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Editorial
Quality of life in skin disease

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The issue of *q*uality *o*f *l*ife (QoL) has long been debated by moral philosophers, social scientists and psychologists like Socrates, Aristotle, Bentham, More, Ryce etc. but its impact on health and social care system has been in limelight during last 50-60 years.[1] Since the advances in diagnosis and therapeutics have eradicated/controlled many life-threatening infections and inflammatory disorders, the emphasis has been changed to the alleviation of the chronic conditions in the fields of pulmonology, cardiology, rheumatology, neurology and dermatology etc.

QoL remains a vague and abstract term. Different old and modern descriptions have been given but in simple words it can be defined as *the degree to which a person enjoys the important possibilities of his or her life*.[2] Possibilities result from the opportunities and limitations each person has in his/her life and reflect the interaction of personal and environmental factors. Enjoyment has two components: the experience of satisfaction or the possession or achievement of some characteristic, as illustrated by the expression: "He enjoys good health." This conceptual framework has three life domains i.e. *Being* (who one is), *Belonging* (connections with one's environments), and *Becoming* (achieving personal goals, hopes, and aspirations), each of which has three sub-domains.

The extent of a person's QoL in the areas of *Being*, *Belonging*, and *Becoming* and their sub-domains is determined by two factors: importance and enjoyment. Thus, QoL consists of the relative importance or meaning attached to each particular dimension and the extent of the person's enjoyment with respect to each dimension. In this way QoL is adapted to the lives of all humans, at any time, and from their individual perspectives. This sensitivity to the specific life situations of individual people also presents a limitation, namely that people may be highly satisfied with the important possibilities of their lives within an environment that is of poor quality. This may result from people being unaware that better quality is possible, or from people being consciously aware that they have to suppress the importance of some possibilities because of their present circumstances. For example, people living in an area like Chitral may consider their quality of life to be good because they have had no opportunities to know other possibilities and have no power to effect change in any case. Thus quality of life needs to include the quality of the environment in which the person lives. To address this, we consider that a quality environment is one which: provides for basic needs to be met (food, shelter, safety, social contact), provides for a range of *opportunities* within the individual's potential and provides for *control* and choice

within that environment. Thus, a person's perceptions concerning his/her decision making regarding the important possibilities of his/her life and the extent of his/her potential opportunities in the areas encompassed by *Being*, *Belonging*, and *Becoming* are indicated by the *Control* and *Opportunities* scores.[2] In contrast to QoL health related QoL (HRQoL) is more narrowly defined relating only to health. HRQoL is defined as the capacity to perform the daily activities appropriate to person's age and major social role. The role could be paid employment, school, housework or simply self-care. Deviation from normality results in a decreased QoL.[3]

Since the WHO definition of health as a state of complete physical, mental and social well-being and not merely the absence of a disease or infirmity, the treatment outcomes are based on patients' subjective assessment in addition to the objective clinical parameters. Two patients with identical clinical criteria of a skin disease may dramatically differ in the response to their disease. Similarly this may be reflected in their desire to seek medical advice or compliance with treatment regimens.[4]

The skin as an organ of communication represents various socially important attributes such as age, social status, wealth and sexuality. Physical appearance plays a major role in human transactions. An attractive appearance has positive influence on QoL. Skin diseases, unless erythrodermic or generalized, rarely cause total physical disablement in the patients but they frequently disfigure them. Consequently, the psychological and occupational impact of a skin condition e.g. eczema, psoriasis, acne, vitiligo, melasma, alopecia, changes of aging etc. is much more relevant than the pure physical limitations. Hence, the traditional patient-based outcomes e.g. mortality, length of hospital stay, recurrence rates etc. are not relevant to dermatological diseases. Even the symptom of itch is often clinically scored by QoL impact, whether the itching interferes with sleep or performance at school or work. Similarly, patients suffering from sexually transmitted diseases, besides physical symptoms, may feel dirty, unlovable, unacceptable and less desirable sexually, have lowered self-confidence, and develop fear to transfer the disease to their partners.[5]

A number of disease factors influence QoL. For instance, onset during teen age when the development of personality occurs, involvement of visible parts particularly the face, chronic course of dermatosis, and the misconception that every visible skin condition is infectious/contagious or life-threatening may greatly hamper QoL. Similarly, the cultural, educational and religious background is another important determinant in this regard.[6]

In general, effects of skin disease on QoL are either psychological or physical.[7] Psychological effects could be either cognitive, social, or emotional. Cognitive effects are beliefs about self or others related to skin disease e.g. people talk about my skin disease in my absence. Social effects relate to those of avoidance of social situations that the patient ascribes to skin disease e.g. I avoid gatherings due to my skin disease. Emotional effects could be those of depression, fear, embarrassment, or anger. Depression refers to the expression of despondent feelings ascribed to skin disease

e.g. my skin problem makes me hopeless; fear refers to worry e.g. I am concerned about my skin condition; embarrassment refers to feeling of social anxiety e.g. I am ashamed of my skin condition and anger refers to hostility e.g. my skin condition makes me irritable. Physical effects of skin disease could be either discomfort or physical limitations. Discomfort refers to symptoms ascribed to skin disease e.g. my skin itches and limitation means impaired physical function due to skin problem e.g. my skin condition makes moving around difficult.

In dermatology, evaluation of QoL is relevant for patients, clinicians, the pharmaceutical industry, and politicians. For the patient and the dermatologist, assessment of QoL may improve the effectiveness of a treatment by allowing the benefits of alternative therapies to be evaluated. For the pharmaceutical industry, QoL assessments may be used to compare the efficacy of two drugs. Finally, politicians can use QoL data to allocate medical resources.[8]

The method for measurement of impact on QoL is questionnaire-based. For this many instruments have been devised. These include disease-specific questionnaires e.g. psoriasis disability index, acne disability index etc.; dermatologic-specific questionnaires e.g. skindex, SF (short form)-36, dermatology life quality index etc.; general health questionnaires; and QoL measurement in children e.g. pediatric symptom checklist etc. An ideal instrument should be reliable and valid (content and construct wise). It should be concise to make it practical and time saving in the busy clinical or research settings. An ideal instrument should not only be able to distinguish the burden of skin disease in different populations at one time (discriminative function) but also be able to measure how patients' QoL changes as their skin changes (evaluative function).

It is hoped that in future, QoL will be pivotal issue in clinical studies, pharmacological research and medical audit in the field of dermatology.

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