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Quality Of Life-A Beginner's Guide

Vaishnavi Bakka and V. Asha Jyothi*
Department of Pharmacology, Sarojini Naidu Vanita Pharmacy Mahavidyalaya, Tarnaka, Hyderabad.

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*Corresponding Author Email: ashajyothivadlapudi@gmail.com

ABSTRACT

In the field of pharmacy practice the outcome studies have a special place in the assessment of the Quality of health. The quality of health is measured by the quality-of-life tools. World health organization has recommended importance of measuring QOL using tools. In the present article a comprehensive detail of the QOL tool is given the detailed manner.

KEY WORDS: QOL, HRQoL, Quality of life, sf-36

INTRODUCTION:

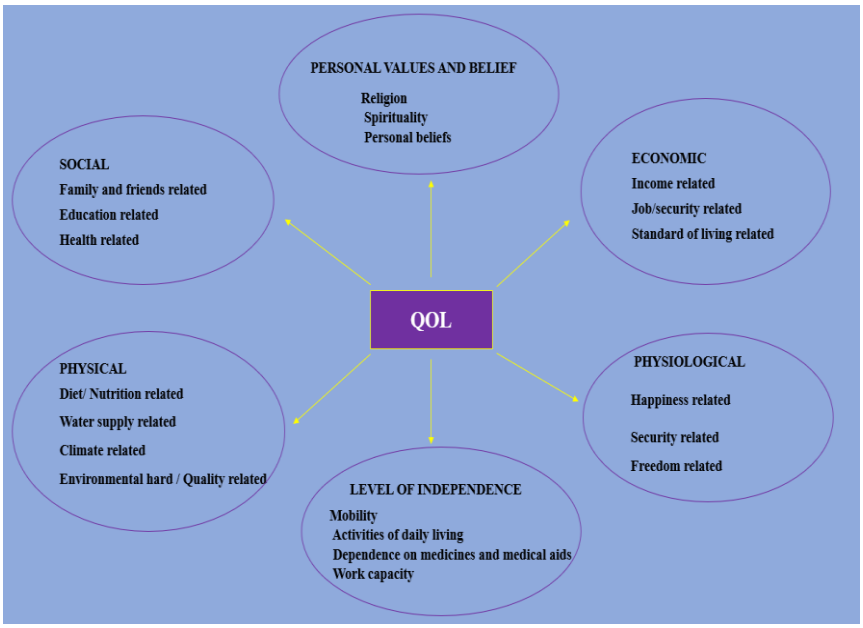
WHO defined health as not just the absence of disease and infirmity, but it is also a state of complete physical, mental and social well-being. (1)

History:

After the end of World War II, the term QOL was commonly used. Initially the term QOL was used for "material goods "such as car, house, etc. (2) In 1972, the pub med has no publications under the topic of QOL. (3) However, in 1973 there were only 5 articles available worldwide under QOL, when used as a reference keyword in the Midline database. In the following 5 years of time period there were 195,273,490,1525 of QOL articles (4) from then over the subsequent 30 years the number of articles on the keyword QOL was increased tremendously. In the year 2005, the Pub med has recognized 5345 articles (3).

In medical and nursing journals the QOL is most commonly used, but in fact here they are actually referring to Health-related-quality of life and not just the quality of life itself (that is just the measurement of single domain of QOL) (2).

Different domains of QoL:



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DEFINITIONS and TERMS:

Terms like QOL and HRQOL are widely used in literature but there is an ongoing debate about the correct definitions of these terms. [5]

QOL: Defining QOL is challenging as there are many approaches to define QoL. QOL Is defined as "conscious cognitive judgment of satisfaction with one's life" [6] and "an individual's perception of their position in life in the context of the culture and value systems in which they lived. And in addition to their goals, expectations, standards, and concerns." [7]

It is a broad concept that covers all the aspects related to human experience about necessity in life (i.e) It is related to all the factors that have impact on individual's personal life. It characterizes how happy or satisfied an individual is with their personal life as a whole [8]. Therefore, while doing assessment of QOL, following aspects must be considered. Physical, Material, Emotional well-being, Social along with the extent of personal development. [9] Beliefs, Relationship, Level of autonomy. [10]

HRQOL: Defining HRQL is a bit problematic because there are many definitions to it.

First definition: Ranging from individual fulfillment to the ability to lead a 'normal' life.[11]

Second definition: "How well the person functions in their life and their perceived well-being in physical, mental, and social domains of health."[12]

Third definition: It focuses on the aspect of the QOL that are affect by health. "The effect of disease or disease treatment on the normal lifestyle or wellbeing. A specific definition has been proposed 'Health related quality of life is the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment, or policy'.[13]

Fourth definition: "Health related quality of life includes only those factors that are a part of an individual health, while excluding all the non- health related aspects". [14]

Fifth definition: It refers to "values assigned to different health states". [5] These values used to calculate the QUALITY ADJUSTED LIFE YEAR (QALY).

What is a Quality-Adjusted Life Year (QALY)? QALY represents the impact of a therapy on the length of life while considering changes in the health-related quality of life (HRQoL). [16]

HRQoL is calculated on a scale

Values: (zero = dead)

(one = full health)

(<1 = loss of QOL due to disease state) [16]

Table 1: Difference between QOL and HRQOL.

QOL: QUALITY OF LIFE	HRQOL: HEALTH RELATED QUALITY OF LIFE
QOL is a broad concept that covers all the aspects of human life.	HRQOL only focuses on the effects of disease and specially on the impact of treatment on QOL.
QOL is much more than health status, functional ability or clinical symptoms. It is multidimensional	HRQOL is only one single dimension of QOL.
It can be defined in many ways which makes its measurement difficult.	Its measurement is simpler the QOL.
It includes evaluation of non-health related features of life.	HRQoL is connected to an individual's health or disease status.
QoL can help us understand those aspects of life that extend beyond health such as education and the social environment	HRQoL can help us understand the distinction between aspects of life related to health

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Methodological issues in measurement of HRQOL:

HRQOL assessment has become more advanced [17] as the application of the HQROL is widely applied to various diseases, conditions and populations A good HQROL measurement must include all the factors such as physical, physiological, social functioning and also generic core and specific disease terms. [8]

Instruments: Instruments used must be easy to handle for every individual in terms of reading, language usage, etc. One must also give reliable results for all types of patients. [8]

Standard QOL Measures: Fitzpatrick and his colleagues (1998) Has developed the following criteria for the assessment of standard HRQOL measures. Such as reliability, precision, validity (measures can differentiate Health and illness), Responsiveness (Measures can detect important clinical changes), acceptability (Patients are willing to complete Measures). And feasibility (The timing and cost of the measures are rational.) [8]

Important issues in measuring HRQOL: 1. Objectivity versus subjectivity. 2. generic versus specific. 3. Self- report versus proxy report. 4. Validity. 5. unidimensional versus multidimensional. 6. Reliability. 7 the criteria for selecting HRQL. [8]

Measuring HRQOL

The data are collected by HRQL surveys called as “instruments” these instruments are typically questionnaires, contains questions are also called as “items” that are organized in a scale form. Each scale measures a different domain of HRQL. Some scales have many items whereas there may also be only one item or 2 items in the other scales. Each item contains a “stem” a (question or statement) and also a response set

Types of response sets:

1. Likert scale
2. Likert type scale
3. Visual analogue scale
4. Numerical rating scale

And other response sets have been developed especially for children, low literacy people and other populations. [18]

The HRQOL instruments gives the best results when they are self- administered, compared to caregivers (or) spouses. Proxies report is considerable only when the patient is not in a condition to complete the instrument. [19]

Instruments to measure the QOL: There are various general instruments to measure the quality of life.

EORTC QLQ-C30 (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire): It contains 30 items addressing various aspects of qol. The questions are then grouped into five functional domains (role, physical, emotional, social and cognitive).

In addition, there are three symptom scales for fatigue, pain and nausea\vomiting and these individual questions concerning common symptoms in cancer patients, and the two questions are for the overall quality of life. [20]

FACT-G (Functional **Assessment of Cancer Therapy-Generic):** It includes 27 items to measure four domains of HRQOL in cancer patients: Physical well-being, Emotional well-being, Functional well-being, Social well-being. [21]

SF-36 (Short Form-36): It is one of the most used instruments. it is a 36 items instrument containing physical health:

- Physical functioning (10),
- Role limitation (physical) (4),
- Bodily pain, General health (5)
- Mental health**:**
- Role limitation (emotional) (3),
- Vitality (4),

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- Mental health (5),
- social functioning.

The SF-36 is a 36-item questionnaire which measures eight multi-item dimensions: physical functioning (10 items), social functioning (2 items), role limitations due to physical problems (4 items), role limitations due to emotional problems (3 items), mental health (5 items), energy/vitality (4 items), pain (2 items) and general health perception (5 items). There is a further unscaled single item for asking respondents about their health change over the past year. For each and every dimension, item scores are coded, summed and then transformed on to a scale from 0 (relates to worst possible health state measured by the questionnaire) to 100 (relates to best possible health state). [22, 23, 24]

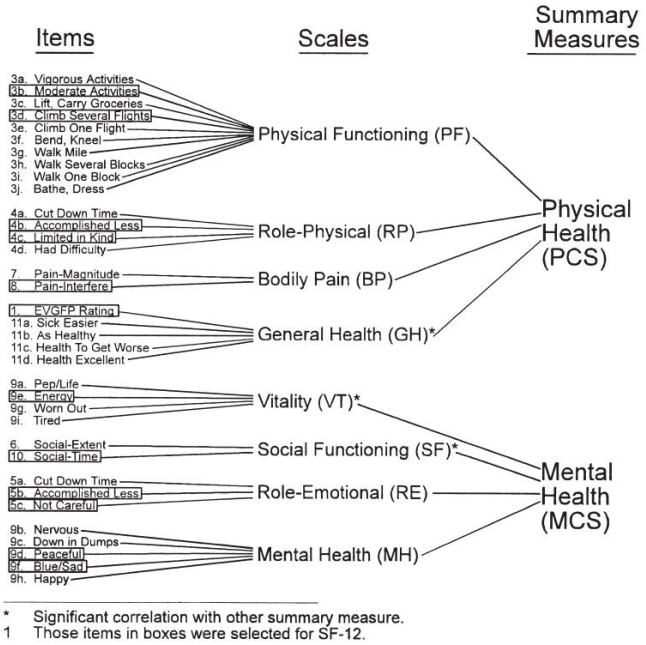

FIGURE 1. SF-36 and SF-12 measurement model (Source: [14,42]).

WHOQOL (World Health Organization Quality of Life Assessment.): (44)

It is a 100 items instrument containing 6 domains and 25 facets. The six domain scores denote an individual's perception of quality of life.

6 Domains: physical health, psychological health, level of independence, social relationships, environment, spirituality/ personal beliefs/ religion.

Facets: 24 facets, each consisting of 4 items, distributed across domains and one general facet (overall quality of life and general health).

The scores of Domains and facet are scaled in a positive direction where higher scores represent the higher quality of life. Three facets (pain and Discomfort, Negative Feelings, dependence on medication or treatment) are not scaled in a positive direction, this means that these facets with higher scores do not denote higher quality of life. [25,26,)

WHOQOL-BREF: It is a 26-item instrument consisting of four domains: (7 items) of physical health, (6) items of psychological health, (3 items) of social relationships, and (8 items) of environmental health it also contains QOL and general health items. [27,42,43)

Quality of Well Being scale (QWB): The original QWB contains only 18 items and summarizes 3 aspects of health status like mobility, physical activity, and social activity. QWB scoring ranges from (0) for dead and (1) for asymptomatic full function. [28,29,30)

Sickness Impact Profile: it measures health status by assessing the impact of disease on changing daily activities and behavior. Test-retest reliability (r = 0.92) and internal consistency (r - 0.94) were high. [31] It has 136 items with a yes or no response. The major domain on this tool is psychosocial and physical domains. It has 12 categories: sleep and rest, eating, work, home management, mobility, body care and movement, social interaction, recreation and pastimes, ambulation, alertness behavior, emotional behavior, and communication. [32]

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Nottingham Health Profile: This questionnaire is divided into 2 parts: The first part contains 38 self–administered items divided into 6 domains: Pain, Physical mobility, Sleep, Emotional reactions, energy and social isolation. [33]

second part consists of seven statements regarding areas of life that are commonly affected by health: paid employment, jobs, social life, personal relationships, sex life, holidays, hobbies and interests. Scores range from 0 (no distress) to 100 (severe distress) [34-35] and the responses on both the parts are yes/ No. [36]

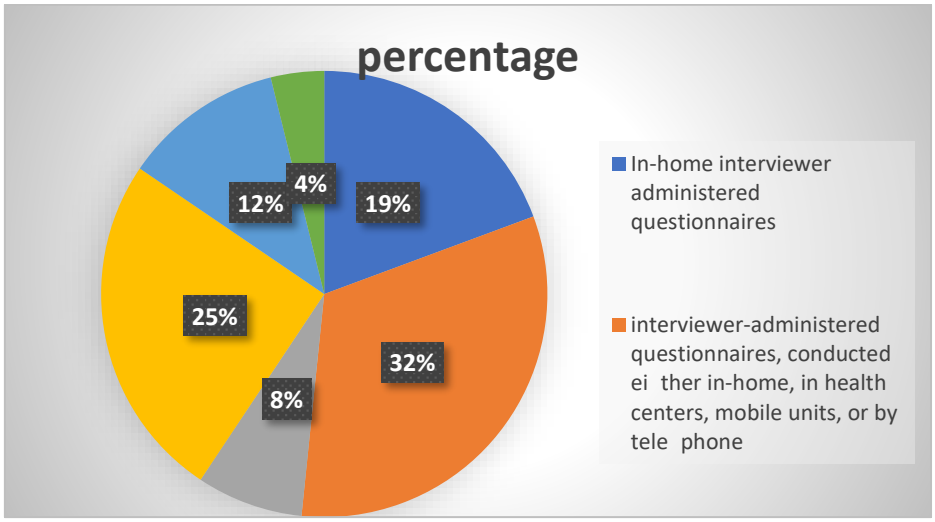

Figure 2: Percentage of the data collected by various methods.

Reliability, validity and responsiveness: The development and validation of new instrument and scale is a tedious process. Hence it is always advisable to prefer instruments that are already been validated and published. The instruments used for HRQOL must show the reliability, validity and responsiveness. [37-45]

Reliability: It gives information about how reproducible the scale is. A reliable questionnaire means it is accurate over time. [38]

Test-retest: it is a measure of stability of response over time. [38]

Internal consistency: It is a measure of how similar the individual responses are across several items. It indicates homogeneity. [39]

Cronbach's coefficient alpha: It is a statistic which is used to quantify the internal consistency of a scale. [39]

Generally, for group comparisons, the reliability statistics when measured by these two methods should not cross 0.70 and in case of individual patient the reliability coefficient must at least should be 0.90. [37]

Validity: It is defined as how well the scale or instrument can estimate the attributes it is intended to do. [40]

Content validity: it is also referred as face validity, it involves the qualitative assessment of scope, completeness and the relevance of the proposed scale. [37]

Criterion validity: It is more qualitative approach helps to access the performance of scales and instruments generally as per accepted standards or gold standard measure. [41] The validity statistics should not exceed 0.70. [37]

Construct validity: It refers to the extent up to which a measure is good representation of the construct. This construct validity has 2 other forms namely convergent validity and divergent validity. [41]

Convergent validity implies that many various methods for obtaining the same information about the given trait or concept that produce same results. [37]

Divergent validity refers to the scale that doesn't correlate too closely with similar but the distinct concept or traits. validation is always in ongoing task. [37]

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Table 2: List of the QOL tools for respective diseases

S.NO	DISEASE	Generic Health-Related Quality of Life Instruments in various diseases
1	Adult Asthma	EuroQol (EQ-5D)
		Nottingham Health Profile
		Sickness Impact Profile
		SF-12 Health Survey
		Medical Outcomes Study SF-36
2	Chronic Obstructive pulmonary disease	Dartmouth COOP Charts
		EuroQol (EQ-5D)
		Functional Performance Inventory
		Measure Your Medical Outcome Profile (MYMOP)
		Nottingham Health Profile
		Quality of Well Being
		SF-12 Health Survey
		Medical Outcomes Study SF-36
		Sickness Impact Profile
		World Health Organization Quality of Life assessment instrument (WHOQOL-100)
		Airways Questionnaire
3	Cystic Fibrosis	Cystic Fibrosis Questionnaire (CFQ); Cystic Fibrosis Questionnaire Revised (CFQ-R)
		Child Health Questionnaire - Parent Form 50
		Quality of Well Being
		Nottingham Health Profile
		Medical Outcomes Study SF-36
		Self-Administered Dependency Questionnaire
		Sickness Impact Profile
		Functional Status II-R (FS II-R)
4	Lung cancer	Daily Diary Card (Geddes)
		Daily Diary Card (Medical Research Council)
		Health and Activities Limitation Index (HALex)
		EuroQol (EQ-5D)
		Health and Activities Limitation Index (HALex)
		Nottingham Health Profile
		SF-12 Health Survey
		Medical Outcomes Study SF-36
		Sickness Impact Profile
5	Lower Respiratory Tract Infections	Measure Your Medical Outcome Profile (MYMOP)
		St. George's Respiratory Questionnaire
		Nottingham Health Profile
6	Community-Acquired Pneumonia	Sickness Impact Profile
7	Pulmonary Hypertension	Nottingham Health Profile
		Medical Outcomes Study SF-36

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