

Review Article

Concept of quality of life in health care research: a review

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ABSTRACT

Quality of life (QoL) is the most studied concept in health care research. With an increase in life expectancy and consequently with more prevalence of chronic diseases, the QOL needs to be paid attention. It is a multifactorial concept and many tools are adopted to study QOL. The present article analyses the concept of QOL in the context of healthcare research. Articles for this were searched from PubMed, CINAHAL, Cochran and EBSCO. A detailed review of QoL in health care research including its components, models and various tools being used with their application are discussed in the current article.

Keywords: Health status, QoL, QoL models, WHO, WHO QOL -100

INTRODUCTION

Traditionally common indicators used for evaluating the state of the population health were life expectancy and the cause of death. But with an increase in life expectancy, there was a felt need to find out such measures for health which can reflect the quality of all the years lived.¹ The term QoL was first used in the form of a keyword in the medical literature databases in 1975.² Initially the socio-psychological aspect of QoL and its determinants were identified. During the last decade of the 20th century, researchers started focussing on the assessment of subjective aspects of QoL of individuals.³ Few years later, the World Health Organization affirmed that there is a need for evaluate and enhance people's QoL.¹ Since then it has been widely used for the evaluation of individual's feeling about his/her well - being focusing on various favourable and adverse conditions of life. An individual's feelings about their own life are given prime consideration in measurement. QoL has different meanings to different people and as per area of application. The term health-related QoL (HRQoL) is more commonly used in health care research to remove any ambiguity in the definition of QoL.

In 1980s, term 'HRQoL' was first introduced in published medical literature. It includes all those aspects related to QoL which relates to health. However, in literature both terms i.e., QoL/ HRQoL are often used interchangeably, but these two are distinct concepts. QoL is reflected as overall satisfaction of person with his /her life, which may be evaluated as single concept or can be split into various domains. Whereas HRQoL as a specific concept includes all aspects of health and is evaluated domain-wise. So, it can be considered "an individual's subjective assessment of his QoL in relation to physical, psychological and social domains of health."⁴ However WHO has used and defined term QoL to be used in field of health care.¹ Some definitions even fail to make distinction between HRQoL, QoL and health. Various questionnaires claiming to measure HRQoL are actually measuring individual's health status as perceived by him/her. So, concept of HRQoL is perplexing. Proposed solution is defining HRQoL as way health is being empirically estimated as affecting QoL.⁵ QoL relates to overall definition of health, which includes individual's perception of his own life, focussing on all human life dimensions.⁶ In traditionally used HRQoL utility measures more weightage is given to physical domains,

however it is important that while defining itmental and social domains should be equally emphasized.^{7,8}

Definition of QoL

WHO has defined QoL as “an individual's perception of their position in life in context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is broad-ranging concept affected in complex way by person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.”¹

Rice (1984) defined QoL “as a degree to which the experience of an individual's life satisfies that individual's wants and needs (both physical and psychological). Much of the debate about how QoL should be defined has centered around subjective versus objective approaches. Rice further defines objective QoL (OQoL) as degree to which specified standards of living are met by objectively verifiable conditions, activities, and activity consequences of an individual's life and subjective QoL (SQoL) as set of affective beliefs directed toward one's life.”⁹

Another definition was “measure of difference between hopes and expectations of individual and individual's present experience. HRQoL is primarily concerned with those factors which fall within spheres of influence of health care providers and health care systems.”¹⁰

HRQoL

Since health is considered multidimensional concept, the HRQoL also incorporates all domains of physical, mental, emotional, and social functioning.⁷ HRQoL is dependent on one's health status and it focuses on the consequences of one's health status on QoL. Centre for disease control has defined HRQoL as “an individual's/group's perceived physical and mental health over time”¹¹ Table 1 highlights because it is pertinent to measure QoL in health care.

Table 1: Measuring QoL in health care research.^{4,11}

S. no.	Measuring QoL in health care research
1	It may aid in providing high-quality and patient-centered care as it helps to assess patients' own perspective of their life quality.
2	QoL assessment can be beneficial in improving self-management skills by providing feedback to patients.
3	Measuring QoL can improve healthcare workers' awareness of patient concerns and patient-provider communication.
4	It can help to ascertain the burden of various preventable diseases, trauma and disabilities
5	It may provide novel inputs about the relation of HRQoL with various risk factors.
6	It will aid in keeping track of the progress of a nation in achieving its health objectives.

DOMAINS OF QoL

WHO has divided QoL into four broad domains and 24 facets in total under these domains as discussed below

Physical health: This domain includes facets associated with physical health and includes energy, pain, discomfort, sleep, rest, etc.

Psychological: This domain incorporates psychological aspects of health and QoL. Its facets are based on bodily image, negative and positive feelings, self-esteem, thinking, memory and concentration.

Independence level: It takes into consideration how independent a person is in his/her life. Facets of this domain consider mobility, ability to perform daily living activities, capacity to work and dependence on medicinal assistance.

Social relations: It includes the facets related to social as well as personal relationships.

Environment: This domain takes into account the environmental component of QoL. It includes the availability of financial resources, access to health care, the environment of home, opportunities to learn new skills and recreational opportunities etc.

Spirituality/religion/personal beliefs: This domain has a single facet assessing religion/ spirituality/ personal beliefs.¹²

DETERMINANTS OF QoL

QoL is determined by a number of factors, which include physical health conditions, mental well-being, social conditions etc. Kivits et al performed secondary analysis of epidemiological data of HRQoL from 2 national surveys and revealed that the important determinants of QoL are main social indicators like living as couple, educational status, occupation and income per household, independent of age and gender.¹³ Singh et al conducted a study to assess HRQoL among representative populations of South Asia.¹⁴ This study revealed that HRQoL was significantly associated with age, gender, education, income, and employment status. In a study of Jordanian population by Matalqah et al it has been revealed that many physical and emotional factors like age, presence of chronic disease, and stress due to lower socioeconomic status were affecting HRQoL.¹⁵ QoL also varies as per disease status as review conducted by Basavaraj et al has revealed that physical symptoms, drug therapy, psychological state of health, social support, using coping-strategies, level of spiritual wellness, and presence of psychiatric illness are important predictors of QoL in PLHIV.¹⁶ Similarly a study by Cho et al stated that HRQoL in patients with chronic hepatitis C is linked with age, gender, educational status, living type, employment, monthly income and presence co-morbidity.¹⁷

TOOLS TO ASSESS QoL

There are various ways to assess HRQoL. This can be measured by using subjective measures as well as objective assessment tools. Selective tools may be required for the assessment of the QoL in different populations or different disease states. HRQoL measures can establish the range of problems that affect patients,

these can help to identify any ongoing problems that might get ignored otherwise. These can also be a predictor of treatment outcomes. HRQoL measures can help to calculate quality adjusted life years by combining them with measures of time in a particular health state. These measures of HRQoL can be classified as generic, disease-based tools and population-specific tools for measuring HRQoL (Table 2).¹⁸

Table 2: Commonly used QoL instruments.

Instrument type	Domains/dimensions
Generic instruments	
Assessment of QoL-4D (AQoL-4D) ¹⁸	Independent living, relationships, mental health and senses ¹⁸
Control, autonomy, self-realization and pleasure-16 (CASP-16) ¹⁹	Control, autonomy, self-realization and pleasure ¹⁹
EQ-5D and EQ-VAS ^{20,21}	Mobility, self-care, usual activities, pain and discomfort, anxiety and depression. EQ VAS incorporates a Visual Analogue Scale. It captures the subjects' overall assessment about their health on a scale ranging from 0 (worst state of health imaginable) to 100 (best state of health imaginable). ^{20,21}
CDC HRQoL-4 healthy days and CDC HRQoL-14 healthy days measures ²²	CDC HRQoL-4 healthy days includes 4 survey-based questions to assess HRQoL. CDC HRQoL-14 Healthy Days measures include four questions of CDC HRQoL-4 Healthy Days and five activity limitation questions, five additional healthy days HRQoL questions that are measuring recent symptoms of pain, depression, anxiety, sleeplessness, and vitality. ²²
PROMIS patient-reported outcomes measurement information system-global health scale ²³	Depression, anxiety, pain interference, physical function, fatigue, sleep disturbance, ability to participate in social roles and activities. ²³
SF-36 medical outcomes study short-form 36 ²⁴	Vitality, bodily pain, general health perceptions, physical functioning, mental health physical role functioning, emotional role functioning, social role functioning ²⁴
World health organization qol assessment (WHOQOL-100) ¹² and world health organization QoL assessment-abbreviated version (WHOQOL-BREF) ¹²	Physical health, psychological, social relationships, and environment. world health organization QoL assessment-abbreviated version (WHOQOL-BREF) is a short version of WHO-QOL 100 ¹²
Disease-specific questionnaires	
Asthma-specific HRQoL (AQLQ-J) ²⁵	It assesses the QoL of asthma patients across four domains of activity limitation, symptoms, emotional function and environmental stimuli ²⁵
The European organization for research and treatment of cancer QLQ-C30 (EORTC QLQ-C30) ²⁶	Assesses QoL of patients with cancer by incorporating 9 multi-item scales including five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomiting), a global health and quality-of-life scale, several single-item symptom measures ²⁶
Caregiver QoL index-cancer (CQoLC) ²⁷	A 5-point rating scale measuring QoL of family caregivers of the patients suffering from cancer across four domains of physical functioning, emotional functioning, family functioning and social functioning ²⁷
Breast cancer chemotherapy questionnaire (BCQ) ²⁸	Assessing QoL of women undergoing adjuvant chemotherapy. The BCQ is comprised of 30 questions focusing on various aspects including loss of attractiveness, fatigue, physical symptoms, inconvenience, emotional distress, feelings of hope and support from other ²⁸
Palliative care QoL instrument (PQLI) ²⁹	This measure QoL of patients with advanced cancer undergoing palliative care through six multi-item and one single-item scale focusing on activity, health status, self-care, choice of treatment, support, communication, psychological effects and overall QoL ²⁹
The functional assessment of cancer therapy –general (FACT-G) ³⁰	Measures the QoL of cancer patients by incorporating four subscales with 5 point rating of physical well-being, social/family well-being, emotional well-being, functional well-being ³⁰
Dermatology life quality index ³¹	Assesses QoL of patients suffering from dermatological conditions across six domains of symptoms and feelings, daily activities, leisure, work and school, personal relationships, treatment ³¹

Continued.

Instrument type	Domains/dimensions
Inflammatory bowel disease questionnaire (IBDQ) ³²	It assesses bowel as well as systemic symptoms, emotional and social functions. It covers IBD-related symptoms, physical, emotional, and social domain ³²
WHOQOL –HIV BREF ³³	Assesses the QoL of PLHIV in domains of physical, psychological, level of independence, social, environmental, and spiritual ³³
Chronic liver disease questionnaire (CLDQ) ³⁴	Assesses the QoL of patients suffering from chronic liver diseases in domains of abdominal symptoms, fatigue, systemic symptoms, activity, emotional function, worry ³⁴
Functional assessment of cancer therapy-hepatobiliary (FACT-Hep) questionnaire ³⁵	Measures HRQoL of patients suffering from hepatobiliary cancers. It consists of the 27-item FACT-G, which assesses generic HRQL and 18-item Hepatobiliary Subscale (HS), which assesses disease-specific issues. ³⁵
Sexual QoL questionnaire ³⁶	Was developed to assess sexual QoL and satisfaction with treatments for erectile dysfunction among patients and their sexual partners ³⁶
Population specific questionnaires	
Pediatric QoL inventory (Ped) oral health scale ³⁷	Measures QoL in children with oral health problems and oral health QoL in children with other disorders in areas of physical functioning, role functioning, social functioning, emotional functioning ³⁷
Child health and illness profile-adolescent addition ³⁸	Measures the QoL of adolescents in 6 domains with 20 subdomains. The domains are discomfort, disorders, achievement (of age-appropriate social roles), satisfaction with health, risks and resilience ³⁸
WHOQOL-OLD ³⁹	Measures the QoL in elderly in domains of sensory functioning, past, present and future activities, autonomy, social participation, death and dying and intimacy ³⁹
Older PEOPLE'S QOL questionnaire (OPQOL) ⁴⁰	Measures QoL of elderly across dimensions of life overall, their health, independence, control over life and freedom, social relationships and participation, financial circumstances, home and neighborhood, psychological and emotional well-being, culture and religion ⁴⁰

CHOOSING A SUITABLE MEASURE OF THE QoL

It becomes important to choose an appropriate measure of QoL to obtain a reliable and accurate measurement. It has been advocated that generic and specific instruments should be used in combination in order to get a better explanation of the association between disease-related changes in the status of patient patients as well as both disease-based treatment as well as general functional status. Certain points should be considered while choosing a measure of QoL (Table 3).^{41,42}

Table 3: Important considerations while choosing a measure of QoL.

S. no.	Important considerations while choosing measure of QoL
	The chosen instrument should be-
1	Covering all the relevant domains
2	Specifications regarding population it was intended to be used
2	Validity, reliability and appropriateness
4	Any floor and ceiling effects
5	Ability to differentiate the QoL overtime
6	Ease of administration and who will administer it
7	Any prior training required for administration

MODELS OF HRQoL

Various models of QoL have been proposed. However, this paper restricts to the commonest ones.

Wilson and Cleary's model of HRQoL

This model assumes that health is considered as a state existing on a continuum of the increasing bio-psycho-social complexity beginning from biological and ending at complex and integrated measures as physical functioning and general health perceptions. There are five levels as per the model which includes biological factors, physiological factors, symptoms, functioning, general health perceptions and overall QoL. This model presents a classification scheme for different measures of health outcomes. This model will help to identify how HRQoL is affected and ways to improve it.^{43,44}

Ferran and colleagues' QoL model and QoL index

This model assumes that QoL is an individualistic phenomenon and is dependent on the uniqueness of the experience of life for every person. This model defines QoL "as satisfaction with the aspects of life that are important to the individual." The QoL is divided into four domains including health, functioning, psycho-spiritual, socio-economic, and family domains. The "Ferrans and powers QoL index" was developed based on this model.⁴⁵

Centre for health promotion model

This model was created by Dennis et al at the University of Toronto. This refers to the QoL in the context of disease. This model is based on WHO's definition of the QoL. QoL as per this model is defined as "the degree to

which a person enjoys the important possibilities of his or her life". This model has divided QoL into three subdomains including being, belonging and becoming. Importance and enjoyment are two important factors in determining QoL. So QoL is "relative importance attached to each particular dimension and the extent to which a person enjoys with respect to each dimension".⁴⁶

World health organization international classification of functioning disability and health (WHO ICF)

This model provides a description of health and its states and gives a common language suitable to be used across disciplines and cultures. The WHO ICF model has been divided into two parts. The first part takes into account the functioning and disability and the second part addresses many contextual factors like environmental and personal. However, the WHO ICF is not specific to HRQoL, rather it provides a base for mapping and classification rather than as a guide for the generation of hypotheses in the field of HRQoL.⁴⁷

Bakas et al have concluded that Ferran and colleagues' model which is a revised version of Wilson and Cleary model can play a very important role in guiding the HRQoL research and practice.^{42,44,45,47} Frequent use of this model will provide aid in testing further refinement and evidence about association among HRQoL concepts, which are common across different populations. Using the same model will also help in comparing HRQoL across various populations and advance the knowledge base in the field of HRQoL.

THE GREY ZONE AND WAY FORWARD

No matter how much attempt is made to assess the QoL but this concept can never be fully captured as it is a highly individualistic concept and has different meanings for different people. Whenever the concept of QoL is used in health care, its aim is to have a patient-centred approach rather than a disease - centred approach. But only QoL is not a sufficient measure to assess patient outcome. In literature overlapping use of the term QoL and HRQoL cause confusion over the meaning and distinction of these two terms. So, the assessment of the QoL should act as an adjunct not as a substitute to assess patient-centred outcomes. Multidisciplinary approach should be adopted while assessing QoL. Reliance should not only be made upon the assessment tool but effective communication techniques and effective relationships should be established with the patient in order to get in-depth insight into the patient's QoL. As the QoL is an individual concept, strategies to improve it should also be individual and designed in such a way that these get customized as per individual patients' needs.

CONCLUSION

QoL is an important concept in the field of health care. It has different determinants as per the disease condition of

the patient. Assessment of QoL will help to improve the health status of patients and the quality of care provided. However, the researchers need to be careful while choosing the appropriate measure of QoL as per the need of the group to be studied.

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