to most questionnaires which are hospital based, the SDDI was developed and validated in a rural community (village) in Nepal [11]. Identifying the various life aspects affected in this culture, was a challenge. The population was mostly illiterate and methodologies requiring reading and writing could not be used. Instead, we found in-depth interviews and focus group discussions to be an appropriate procedure. In these remote areas it was not possible to reach individuals twice for a test-retest correlation test. Neither was a comparison with other QoL instruments feasible as no life quality measures for SDs existed for Nepal. Therefore, we established a conceptual validity, as performed for DLQI, by comparing the impact on QoL in villagers with SDs with those without skin problems[11]. Further, the internal consistency of the questionnaire was acceptable (Crohnbach´s alpha 0.77).

In our final test of the SDDI questionnaire, the mean total score for 212 volunteer individuals with various SDs was of 13.2, indicating a significant impact on the QoL. In most SDs – eczemas, pigment disorders, acne, warts, and scabies – the score ranged from 12 – 15, as defined equivalent to a significant effect on QoL. The SDDI was reliable in discriminating between QoL in cases and controls in the overall score as well as in individual Qs. The scoring and the interpretation of the scores are as in most other questionnaires, arbitrary and gives an approximate indication of the impact on QoL, and the finding in the test population is consistent with our experience from clinical practice. Regarding single questions, Q1 the general well-being (3.9±0.2) had as expected the highest impact on QoL, mainly due to markedly distressing itch and pain. This is in line with the DLQI study, where the question concerning symptoms and feelings similarly had the highest score[11]. As expected, there was a high score for Q5 (1.6±0.1), which addresses beliefs that SDs are due to, blood impurity , sins in previous life, evil spirit or snake curse. This might be one reason why the villagers are worried, when they have skin problems. For any health problem, people living in the rural areas have difficulties to reach specialists and treatment is costly, which is reflected in Q10 regarding treatment (1.2±0.1).

Considering the six aspects of life, the most affected was the psychological well-being (score 4.2±0.2) followed by the general well-being. The psychological influence due to SDs might not be as apparent as a physical handicap and is often difficult to quantify, but its profound impact on QoL was clearly revealed by the high score in this questionnaire.

In practical use, this SDDI questionnaire with 10 simple Qs was shown to be robust, easy to use and well accepted by the selected population. The SDDI clearly covered all aspects of QoL related to SDs and was reliable in the overall score as well as in individual Qs by clearly discriminating between individuals with SD and those without.

Conclusion: This study indicated that this SDDI questionnaire is a useful instrument to assess the impact of SDs on QoL in Nepal, in particular in rural areas. We are now performing a large study to measure the prevalence and the QoL in individuals with SDs in various eco-climate regions in Nepal using the SDDI. In the future the SDDI questionnaire has to be tested in patients attending dermatology out-patient clinics in Nepal, to determine its usability in routine dermatology practice. We are convinced that the use of SDDI will expand the holistic perspective and improve the quality of overall dermatologic care.

Conflict of interests: None declared.

Acknowledgement:

We would like to thank Linköping University, Sweden for research funding, and the inhabitants of Talku village for their cooperation.

References

1. Schmeller W, Dzikus A. Skin diseases in children in rural Kenya: long-term results of a dermatology project within the primary health care system. Br J Dermatol 2001; 144:118-124.
2. Mahé A, Prual A, Konaté M, Bobin P. Skin diseases of children in Mali: a public health problem. Trans R Soc Trop Med Hyg 1995; 89:467-470.
3. Dogra S, Kumar B. Epidemiology of skin diseases in school children: A study from Northen India. Pediatric Dermatology 2003; 20(6):470-473.
4. Annual Health Report 2010 and 2011, Department of Health Services. Ministry of Health, Kathmandu, Nepal.
5. Ryan TJ. Disability in Dermatology. Br J Hosp Med 1991; 46:33-36.
6. Finlay AY. Psychological impact of skin disease. In: Seymour CA, Heagerty A M. editors, Horizons in medicine 4, London: McGraw- Hill, 1993; 172-179.
7. Ramsay B, O'Reagon M. A survey of the social and psychological effects of psoriasis. Br J Dermatol 1988; 118:195-201.
8. Yasuda H, Kobayashi H, Ohkawara A. A survey of social and psychological effects of psoriasis. Jap J Dermatol 1990;100:1167-1171.
9. Koo JYM, Smith LL. Psychological aspects of acne. Pediatr Dermatol 1991; 8:185-188.
10. Porter JR, Beuf AH, Lerner A, Nordlund J. Psychosocial effects of vitiligo: a comparison of vitiligo patients with 'normal' control subjects, with psoriasis patients, and with patients with other pigment disorders. J Am Acad Dermatol 1986; 15:220-224.
11. Finlay AY, Khan GK. Dermatology life quality index (DLQI): a simple practical measure for routine clinical use. Clin Exp Dermatol 1994; 19:210-216.
12. Finlay A Y. Quality of life measurement in dermatology: a practical guide. Br J Dermatol 1997; 136:305-314.