CHAPTER IV

A CROSS SECTIONAL SURVEY OF QUALITY OF LIFE (QOL) OF PATIENTS WITH CHRONIC ILLNESS

4.1 INTRODUCTION

QOL is a concept introduced in medical care in the middle of the sixties. Even though welfare of the patients has been the central theme of health care systems, the ultimate driving force for clinicians to ensure this has been provider-centered model of care. The ultimate measure of success of any treatment regime or management program of health should be measured by the ability to improve the QOL of the recipient rather than just a prolongation of survival and / or prevention of complications. Even though this concept of QOL is attaining importance, there is no universally accepted definition for it. In this study, the Portuguese definition is used.

An individual's overall satisfaction with life and one's general sense of personal well being in the context of the cultural and value system in which they live, and in relation to their goals, exceptions, standards and concerns." (Riberio, Mendonca, Martins & De Silva, 1998).

Any chronic illness, even those where physical pain may not be prominent, will have a negative impact on a person's perception of self. This in turn will adversely effect his physical and psychological capacity to cope with the condition, thereby starting a vicious cycle of deterioration of health. Epilepsy which is a chronic and socially debilitating illness will not be an exception. In order to assess the ultimate impact of the proposed epilepsy control program the serial estimation of the QOL of the patient

is used as one of the measures. It is envisioned that after the initiation of proper treatment leading to better control of fits, the QOL index of the patients will gradually improve. There is evidence that the QOL in the patient with epilepsy is affected by various factors. An European study has suggested that those with more frequent seizures report a greater impact of epilepsy on their daily lives, more feelings of stigmatization and poorer overall health status. Moreover, patients with mixed seizure type reported a greater impact, more stigmatization and poorer overall health than those patients who had only tonic seizures. (Baker, Jacoby, Buck, Stalgis, & Monnet, 1997).

In the following section, this concept is used to assess the overall impact made by the institution of treatment in the QOL of a patient with chronic illness. The instrument used in the assessment is the Duke Health Profile (Parkerson, 1990) developed and tested in 1990. This was derived from the Duke-UNC Health Profile (DUHP), a 63-item measure designed to measure outcomes in the primary care setting. The limitations in the DUHP stimulated the development of an abbreviated version called the DUKE Health Profile (Appendix 9). This instrument extends the WHO triad of physical, mental, and social domain by adding self-esteem and self-perceived health; positive and negative aspects of health are covered separately. It is a self reporting questionnaire comprising of seventeen items dealing with different aspects of human perception about his own psychological , social and physical state of wellbeing. The time frame extends to the present or the past week The responses to all the seventeen items are scored on a zero to two scale. None of the items are weighed. The grouping and manipulation of different item-scores yields scores for six health domains and five dysfunction measures. The domains are - physical

health, mental health, social health, general health, perceived health and self esteem. The dysfunction measures are anxiety, depression, pain, disability and anxiety-depression. In essence, this gives a profile of the patient rather than a unitary score. The reliability, validity, the raw scores and the method of calculation of domain scores are indicated in Appendix 9.

This instrument can be used for a cross sectional assessment of a patient at one point of time. It can also be used repeatedly on the same patient at regular intervals to monitor the overall change brought about by the treatment regime. In this exercise, it is used for the former objective but will be used later for the latter purpose of assessment of the effectiveness of the program.

4.2   OBJECTIVES OF DATA EXERCISE

4.2.1   General Objective

The overall objective of the data exercise is to test the 'Duke Health Profile' in the assessment of QOL in patient population by testing it on patients with chronic illness and normal population.

4.2.2   Specific Objective

◆ To assess the QOL of patients with chronic illness.

◆ To assess the QOL of normal population.

4.3   METHODOLOGY

DUKE is a tool developed and tested in the western population and was formed as a short and quick assessment tool to be used in the primary care setting.

This was the main reason for selecting this instrument and a measure and not any extensive research tool used in academic QOL studies in epilepsy. It does not have any culture laden questions but does have idiomatic expressions which had to be translated into eastern concepts. As a test to whether this tool is at all appropriate to the Thai culture, it had to be tested on normal population and then on patient population. The groups were not intended to be compared among themselves but treated as mini-studies on their own merits.

4.3.1   Sample selection, size and sampling technique

Purposive sampling technique was used in both instances. Volunteers from the administration section of College of Public Health were requested to fill the questionnaire for the 'normal' group. 30 consecutive patients with the diagnosis of Diabetes mellitus attending the medical OPD at Nakhonratchasima Hospital at Nakhonratchasima Province, Thailand, satisfying the following criteria were included in the second part of the study.

Inclusion criteria

- ◆ Patients with the diagnosis of non insulin dependent diabetes mellitus.

- ◆ Duration of treatment at least 6 months to exclude acute reaction to stress caused by diagnosis of chronic illness.

Exclusion criteria:

- ◆ People who were severely ill at the time of interview (needing to be supported).

- ◆ People who did not give informed consent for the interview.

- ◆ If an individual did not grant consent, then the next case was taken.

4.3.2 Instruments

♦ The Duke Health Profile was used to access the QOL in both groups. The questionnaire was translated into Thai language using the forward-backward method (Appendix 10).

4.3.4 Data collection

♦ Informed consent was taken.

♦ The technical details were filled up by one of researchers by asking the patient and consulting the patient file.

♦ After initial assessment, if the patient could read, comprehend the questions and write, he/she was given the Health Profile questionnaire to be filled up. In the cases where the patient or the party could not read or write, the researcher with the help of interpreter, staff nurse at the OPD helped in the filling up of the questionnaire.

♦ Strict confidentially was maintained by not recording the name of the patient.

♦ Whenever possible, the patient was encouraged to answer the questions instead of the patient party answering for him.

4.3.5 Data management

Data cleaning - the questionnaire were checked to see whether there were any missing items.

Data analysis - The information was be fed into a program developed in Epi 6 software and checked by double entry technique. The final analysis was done with SPSS package.

4.4 RESULTS

The results of the different findings are given below. For simplicity, the domains in all the tables have been maintained to be in similar order and is represented in all the tables by the same legend.

Table 4.1   The QOL scores in different domains of the two groups

	NORMAL		PATIENT	
	Mean	Std. Deviation	Mean	Std. Deviation
A. Physical health	76	22.53	52.66	22.27
B. Mental health	72.33	15.01	58.33	23.93
C. Social health	76	14.04	63.67	19.39
D. General health	74.78	12.46	58.22	17.08
E. Perceived health	65	37.49	38.33	44.88
F. Self esteem	83.67	11.29	72.33	21.12
AGE of RESPONDENTS	28.33	6.75	23	3

4.5 DISCUSSION

It has been observed that roughly 1/3 of the sample in both the groups have shown a tendency to respond in the midline i.e. more than 10 responses out of 17 being in the midline. This is a normal experience when people who are not very willing / cooperative are made to answer questionnaire where the response has to be given in a sliding scale. The subjects were requested to fill the questionnaire in a circumstance where participation was more or less 'forced'. There was no outright rejection of the request.

In the normal population, the mean score in all the domains were lower than the optimum of 100 with the best scores for self esteem (83), social health (76), and mental health (72) with perceived health scoring the lowest of 65. Even though the ultimate scores for identical domains in the patient population was lower than the normal population, the trend remained the same. Here also self esteem was the highest at 72 followed by social health (63) and mental health (58) with perceived health getting the lowest at 36. The score for the three domains of self esteem, social and mental health are based on five questions each so any one response being in the extreme will affect the total score less than the perceived health domain which depends on just one question. It could be due to this lack of buffer or the question itself, "I am basically a healthy person" when translated idiomatically does not mean the same in the eastern culture that has given rise to this low score.

4.6   LIMITATIONS

There have been various limitations in the conduction of this study, both in the process and the procedure. The limitations were largely due to small sample size and the inability for the sampling procedure to be randomized in the survey part of the exercise. This was basically due to the inaccessibility of a larger sample as a result of unforeseen and unavoidable circumstances. The initial plan was to use patients with epilepsy but due to the very low inflow of epilepsy cases, (3 - 4 new cases per week) and the short time available, another chronic illness was chosen as the sample population for the chronic cases.. Non insulin dependent diabetes was taken as a prototype because of the chronicity, no mood altering side-effects of the drugs used and the availability of the patients. As a result, the findings of this study cannot be generalized and has to be limited to represent only this sample. Problems of

communication mostly due to language barrier also needs to be mentioned but this was tried to be minimized with the help of a local colleague and a staff nurse at Korat Hospital, but could not be eliminated altogether.

4.7   IN-DEPT INTERVIEW

The following status report is based on an in-dept interview with Thanin Asawavichienjinda M.D., at Maharat Nakhonratchasima Hospital, Nakhonratchasima Province, Thailand. He is the consultant Neurologist and is presently doing extensive research on QOL in epileptic patients. The average number of new cases of epilepsy seen is 3 - 4 / week, out of a total of 30 - 35 neurology cases.

Epilepsy, in Thailand follows the same pattern as in other countries. The most common cause for secondary epilepsy is cysticercosis followed by tuberculoma. In the government hospital setting epilepsy falls under the domain of Neurology , but in private practice, graduate doctors in all discipline are involved in the management of epilepsy. In the periphery, referral to a neurologist is an exception rather than a rule, however in the hospital setting where neurology service is established, all cases are referred. The lowermost level at which epilepsy can be diagnosed and treatment started independently is at the level of Junior Doctor (M.B.B.S.). They may use the whole spectrum of anti-epileptic drugs but phenobarbitone is common. Once diagnosed, the patient may be followed up and treatment continued by the health posts where phenobarbitone is available.

In a referral center, the basic investigations carried out are routine hemogram and electrolytes. EEG is not done as a routine. The prevalent pattern is to continue treatment for 3 - 4 years after last fit, but there are individual variations according to physicians and the case profile. The trend of management is mono-therapy. The average default rate is not known.

The belief system in the community about epilepsy is that of being possessed by the Demon and the traditional healers use 'Holi water' in the treatment.

4.8   LESSONS LEARNED

The most prominent lesson learned during this data exercise was the sense of time management. It was virtually impossible to get a sizable patient population of epilepsy (it would have taken 8-10 wk. For the data collection) so the type of patient had to be changed into a more available diagnosis. The literature relating to the DUKE says that it takes 2-3 minutes to complete but it was seen that 15-20 min were needed for one questionnaire.

As the results in the normal population suggests, some of the questions have to be reevaluated in the cultural context to see the appropriateness. Questions number 9,15, 16 and 17 has to be reassessed in the cultural context to see that it is idiomatically translated.

To minimize the tendency of midline responses postal questionnaire or cross checking appropriate questions from informed patient party can be tried. But this also has its own fallacies. While working with epilepsy, it has been noticed that there are statistically significant mean differences between patient and proxies report for 5 of 17 QOL scales. For health perception, and seizure distress the bias is in the direction of proxies reporting worse QWOL than patients For the three measures of cognitive function - language, attention and memory, the bias was in the direction of the proxies reporting better QOL than patients. Overall, there was better agreement between patient and proxy reports for patients with higher educational achievement (Hays, et al., 1995).

In reality, as this questionnaire will be used as a single package with history taking, this tendency may be less.

4.9 REFERENCE

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