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Review Article

# HEALTH RELATED QUALITY OF LIFE (HRQOL) – WHAT IT IS AND HOW IT IS MEASURED: STUDIES FROM THE WORLD AND COMPARISON WITH PAKISTAN

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#### Abstract:

**Objectives:** A narrated review was conducted to (a) identify the most frequently used health-related quality of life (HRQOL) tools worldwide and (b) comparisons of those tool and their usage in Pakistan.

Methods: The online search engines were consulted using the included and predefined criteria. We reviewed titles, abstracts, and then full-text articles related to their relevance to this review. Then, the most commonly used tools have been identified, reviewed discussed.

**Results**: Of 865 titles identified, 153 articles from various countries met the inclusion criteria. The most frequently used HRQOL tools were: EQ5D, SF and WHOQOL. Out of these EQ5D and SF tools mostly used in studies conducted in Pakistan.

**Conclusion**: It is evident that disease-specific studies have been conducted in Pakistan by using various tools, however, no population norms ever reported in Pakistan.

**Keywords**: qol, hrqol, norms, pro, generic tools, disease specific tools

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#### **INTRODUCTION:**

#### **BACKGROUND**

The health itself is a complete term used to describe the various components included physical, mental and societal quality. According to WHO, "State of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity"[1]. Health status, functional rank, and quality of life are commonly used interchangeable terms to refer to the "health". This domain ranges from happiness to death; Death is considered to have negative values of life and happiness are considered as positive traits [2].

As discussed as a matter of wellbeing, it reflects Quality of life (QOL). QOL ascends as notion surrounding features of bodily, communal, emotional and divine happiness. When reflected as characteristic of QOL, health is superlative belief that are usually signify the quality of life, it is measured to plunge beneath the concern of healthcare team members, that is seen as an objective of a health care intrusion. Consequently, "HRQOL" at times chosen over QOL [3]. HROOL Approaches concerned with are increasingly renowned significant the endowment of assessable results for well-being intercessions which consider being obligatory information-based constituent of communal wellbeing plan. [4].

Background in which individuals live is of great status is his health status and QOL. Which is progressively documented that health is preserved and enhanced not only through the progression and application of health science. WHO describes, foremost determinants of healthiness comprise the communal and monetary setting, bodily setting, and the creature's specific aspects and features as well as behaviors [5]

More precisely, key features that influence whether people are healthy or unhealthy include: Socio-Economic status, Education and literacy, Employment and working settings, Social surroundings, Individual's health and wellbeing practices, Managing skills, Healthy growth of child, Healthcare facilities, Gender, Age and Values and cultures or norms [5].

#### WHAT IT IS:

Within the domains of health: health status, functional status, and quality of life considered to be the main determinant of health. Within this context, Quality of life (QOL) is a concept encompassing aspects of physical, social, emotional and spiritual wellbeing [6]. QOL mentions broader concept which contains the individual's viewpoint of their overall QOL and valuation of definite components of QOL. This definition combines two different features of QOL which are subjective and objective in nature [7].

QOL concept has frequently studied in various domains of life classified as seven distinct domains [8]. These domains are reported by Cummins et al where they argued that QOL is comprised of objective and subjective parts. These dimensions and domains were: material well-being, health, productivity, intimacy, safety, place in the community and emotional wellbeing [9]. Person's observation of their situation in life in the contextual of traditional and rites and value outlines in which they live and in relation to their objectives and goals, prospects, values and concerns. These parameters affect physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment [10].

Various scopes or features were identified which are responsible for affecting QOL in various area of science, like; freedom, political stability, economic environment, convenience of education, social security - features of exterior setting; health individual condition, security, instructive accomplishment, family, income, housing features of internal environment [11]. Definition of QOL has led to numerous problems regarding the conceptualization and making the operative term. Researchers have observed significant differences in how this definition applies to the determinants of perceived OOL. OOL could be realized through a comprehensive assessment of life satisfaction, as well as measurement of the more specific and detailed dimensions of this concept [12].

QoL and HRQOL frequently utilized alternatively, nevertheless characterize different notions. Researchers have recognized eleven different definitions of QOL and HRQOL across fourteen generic and 20 plus disease-specific measures. Although it is documented that there should be a division between QOL and HRQOL [13].

There are domains of QOL, for example, health, occupations, living standards and house occupancy, institutes, and the locality. Furthermore, features of culture, standards, and spirituality are also significant facets of complete QOL that add to the complexity of its measurement. Although health is an important domain of complete quality of life [14].

The impression of HRQOL and its factors progressed since the 1980s to include those features of complete QOL that can be undoubtedly exposed to affect health in terms of physical or mental health [14]. With respect to Personal level, it contains physical and mental health observations and connections, comprising health dangers and situations, functional standing, social provision, and socioeconomic situation. Though, facets of health do not seem to take through attitude on

QOL. These comprise an ailment, experience, or hereditary tendency that is unidentified to person without signs [15]

These factors except for health conditions however go beyond the concept of health, and being health care provider the term that reflects QOL is considered to be fall under health. So, the preferred term used to describe as QOL is Health-related quality of life (HRQOL). When considered as a dimension or domain of quality of life, it is best to think that they generally represent the quality of life that is considered to be under the concern of health care providers or that is likely to be the goal of an intervention of medical attention. Therefore, the term HRQOL has sometimes been preferred [16].

#### **HOW IT IS MEASURED**

Measures of HRQOL are increasingly recognized as an important provision in measured results of medical intervention. This is an essential component of evidence-based public health policy, aspiring to the ultimate health goal of all. [17]. HRQOL is an aggregate of two, viz. Health and Quality of Life (QOL). Many descriptions of these terms have been offered from time to time. Consequently, health is an ambiguous term, and/or a term with numerous connotations [18].

Measuring the HRQOL Numerous methodological procedures stated in the scientific literature to HROOL. HROOL measurements encompass objective and subjective well-being dimensions [19]. Objective well-being measures include variables that can be measured in the relationship of quantity or frequency such as a number of times the patients were admitted to the hospital, the distance a patient can walk or the ability to climb the stairs. These measures also showed employment status, income, communication with families and friends and average of the housing. The subjective well-being measurements are those procedures, which cannot be measured accurately by anyone other than the patient himself or herself, such as level of pain or distress, level of satisfaction with their daily activities, leisure time, the medical care they receive or overall life [19].

#### **METHODS:**

*Study questions*: What health-related quality of life tools used? What HRQoL studies done in Pakistan?

The search for articles including research in electronic databases and manual searching of citations in original editions was identified. The electronic database researched were International Literature in Health Sciences (MEDLINE) in between January/2000 and December/2017.

For the search for articles, we used descriptors descriptive of Health Sciences: hrqol; generic tools; disease-specific tools. To refine the search the following terms were added to these combinations: eq5d, sf12, whoqol, pro. In the end, there were 153 combinations among the descriptors to obtain the maximum of references possible.

Based on this action, a list of articles was created for inclusion in the study. The abstract is compiled and guided by the goal of the article.

Criteria include: to be a research article, a case study and systematic reviews in journals particularly in Pakistan about QOL, HRQOL assessment, generic tools, disease-specific tools to assess HRQOL, patient-specific tools and general population studies, patient-reported outcomes, EQ5D, SF health survey, WHOQOL in which there were data about assessment of HRQOL inpatient or disease-specific as well as general population

#### Generic and disease-specific measures of healthrelated quality of life

The valuation of HRQOL is a vital component of healthcare assessment. A number of generic and specific HRQOL tools established so far. Generic HRQOL tools are proposed to be applicable across widespread populations and interventions. Specific HRQOL measures are designed to be applicable to specific interventions or in a certain condition, may be any disease condition [20].

The quantification of HRQOL broadly separated into generic and disease-specific. *Generic measures* are appropriate across diverse disease populaces and therefore are repeatedly used to associate with HRQOL in groups with numerous diseases and to those in the general population. *Disease-specific* tools include objects that are applicable to a particular condition or disease state. Compared to generic measures, disease-specific measures have greater sensitivity and specificity and are better at detecting treatment effects and changes across time [13, 21, 22]. However, studies shown in table 1 reparented main HRQOL tools used in general or disease-specific studies.

Table 1: showed Generic and Disease Specific Studies Worldwide and Pakistan

| Tool/Instrument                                  | Studies Worldwide   | Studies in Pakistan   |
|--|---|---|
| CDC HRQOL–14                                     | (Moriarty et al., 2003) (Mielenz et al., 2006) (Joseph et al., 2014) [23-25]  | xxxx  |
| Short-Form Health Survey<br>(SF-36, SF-12, SF-8) | (J. E. Brazier et al., 1992) (Aaronson et al., 1998) (Sullivan et al., 1995) (Montazeri et al., 2005) (Fukuhara et al., 1998) (Alonso et al., 1995) (Hopman et al., 2000) (Bullinger, 1995) (Lyons et al., 1994) (Bousquet et al., 1994) (Apolone et al., 1998) (J. Brazier et al., 1998) (HÅvard Loge et al., 1998) (Leplège et al., 1998) (Anderson et al., 1996) (Turner-Bowker et al., 2003) (Tokuda et al., 2009) (Ware et al., 1998) (J. E. Brazier et al., 2004) (Hays et al., 2001)               | (Ul-Haq et al., 2013) (Nisar et al., 2008) (Awan, Waqas, Mumtaz, et al., 2011) (Awan, Waqas, Aslam, & Abbas, 2011) (Awan, Waqas, Aslam, & Sarwar, 2011) (Riaz et al., 2013) (N ul Haq, Ali, et al., 2016) [46-52]   |
| EuroQol Five Dimensions (EQ-5D)                  | (König et al., 2009) (Kularatna et al., 2014) (Burström et al., 2014) (Sun et al., 2011) (Kularatna et al., 2014) (Gundgaard et al., 2006) (Kind et al., 1999) (Clemens et al., 2014) (de Miranda Menezes et al., 2015) (Luo et al., 2005) (Sørensen et al., 2009) (Lamers et al., 2005) (Burström et al., 2001) (Schrag et al., 2000) (Solli et al., 2010) (Lubetkin et al., 2005) (Pickard et al., 2004) (Jansson et al., 2009) (Granja et al., 2002) (Seong et al., 2004) (Stark et al., 2010) [53-72] | (Noman ul Haq et al., 2012) (Saleem et al., 2014) (Saleem et al., 2014) (Nazir et al., 2015) (M. A. Hassali et al., 2016) (N ul Haq, Ahmed, et al., 2016) (Husain et al., 2016) (HAYAT et al.) (N ul Haq, Akram, et al., 2015) (N ul Haq, Iqbal, et al., 2015) (Ilyas et al., 2017) (Ilyas et al., 2017) (Akhtar et al., 2014) (N Ul Haq, Baloch, et al., 2015) (M. Hassali et al., 2013) (Haq N, Sajjad B, et al., 2017) [73-87] |
| Assessment of Quality of Life (AQOL)             | (Richardson et al., 2014) (Richardson et al., 2012) (Richardson et al., 2009) (Chen et al., 2014) (Maxwell et al., 2016) (Campbell et al., 2016) (Hawthorne et al., 2005) (Chen et al., 2015) [88-95]   | ××××  |
| Health Utility Index Mark 3<br>(HUI-3)           | (Furlong et al., 2001) (Luo et al., 2005)<br>(Grootendorst et al., 2000) (Oostenbrink et al., 2002) (Kopec et al., 2003) (Glaser et al., 1999)<br>[96, 61, 97-100]  | xxxx  |
| Fifteen Dimensions (15 D)                        | (Ilonen et al., 2010) (Räsänen et al., 2007) (Hannula et al., 2014) (Sintonen, 2001) (Saarni et al., 2006) (Sintonen et al., 1993) (Hahl et al., 2002) [101-107]  | xxxx  |
| Quality of Well-being (QWB)                      | (Andresen et al., 1998) (Kaplan et al., 1989) (Kaplan et al., 2000) (Balaban et al., 1986) (Patterson et al., 1996) (Orenstein et al., 1990) (Orenstein et al., 1991) (Kasckow et al., 2001) [108-115]  | xxxx  |
| Personal Wellbeing Index<br>(PWI)                | (Tomyn et al., 2011) (Tomyn & Cummins, 2011) (Wills, 2009) (Cummins et al., 2005) (Smyth et al., 2010) [116-119]  | ××××  |
| Satisfaction with Life Scale (SWLS)              | (W. Arrindell et al., 1991) (W. A. Arrindell et al., 1999) (Glaesmer et al., 2011) (Gouveia et al., 2009) (Abdallah, 1998) (Durak et al., 2010) [120-125]   | xxxx  |
| Health Assessment<br>Questionnaire (HAQ)         | (Pincus et al., 1983) (Poole et al., 1991) (Kirwan et al., 1986) (Rannou et al., 2007) (Häkkinen et al., 2005) [126-130]  | (N ul Haq, Rekky, et al., 2016)<br>[131]  |
| WHO Quality of Life-BREF<br>(WHOQOL-BREF)        | (Min et al., 2000) (Yao et al., 2002) (Nedjat et al., 2008) (Jang et al., 2004) (Cruz et al., 2011) (Sathvik et al., 2008) [132-137]  | (Iqbal et al., 2014) (Haq N, Bibi P, et al., 2017)<br>[138, 139]  |

#### **RESULT AND DISCUSSION:**

We have found more than 100 HRQoL related studies and only the most relevant ones have been included in this review. These studies have validated and combined specific tools used by the general public or patients with the disease to evaluate the effectiveness and sensitivity of the instruments. Several methods of data collection and data analysis methods have been used in the studies, depending on the objectives and objectives of the researcher in order to generate relative benefits when using a tool. Specifically or to determine the effectiveness of a particular instrument. [140].

# Population norms or HRQOL in Healthy population

It is evident from the review, no study in Pakistan has been conducted by any tool where general population norms for Pakistani population were documented. The most frequent tool used in Pakistan to assess HRQOL was EQ5D which is again tested to report disease-specific population [73-87]. Though this tool was used and scored by using values derived from the UK general population survey reported in 1995 [140]. The population norms for the EQ-5D by sociodemographic are presented from other countries such as Australia [59], Brazil [60], UK [58], Sri Lanka [54], US [61], Danish [62] and China [56]. These Norms can be used to compare the health status of specific groups i.e. disease state with that of the general population. These Population norms are an important reference point for assessing outcomes in assessment of health programs and policies [141]. There was no any study which reported health status or general population norms for Pakistani Population.

#### **CONCLUSION:**

It is obvious from the result of different studies that no sole tool is generally appropriate for the general population and particular disease state to assess patient-reported outcomes (PRO). The choice of instrument should depend on the study objectives. Clinical studies for many years been using diseasespecific tools to assess HRQOL. There are now a great number of these tools, which are usually used for economic evaluation. They are designed to assess the quality of life, and changes in quality of life, in specific diagnostic groups or patient populations. It is further concluded that specific tools have been tested to report health status of a disease state as well as in general population. It is evident that disease-specific studies have been conducted in Pakistan by using various tools however, no population norms ever reported in Pakistan.

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