Quality of Life

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As professionals usually accustomed to speak to members of our own profession it is indeed a welcome change to address a distinguished gathering comprising of the laity as well as other professional. The ceremonial induction of the President of the College is one of the few occasions when one gets such a chance. It is also one that we accept with great trepidation for the simple reason that, making the right choice of a subject is a most difficult task. Just as much as a purely medical subject would be obscenely out of place so would one that interests only the laity be garishly inappropriate. Hence the compromise to pick one that should in my opinion be of interest to both groups: its other advantage is that one can talk about this subject without recourse to technical jargon which often drives the audience to boredom if not to slumber.

Quality of Life (QOL)

QOL is the new catch phrase in the practice of medicine. Like happiness, it is one of those terms we all understand but for which precise definition does not come easy. Most lay people are aware of the havoc and despair created in the lives of patients and their families by a diagnosis of cancer or its treatment. The cause of the illness is difficult to explain, the course of the disease could be unpredictable and it is apparent that even the experts do not have all the answers. Furthermore people are often told "there is nothing more we can do for you" or "you have only six months or one year to live". It is therefore not surprising that QOL is a very big issue in the field of cancer than it is in the other diseases which are numerically a bigger cause of illhealth and death in the population.

For the purpose of this address I would like to exclude the complex and highly emotive subject of cancer and confine myself to the ambulant or outdoor patient who suffers from chronic or long lasting disease. Diabetes mellitus and high blood pressure are two such diseases which affect an increasing number of the middle aged and the elderly in our population; these diseases do not seem to affect one's health in a big way as they are often symptomless and are picked up on routine medical check ups. But once diagnosed and the importance of changing life style and curtailment of certain freedoms are explained, a person is bound to feel very unhappy and miserable within oneself. It is this situation that brings us to the concept of QOL of an individual.

The WHO definition of QOL states that "it's a state of complete physical, mental and social well being and not merely the absence of disease or infirmity." This slide gives the definition as enunciated by the W.H.O. This definition is deliberately general and refers to a range of emotional and social issues. For many this generality is central to any definition of QOL and is the essence of its merit over traditional and narrow indices of physical ill health; thus the contemporary definition of QOL encompasses a broad range of issues such as shown in this slide: Standard of living, experience of physical pain, physical mobility, opportunities for education, family, social and community relationships as well as more importantly an individual's level of satisfaction with the measured outcomes. To illustrate this point one can think of a physician trying very hard to keep his patient's blood pressure or blood sugar around normal levels; in trying to maintain these levels the patient's blood pressure or blood sugar could fall to very low levels causing unpleasant symptoms such as fainting, severe sweating, weakness, and pangs of hunger. In other words though the measured objectives are satisfactory the patient's own experience leaves much to be desired. Hence inclusion of this criterion. The meaning of QOL also changes with age. To the young people QOL denotes, superior health with the ability to run a mile or dance all night. To the average house wife it would mean, the ability to do all the household chores such as washing, ironing cooking and cleaning up the house. To the elderly, the capacity to live independently, do their own shopping and attention to toilet needs by themselves, would determine their QOL. Thus the factors determining QOL can be very personal, subjective and difficult to quantify; despite these drawbacks many clinicians now accept that QOL is a valid end – point in clinical trials and that in certain situations such as palliative chemotherapy trials in cancer treatment QOL may be the primary index of benefit. In view of the newly

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acquired respectability of QOL as a valid out-come measure there are elaborate questionnaires designed for assessing QOL called the QOL instruments. These have been developed specially because of steadily increasingly emphasis on QOL outcomes for a variety of reasons. For eg. provision of pharmaco-economic data, comparison of interventional procedures, resource allocation and increasing awareness among patients of their "consumer" rights.

My interest in this concept stems from the fact that it has particular relevance to diabetes mellitus (DM) and high blood pressure (HT); these are two chronic diseases which entail enormous costs of caring. They are also liable to short term and long term complications with a high degree of potential for patient participation in management decisions. Most people are aware of the potential seriousness of the untreated disease.

Diseases like DM and HT cannot be cured but have to be endured and for this we have the endearing term "management" of the disease. At this point I must make myself clear to the non-medical members of the audience what I mean by "curing" a disease. There is no man on earth who can say to a sufferer from DM or HT "take these medicines and follow this course of action for a few weeks or months and you will never suffer from it again for the rest of your life; further you will not have to place any restrictions on your life style and food habits." No sensible physician will ever make such a claim but there are amongst us those who occasionally take leave of their senses.

The extant notion among patients that doctors possess limitless curative power, and the reluctance on the part of some doctors to give up their aura of omnipotence make it difficult for the average doctor to admit that some diseases, at least in our present state of knowledge, cannot be cured. To add to this difficulty is the traditional view of disease that emphasises "curing of disease"; this is a concept that is central to acute care medicine but has little relevance to chronic disease.

If that is the truth about these diseases what can be said of the QOL of those affected once they are told that there is no lasting cure for them?

Two questions that patients often pose "what is the use of living like this and how long can I go on like this?" reflect the depths of despair that these people find themselves in once a doctor makes such a pronouncement.

A major obstacle to the assessment of QOL in a patient is the attitude of the physician whose concept of health and illness may be narrow. His concept of good health and illness may be confined to finding a normal blood sugar or blood pressure level; these no doubt are easily measured and have a clear relation to outcomes in terms of morbidity and mortality. But these measurements may not be the most important outcomes of treatment from the patient's perspective. In other words the doctor must guard himself against treating the disease and not the patients. I dare say that however ignorant and unenlightened some patients may be of their illness, they have a more wholesome view of life than some of the physicians treating them. This may sound a distasteful remark but truth like good medicine need not taste sweet. To add credence to this statement are the findings published in the Journal of the Royal College of Physicians of London a few months ago[1]. It was found that 25% of patients in the U.K. used some form of complementary medicine in addition to the Western or mainstream system of Medicine as we know it. The more startling revelation was that 80% of those using complementary medicine rated their treatment as satisfactory where as only 58% of those using Western medicine were satisfied with that modality of treatment. The main reason given for this discrepancy was that the practitioners of Western medicine are more concerned about the disease and less with the patient.

It is also well known that the expectations and health assessment of the consumers of medical care and those of health care providers do not always coincide. Studies which have compared physicians' and patients' satisfactions and the outcome of the intervention have shown that there is often considerable divergence of views about them[2]. Whereas a self-deluded physician may pat himself on the back that he has done a wonderful job for the patient, the latter may not share his physician's enthusiasm for very valid reasons, from the patient's stand point. Research has also shown that a patient's own judgement about health status has a high predictive value for the outcome of illness. For eg. one study showed that there was a substantially increased mortality for people who perceived their health status as poor, even when the diagnosis and adequancy of medical treatment, were taken into

account[3]. It appears therefore that apart from anything else the assessment of QOL could lead to a more humane approach to the art of healing, in addition to yielding results of practical value.

Let us now see how QOL can be affected in the ambulant, outdoor patient with DM. Once the diagnosis is made he needs to be given a fulsome explanation of the disease in a language the patient understands. The patient expects to receive comfort and reassurance from the doctor after what appears to be devastating news to him. He will have to be told that adjustments have to be made in his life style and that restricitions have to be placed on the choice of his diet.

Unfortunately at this point doctors often fail to grasp the opportunity to open a fruitful diaglogue with the patient. Far too often the physician takes the patient for granted and doles out advice and instructions expecting him to follow them blindly and unquestioningly. Few people in today's society will accept advice blindly; in my experience only pregnant mothers would do so in the belief that the baby may come to harm if the advice is not followed. A few others may do so in order not to offend or displease the doctor, or because of the doctor's paternalistic personality.

It is also known that knowledge alone is not sufficient to effect change in behaviour, especially if it is going to affect their leisure and pleasure. For the patients the perceived advantage must exceed the perceived disadvantages of any change. In other words education of the patient about the disease should be the prime concern and the foundation laid for a two way communication system. It is therefore most unfortunate that communication often takes place in one direction only or not at all.

Let us now delve a little deeper into the diagnosis of a disease like DM. What does it mean to a patient who has been in apparent good health, leading a normal life with little restrictions placed on his pleasurable activities such as wining and dining? Armed as we are with modern concepts of the disease the implications of a diagnosis of DM can indeed be very depressing. Today we know that even the type that can be managed with tablets – and therefore thought to be mild by the public as well as by some members of the profession can leads to equally serious complications as the insulin requiring ones. Having said that let me briefly outline the many different ways in which diseases like DM and HT can affect QOL.

As the broad principles involved in the management of DM and HT are similar I shall deal with them together. I would like to start with this quotation. "Whoever wishes to investigate disease properly should proceed thus:

In the first place to consider the seasons of the year, the waters, the ground and the mode in which the inhabitants live and what their pursuits, whether they are fond of drinking and eating in excess and given to indolence or are fond of exercise and labour" This is that quotation. As you see this perspicacious statement was made by none other than the Father of Medicine, Hippocrates in the 5th. century B.C.

Dietary adjustments

Another very apt quotation from Socrates dating back to 400 B.C. that should make some of us feel ashamed of ourselves.

Let me first refer to the dietary changes which form the cornerstone of treatment of diabetes and to a lesser extent of hypertension. Salt, sugar and saturated fat all of which contribute to the taste and enjoyment of food are the main mischief makers in the diet; if these are denied or seriously reduced the QOL usually suffers. Often we have statements such as these "We don't bring chocolates and ice-cream into this house any more because we feel so bad and so sad that he cannot enjoy what he always loves to do "or" he wants his food cooked separately without adding salt or coconut milk". What additional strain separate cooking involves, only a busy housewife will understand. It is only a thoughtful doctor who will seek the help of a dietician to give a wider freedom of choice in food items to suit individual tastes.

The food industry of course has not been slow in coming up with sugar substitutes which are safe and efficacious.

But a substitute for fat had to wait much longer; it was only last year that the Federal Drug Authority in U.S.A approved the use of a fat substitute called "olestra". The Time magazine aptly greeted the arrival of OLESTRA into the American market[4]. It has the taste, mouth-feel, and texture of natural fat without its harmful effects such as raising blood cholesterol or calorie intake. It is still too early to gauge the response of the American public to this fat free formula but it is certainly a major break through in food technology.

It is in attempts to manage what are called risk factors such as smoking, alcohol abuse, high blood

cholesterol values and obesity that more serious intrusions into the privacy of patients lives and curtailment of freedom are seen. But such intrusions have become necessary in view of epidemiological studies that show the importance of these factors in causing serious complications. For example taking obesity[5] and cigarette smoking[6] the following information has been gleaned from epidemiological data:

Obesity is now considered a chronic disease requiring long term treatment.

Alcohol and tobacco play such important roles in the social lives of some people and in the making of their personalities that life without them is unimaginable. Alcohol not exceeding an approved amount measured in units per week is now no longer frowned upon by the medical fraternity as within these limits it has been found to have beneficial effects on the heart and blood vessels. There are what are called "sensible limits" to alcohol intake as determined by a working group in the UK. Of course, these limits refer only to middle aged men and women who are otherwise healthy; for those who have diseases caused or aggravated by alcohol the sensible limit is zero! The same cannot be said about cigarette smoking, the deleterious effects of which on the health of smokers and non smokers are legion. Numerous other diseases such as cancer of lung and stomach disorders are caused by smoking. There is mounting public reaction to nicotine addicts and increasing anti smoking propaganda. Perhaps a nicotine-less cigarette may not be a pipe-dream at the rate research is being spurred on consequent to worldwide pressure on the tobacco industry.

Monitoring of blood sugar and blood pressure

The potential intrusiveness of blood sugar monitoring can have a strongly negative effect on QOL. This measurement involves time and money as well as the discomfort of a needle prick. Lay people's aversion to needles is understandable but how many doctors fight shy of needles when they themselves become patients? They often go by urine sugar assays which are only rough guides to blood sugar and often avoid specialist advice because of the reluctance to monitor blood sugars.

Similarly for patients with high blood pressure its measurement involves a visit to the doctor or clinic and perhaps a long wait which if not in pleasant surroundings could literally raise the blood pressure. Some who are better off go for electronic blood pressure measuring instruments; these are expensive, sensitive and more liable to errors than the conventional Mercury manometers. But what is more exasperating is the temptation to record the blood pressure needlessly several times a day and then panic at seeing its fluctuations. For this reason I strongly discourage patients taking their own blood pressure on electronic instruments, then worry themselves and their doctors about the significance of minor variations in blood pressure.

Economic costs

Regular travelling to clinics, regular monitoring of blood and urine sugar, non availability of some drugs in the state sector, sterilization of needles and syringes and procurement of disposable syringes can place a heavy burden on the family budget specially of the lower middle class family. This is unfortunate as expenditure on food or a child's education may be bartered for the health of one member of the family. It would be a great boon to needy patients if free travel could be arranged through the state transport services for regular visits to public sector clinics. Diabetics and Epileptics are two groups of patients who if economically deprived deserve such favouerd treatment. Knowing the state of our transport services only a few. I am sure, will abuse it.

The effect on marriage and family life

If unmarried a diabetic or hypertensive patient will have more difficulty in finding a partner, than if he were not so affected. Fortunately for some, Cupid lends a helping hand inviting comments such as "Love conquers all" or "Love is blind" depending on the way one looks at it.

For those who are already married the spouse is expected to play a key role in the management of the diabetes. It is the spouse who often reminds about taking of medicine, testing blood sugar, boiling syringes or testing urine; if the patient fails to cooperate despite exhortations of the spouse, family life could become unpleasant. If the spouse becomes over-protective and domineering instead of being understanding and supportive then more misery may be caused by the spouse than the disease itself. Family physicians, generally speaking are more informed about such relationships than government doctors and are better suited and perhaps better equipped to handle such unsavoury situations. The effect of the disease on sexual function may come in the way of a happy marriage and add to the patient's woes.

Psychological consequences

One of the most important psychological consequences results from being acutely made aware of complications that may arise from the disease. Once a diagnosis of Diabetes or High Blood Pressure is made it is the moral obligation of the doctor to explain to the patient why changes in life style and food habits become necessary. If the patient with his limited knowledge does not find your reasoning convincing enough he may change the doctor ie. go doctor shopping or try an alternative system medicine; or worse still fall prey to quacks who of course have more time on their hands and are generally more articulate and easily approachable.

In order to impress upon the patient the importance of regular and supervised treatment one may be compelled to list the possible complications that may follow non-compliance. The threat of losing one's limbs or eye sight being felled by a stroke, losing the function of the kidneys unbeknown to the patient are frightening possibilities that can motivate many to fall in line. For those on oral treatment the threat of ultimately daily insulin injections with close blood sugar recording can be very real indeed.

How can an apparently normal human being suddenly discovering that he is a Diabetic or Hypertensive cope with the frightening possibilities that the diagnosis portends? Needless to say that the psychological effects of such revelations could be most damaging.

Let me now touch upon a few aspects in the management which are of a more controversial nature; for what is the worth of a Presidential address if it does not raise a few eyebrows!

The first point at issue is whether we can apply results of clinical trials based on populations or groups of patients to individuals. The main reason for this query is the observation many of us have made of people with surprisingly good quality of life and longevity despite breaking all ground rules of health; such examples of heavy smokers, alcoholics and diabetics are only too well known and whatever explanation we can give for such discordant observations the fact of the matter is that they are an acute embarrassment to the profession and to the conformists. The temptation they pose to the faithful is another matter.

Therefore instead of being very rigid in laying down our rules we could be a little lax when dealing with inveterate smokers alcoholics and voracious diabetics; this is in the hope that such laxity would improve patient compliance regarding drug treatment. Laxity is best shown by giving a time limit eg. two to three months over which period one should gradually give up the bad habits. Laxity in relation to quantity of substance abused eg. only to smoke 5 or less cigarettes per day or alcohol 2-3 drinks per day is more difficult to enforce and also makes the patient easy prey to temptation. Even if this reasoning is questionable one cannot deny the fact that a healthy or lasting doctor – patient relationship cannot be fostered, if the irresistible force of a doctor's persuasive argument is met by the immovable object of a patient imprevious to reason. At this point I must hasten to add that this bit of advice should not be taken to mean capitulation to patients' unreasonable demands. It is only a pragmatic move to make the patient realise that you are a caring doctor who understands his difficulty in complying with your seemingly tough diktats.

It should also be stressed that good medical practice need not always be synonymous with patient satisfaction nor instant patient gratification. Some physicians show what one may refer to as an exaggerated therapeutic reflex to prescribe every time a patient walks in reinforcing the belief among the lay public that there is a pill for every ill. We are only too well aware of some members of our profession who have become willing and malleable instruments of their patients; they, all too often accede to every request of their patients sometimes exceeding the norms of rational prescribing. Though such conduct may earn cheap popularity for the physician it is neither ethical nor professional to do so.

Another view point expressed by some is that doctors should only counsel about the risks and benefits of various habits, life styles and allow the patient to judge on his own as to what course of action he wish to follow. This will certainly absolve us of directly interfering with their quality of life. But how many of us have the time to counsel patients after going through the pace of information, education, and communication? Even if one were to agree that we should only counsel there aren't even a handful of doctors trained to do this in a professional manner. The unwillingness to make informed choices even after a patient counselling session is another frustrating characteristic of our patients. Even among members of our profession I dare say there are many who seem incapable of making or willing to make independent decisions on their own even on matters concerning themselves.

It is my opinion that assuming the role of a counsellor will neither help the cause of the majority of patients nor help the profession in improving their image. This is especially so in countries like Sri Lanka where doctors are generally held in high esteem and are expected to do much more than simple doctoring.

Concluding remarks

There is growing emphasis on the importance and legitimacy of patients' perspectives on QOL in most countries. Many doctors as health care providers in our country tend to ignore or gloss over this concept as if it is of no concern to them. Such reactions are a luxury that physicians can no longer afford in this day and age. The best way of exemplifying the importance and relevance of this concept is the personal experience of the physician. If he has been a patient or if he has had to consult a physician on behalf of a near and dear one he will need little convincing to realise the validity of this concept.

The physician's ability to maintain the patient's trust and treat the patient with care, concern, tact and sensitivity have been the hall marks of the traditional physician. If we are found wanting in these respects our future, as members of a noble profession, I emphasise as members of a noble profession is bleak indeed. What I have expressed over the last twenty minutes may appear simple and lacking in profundity but I can assure you that these aspects of patient care will go a long way in improving our professions image as well as that of doctor – patient relationships.

Key points

1. QOL concept has come to stay.
2. It is valid measure of outcome of treatment and is the primary index of benefits in some illnesses.
3. The physician should pay more attention to QOL of patients under his care i.e. he should treat not only the disease but the patient as well.
4. When advising against excessive indulgence in harmful habits and life styles greater compliance is likely to be achieved by showing some laxity.

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