Conceptual Model of Health-Related Quality of Life

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Purpose: *To revise the Wilson and Cleary model of health-related quality of life (HRQoL), with suggestions for applying each of the components, and to facilitate the use of HRQoL in nursing and health care.*

Organizing Construct: *HRQoL, based on relevant literature over the past 20 years.*

Methods: *The original model was revised in three substantive ways: (a) indicating that biological function is influenced by characteristics of both individuals and environments; (b) deleting nonmedical factors; and (c) deleting the labels on the arrows that tend to restrict characterization of the relationships.*

Findings: *Theoretical background is provided for each of the major components of the model, and examples of instruments to measure them, were added.*

Conclusions: *In quality-of-life research, the current challenge is to devise models to clarify the elements of health-related quality of life (HRQOL) and the causal relationships among them. This revision of Wilson and Cleary's model includes a taxonomy of the variables that often have been used to measure HRQoL. This revision should be useful in research and clinical practice.*

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Over the past 30 years, evaluation of quality of life has become increasingly important in health care. Quality-of-life research has increased in methodologic rigor and sophistication. Nevertheless, progress has been hindered by the fact that term "quality of life" has been used to mean a variety of different things, such as health status, physical functioning, symptoms, psychosocial adjustment, well-being, life satisfaction, and happiness. As a consequence, comparing findings across studies to draw conclusions or make application in practice is difficult.

To help solve the problem, the term "health-related quality of life" (HRQoL) was introduced. This term was intended to narrow the focus to the effects of health, illness, and treatment on quality of life. This term excludes aspects of quality of life that are not related to health, such as cultural, political, or societal attributes. Examples are the quality of the environment, public safety, education, standard of living, transportation, political freedom, or cultural amenities. Unfortunately, the distinction between health-related and nonhealth-related quality of life cannot always be clearly made. For example, air pollution contributes to chronic respiratory disease, and long dark winters contribute to seasonal affective disorder. In addition, in chronic illness almost all areas of life are affected by health, and so become "health-related" (Guyatt, Feeny, & Patrick, 1993).

The current need is for causal models that clearly indicate the elements of HRQoL and their determinants. To date, most models have been focused on the identification of domains. These efforts have helped to define the scope of quality of life by making clear that the term refers to all of life, and not just physical health status. However, identifying domains is not enough. For example, the term "physical domain" can refer to pathophysiological changes, symptoms, functional deficits, or perceived health status. A causal model with clear distinctions between the most common approaches used to assess HRQoL was developed by Wilson and Cleary (1995). In this paper we present (a) the theoretical grounding of characteristics of individual and environment, (b) a revised version of their model, and (c) suggestions for applying each of the components in nursing and health care.

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Characteristics of Individual and Environment

Characteristics of individual and environment were included in Wilson and Cleary's original model, but were not discussed in the text. Our revised model is based on the ecological model of McLeroy and colleagues (McLeroy, Bibeau, Steckler, & Glanz, 1988), as modified by Eyler et al. (2002), to explicate the multiple layers of influence on health outcomes at both individual and environmental levels in HRQoL. McLeroy and colleagues' model indicates five levels of influence: (a) intrapersonal factors (characteristics of individual), (b) interpersonal factors (formal and informal social support systems), (c) institutional factors (organizations such as schools and healthcare facilities), (d) community factors (relationships among institutions and informal social networks in a defined area), and (e) public policy (local, state, and national laws and policies). For our revised model, everything other than the individual level is considered an environmental influence. Thus, of McLeroy and colleagues' five levels, intrapersonal factors are individual characteristics and the remaining four levels are environmental characteristics.

Characteristics of the Individual

In accordance with Eyler et al. (2002), characteristics of the individual in our revised model are categorized as demographic, developmental, psychological, and biological factors that influence health outcomes. Thus, we have added an arrow from characteristics of the individual to biological function. Epidemiological evidence indicates links between individual characteristics and biological function, by identifying attributes or behaviors that increase or decrease the likelihood of developing a given health problem. Biological factors include body mass index, skin color, and family history related to genetically linked disease and disease risk. Demographic factors that commonly have been linked to the incidence of illness are sex, age, marital status, and ethnicity. Although these personal characteristics are relatively unchangeable, they are useful for targeting interventions for specific groups. Targeting requires taking into account the subgroup characteristics in order to design group-level interventions (Kreuter & Skinner, 2000). For example, data from the National Health Interview Survey indicated that African American women have a high prevalence of diabetes, increasing with age (American Heart Association [AHA], 2005). In addition, they have higher rates of obesity and lower levels of physical activity than do White American women, which further increase the risk for diabetes and cardiovascular disease (AHA, 2005). Thus, these biological and demographic factors give direction to healthcare providers in targeting whom to screen for health problems such as diabetes, as well as the types of behaviors to target to decrease risk.

Developmental status is also an individual characteristic that is particularly important to consider when explaining health behavior and its resultant effect on biological function. Although developmental status is not a static variable, it cannot be changed or altered by interventions. Nevertheless, interventions designed to change or modify behavior require consideration of an individual's developmental status. For example, women with young children and little time for structured exercise programs might be receptive to learning ways to enhance their daily activities at home and work to reap the cardiovascular benefits (biological function).

Psychological factors are dynamic, modifiable, and responsive to interventions. Cox (1982, 2003) identified cognitive appraisal, affective response, and motivation as dynamic intrapersonal factors. Cognitive appraisal includes factors such as knowledge, beliefs, and attitudes toward an illness, treatment, or behavior. Affective response is the emotion evoked including anxiety, fear, sadness, or joy. According to Cox's conceptualization, motivation is based on the theory of self-determination (Ryan & Deci, 2000), which distinguishes between different types of motivation arising from different reasons for performing a given activity. Intrinsic motivation refers to starting and maintaining a behavior because of its inherent enjoyment or satisfaction. It occurs on the basis of a sense of autonomy or self-initiation and choice. Extrinsic motivation for engaging in a behavior is determined by the rewards externally provided rather than by the feelings the behavior engenders, and thus it occurs in environments instead of by individual choice.

These dynamic psychological factors can influence one another. For example, a woman who has a lipoprotein level placing her at risk for cardiovascular disease, and who has been overweight and sedentary most of her life, might recall the humiliation she experienced in high school when forced to participate in sports. This thought process results in anxiety (affective response) and lack of motivation to change her lifestyle in response to her increased cardiovascular risk. Another woman at risk for cardiovascular disease might regard walking as an activity within her capability, giving her the initial motivation to begin to change her lifestyle. Her motivation might stem from learning (cognitive response) that physical activity provides cardiovascular benefits, such as walking at moderate levels.

Characteristics of the Environment

For the revised model, characteristics of the environment are categorized as either social or physical, in accordance with Eyler et al. (2002). Social environmental characteristics are the interpersonal or social influences on health outcomes, including the influence of family, friends, and healthcare providers (McLeroy et al., 1988). For example, significant others can have a strong influence over when and where health care is sought and whether treatment is adhered to. The effect of this social environment is significantly influenced by an individual's cultural heritage, which can affect participation in preventive care as well as treatment. For example, several studies have indicated that Korean women have much lower rates than do White women in participation in clinical breast examinations and mammography (Chen, Diamant, Kagawa-Singer, Pourat, & Wold,

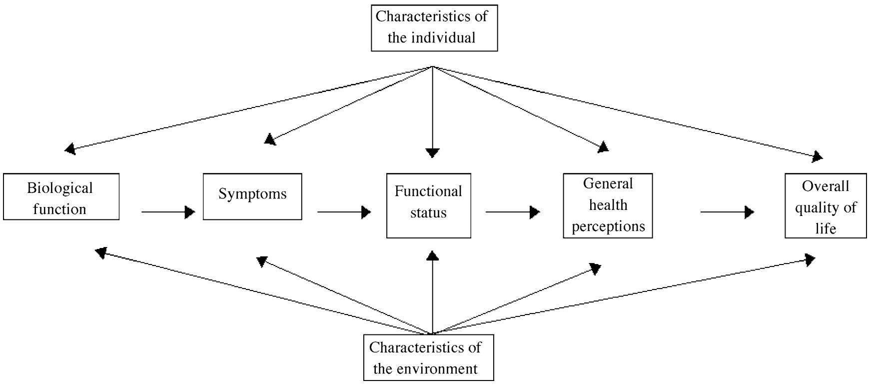

Figure. Revised Wilson and Cleary model for health-related quality of life. Adapted from "Linking Clinical Variables with Health-Related Quality of Life: A Conceptual Model of Patient Outcomes," by I.B. Wilson and P.D. Clearly, 1995. Copyright by *JAMA*. Used with permission.

2004; CDC, 1997). Korean immigrant women with physicians of the same ethnicity have been found to be less likely to have a mammogram than were those with non-Korean physicians (Juon, Kim, Shakar, & Han, 2004). Also, Korean immigrant women have reported that the emphasis on their roles as mothers in their cultural tradition did not allow them to meet their own needs (Im & Cloe, 2001).

Physical environment characteristics are those settings such as the home, neighborhood, and workplace that influence health outcomes either positively or negatively. For example, neighborhoods with walking and bicycle trails, health clubs, and sports fields are more conducive to physical activity. In contrast, communities that have a high crime rates, poor policing, and high levels of pollution have environments that are not conducive to physical activity.

Revisions of the Model

Our revision of Wilson and Cleary's (1995) model of HRQoL is shown in the **Figure**. Our primary focus was the five boxes in the center of the model, which are five types of measures of patient outcomes. First, biological function (originally biological and physiological variables) is described as focusing on the function of cells, organs, and organ systems. Biological function would be assessed through such indicators as laboratory tests, physical assessment, and medical diagnoses. Second, symptoms (originally symptom status), refers to physical, emotional, and cognitive symptoms perceived by a patient. Functional status, the third component, is composed of physical, psychological, social, and role function. Fourth, is general health perceptions, which refers to a subjective rating that includes all of the health concepts that precede it. Fifth, overall quality of life, is described as subjective well-being, which means how happy or satisfied someone is with life as a whole. The arrows indicate the dominant causal associations. Reciprocal relationships might exist, but are not characterized in the figure.

The original model was revised in three substantive ways. First, we added arrows to show that biological function is influenced by characteristics of both individuals and environments. Second, the original model included nonmedical factors as an independent influence on overall quality of life. We chose to delete this box, because all nonmedical factors can be categorized as characteristics of either individual or environment, which already were included in the model. Third, in the original model many of the arrows were labeled by examples. The examples tended to restrict characterization of the relationships. Because comprehensive labeling of relationships would be unwieldy, we decided to omit labels on the arrows entirely in the revised model.

Biological Function

According to the model, biological function (originally called biological and physiological variables) includes the dynamic processes that support life. Biological function is viewed broadly and encompasses molecular, cellular, and whole organ level processes. It can be described as a continuum of ideal function on one end and serious life-threatening pathological function at the other end. Alterations in biological function directly or indirectly affect all components of health, including symptoms, functional status, perceptions of health, and overall quality of life. Optimizing biological function is an integral part of holistic care.

The revised model indicates the effects of individual and environmental characteristics on biological functioning, which was not in the original model. The interaction of individual and environmental characteristics also influences biological function.

Effect of individual characteristics on biological function. Individual characteristics influence a person's biological vulnerability and resilience. Individual genetic characteristics influence biological functioning in congenital and hereditary diseases such as cystic fibrosis and sickle cell anemia. Genetic composition predisposes people to the development of many diseases, including inflammatory, degenerative, metabolic, and neoplastic diseases. Psychological characteristics, knowledge, and attitudes influence choices people make about lifestyle, ultimately affecting biological function. For example, self-efficacy for exercise influences exercise behavior and ultimately affects aerobic fitness and biological function.

Effects of environmental characteristics on biological function. Physical and social factors in the environment affect biologic function. For example, exposure to pathogens in the environment can cause infectious diseases, and living in a high crime community can lead to traumatic injury.

Effects of interactions between individual and environment. The emerging field of genomic science illustrates the effects of individual environment interactions on biologic function. Genomics is the study of the functions and interaction of all genes in the genome (Guttmacher & Collins, 2002), and the interaction of genes and environmental factors as it applies to the expression of common disorders, such as Alzheimer's disease, colorectal cancer, breast cancer, and AIDS. For example, because of the gene-environment interaction some life-long smokers develop chronic obstructive lung disease or lung cancer, but others do not. Because genetic characteristics cannot be altered, clinical interventions are directed toward modifying behaviors to reduce the risk of disease.

Symptoms

Wilson and Cleary (1995, p. 61) indicated that moving attention from the biological and physiological variables to symptom variables requires a shift focus from cellular and organism level to a person level. They define symptoms as "a patient's perception of an abnormal physical, emotional, or cognitive state," which can be categorized as physical, psychological, or psychophysical.

Instruments to measure symptoms can be classified as global measures, condition-specific measures, and symptom-specific measures. Global measures are broad and include many varied symptoms. The Symptom Impact Inventory is an example of a global measure (Miller, Wilbur, Montgomery, Chandler, & Bezruczko, 2001). Condition-specific measures are focused on the symptoms associated with a particular condition and include the Chronic Respiratory Disease Questionnaire (Guyatt, Berman, & Townsend, 1987) and the Unstable Angina Symptom Questionnaire (DeVon & Zerwic, 2003). Symptom-specific measures pertain to a particular symptom, such as fatigue as measured with the Piper Fatigue Scale (Piper et al., 1989) or anxiety and depression as measured with the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

The most common dimensions of symptoms that are measured include frequency, intensity, and distress. Other dimensions that have been incorporated in symptom measures include quality, cause, treatment, consequences, location, and timing. Instruments vary on which dimensions are included and several dimensions might be included in the same instrument.

A variety of theories are focused primarily on symptoms. The Common Sense Model of Illness (Leventhal, Meyer, & Nerenz, 1980) is one theory focused on a person's somatic sensation and the process used to attribute the sensation to illness, external life stressors, or benign sensations. People experience sensations and cognitively process the sensations with the background of previous somatic experiences and with information from the environment. The person's cognitive representation of the symptom includes thoughts about its possible identity (heart attack, pulled muscle, influenza), cause, consequence, progression, and cure. The experience, evaluation, and interpretation of symptoms are part of the characteristics of the individual and the environment. For example, Cameron, Leventhal, & Leventhal (1995) found in a longitudinal study of community-dwelling middle-to-older aged adults that people who experienced symptoms combined with other stressful events reported more negative mood states, rated the symptoms as more serious, reported more distress about the symptoms, and experienced more disruption of daily activities than did people who experienced symptoms without the presence of stressful events. Thus the experience, evaluation, and interpretation of symptoms are influenced by complex interactions with both individual factors (such as knowledge and personality characteristics) and environmental factors (such as interactions with healthcare providers).

Functional Status

Wilson and Cleary (1995) defined functional status broadly, as the ability to perform tasks in multiple domains such as physical function, social function, role function, and psychological function. Functional status can be viewed from various perspectives. Traditional models pertain to functional status from the perspective of disability or disablement, focused on the loss of function and its effects on daily life (Stineman et al., 2005). Alternatively, in the revised model we view functional status by focusing on optimization of the function that remains. Leidy's (1994) framework for functional status is an example of this perspective and it is a useful guide for health care.

According to Leidy's framework, functional status includes four dimensions: functional capacity, functional performance, functional capacity utilization, and functional reserve (Leidy, 1994). Functional capacity is defined as one's maximal capacity to perform a specific task in the physical, social, psychological or cognitive domains. For example, functional capacity might be one's maximal ability in strength and endurance or in aptitude or memory. The second dimension, functional performance, refers to activities that one performs on a day-to-day basis. Functional performance is an integrated response and is determined by multiple factors, including personal choice, values, and motivation. Functional performance could be assessed by the level of physical activity and energy expended or as self-reported activities across multiple categories. Alternatively, functional performance could be measured by daily memory performance. Functional performance also could be influenced by functional capacity, as in cases when reduced capacity limits performance of day-to-day activities. The third dimension, capacity utilization, refers to the percentage of functional capacity that is used day to day. The fourth dimension, functional reserve, refers to the difference between capacity utilization and functional capacity. People generally do not function at 100% of their capacity on a day-to-day basis, and people with high capacity might actually use only a small percentage of their capacity daily. When functional capacity declines because of health problems, a person might be required to use a higher percentage of capacity or to cut back on daily activities. Capacity utilization is closely related to functional reserve and indicates the unused potential. People with low capacity and very low functional performance could have a fairly large functional reserve.

Measures of functional capacity have been widely reported in the scientific literature, and many established measures of this dimension are available. For example, the maximal oxygen uptake is a measure of aerobic capacity and is assessed during a symptom-limited exercise test. The 6-minute walk test and the shuttle walk test are used to measure functional capacity for walking. Similarly, tests of skeletal muscle strength indicate functional capacity for strength. The measurement of functional performance is less advanced. One commonly used measure of functional performance is the Functional Performance Inventory (FPI). Leidy (1999) developed the FPI with people who had COPD; it has the potential to be appropriate for other groups of people with chronic illness, such as chronic congestive heart failure. In addition, two scales from the SF-36 Health Survey (Ware & Sherbourne, 1992) have been used widely to measure functioning: the physical functioning and social functioning scales. The SF-36 is a generic measure that can be used with both healthy people and people with chronic illness. Many investigators also have used the Sickness Impact Profile to measure functional performance, but it is an indirect measure of functional performance and a direct measure of functional impairment.

No instruments are established for the measurement of capacity utilization and functional reserve. Although the concepts of capacity utilization and functional reserve are not readily measured objectively, they are clinically meaningful and could be measured subjectively.

In the revised HRQoL model, multiple factors can affect functional status. For example, functional capacity can be directly affected by biological function and by symptoms, and functional performance can be affected by characteristics of the individual and the environment. In people with COPD, functional capacity can be limited by ventilatory capacity and by symptoms of dyspnea or leg fatigue. However, symptoms alone do not fully account for the decrease in functional capacity. If symptoms are severe enough, they might interfere with day-to-day levels of activity, which might cause a patient to become sedentary and physically deconditioned (decline in functional status). But the extent of the decline in day-to-day activities also could be influenced by individual characteristics, such as self-efficacy and motivation for physical activity, or by social environmental factors, such as social support for physical activity and community safety.

General Health Perceptions

Wilson and Cleary (1995) pointed out two defining characteristics of general health perceptions: (a) they integrate all the components that come earlier in the model, and (b) they are subjective in nature. This component is a synthesis of all the various aspects of health in an overall evaluation. Supporting this idea is the finding that the strongest and most consistent predictors of general health perceptions are physiological processes, symptoms, and functional ability, based on a review of 39 studies of the general population (Bjorner et al., 1996). Although general health perceptions are influenced by the earlier components of the model, they nevertheless are different from the others. Thus using measures of other components, such as functioning or symptoms, to assess general health perceptions is not appropriate. Instead, this component is most commonly measured with a single global question to ask people to rate their health on a Likert scale ranging from poor to excellent. Ratings of general health perceptions are used both as single-item measures and items in a battery, as in the SF-36 Health Survey (Ware & Sherbourne, 1992).

When rating their health, people typically consider various aspects of their health, as well as the implicit importance of each. Further, men and women differed systematically when evaluating their health in general (Benyamini, Leventhal, & Leventhal, 2000). Men's health ratings pertained to serious, life-threatening diseases (such as cardiac disease), but women's health ratings included both life-threatening and nonlife-threatening disease (such as arthritis). In addition, gender differences were found in the effect of negative emotion on general health ratings. For men emotion was linked primarily to serious disease, and for women it was linked to a wider variety of life factors.

Overall Quality of Life

Overall quality of life, the final component of the model, was characterized by Wilson and Cleary (1995) as subjective well-being related to how happy or satisfied someone is with life as a whole. Over the past 30 years the concept of subjective well-being has developed considerably as a general area of scientific interest (for a comprehensive review, see Diener, Suh, Lucas, & Smith, 1999). Subjective well-being does not represent a single construct; it includes pleasant and unpleasant affect, global judgments of life satisfaction, and satisfaction with individual domains of life (Diener et al., 1999). The number of life domains varies among authors, depending on the desired level of generality. At a broad level of abstraction, the domains have been characterized as health and functioning, psychological and spiritual, family, social, and economic (Ferrans, 1990, 1996). This characterization is consistent with prevailing views of the domains of quality of life in the literature, although the specific terminology varies somewhat among authors (Ferrans, 2005).

Many theories and conceptual models have been proposed to explain the components of subjective well-being. Campbell, Converse, and Rodgers (1976) published one of the earliest and most influential reports to characterize the determinants of life satisfaction. They described the relationship between the characteristics of the individual and environment and the level of life satisfaction experienced. In their model, life satisfaction is determined by the person's evaluation of attributes of various domains of life. This evaluation is dependent on the person's perception of attributes, as well as internal standards by which those perceptions are judged. Internal standards include personal values, expectation levels, aspiration levels, personal needs, and comparisons with others. Individual perception is influenced by personal characteristics, such as demographic characteristics, general optimism or pessimism, as well as other attributes of personality.

In concordance with Campbell et al. (1976), Wilson and Cleary (1995) emphasized how patients' values and preferences affect overall quality of life. Because of differences in values, an impairment that makes life not worth living for one person might be considered only a bother for another. For this reason, the importance of values should be part of an assessment of satisfaction with life. Life satisfaction can be measured through a single global question, asking how satisfied the person is with life in general, or through a series of questions about satisfaction with various aspects of life. If scores on a series of questions are simply summed, then each aspect of life is given equal value. However, some instruments include a weighting system to allow for differences in importance for each aspect of life, and thus would indicate differences in values of respondents. Two examples are the Quality of Life Inventory (Frisch, 1993) and the Quality of Life Index (Ferrans & Powers, 1992; Ferrans, 1990). Measuring the importance of various aspects of life also has an additional advantage. Recently, concern has been expressed about the effect of "response shift," which is a change in internal standards and values in response to significant life events. These changes can occur as a result of cognitive, affective, and behavioral processes used to accommodate to illness (Sprangers & Schwartz, 1999). The implication is that changes in instrument scores might sometimes indicate changes in internal standards, rather than in the attribute of interest. A benefit of using an instrument to measure patients' values is that it allows the investigator to determine whether values have changed over the course of the study. If changes have occurred, they then can be accounted for in the statistical analysis.

Conclusions

Identification of the domains of quality of life is an important task that has been reasonably accomplished. However, identification of domains has not remedied the problem of conceptual confusion, nor has narrowing the field to variables that are "health related." Lack of precision in terminology about quality of life has resulted in the use of same terms to mean different things. The current need is for models to clarify the critical elements of HRQoL and the causal relationships among them.

Wilson and Cleary's model (1995) includes a useful taxonomy of the variables that commonly have been used to measure HRQoL. Although the model was published in 1995, it has not been widely used. We revised their original model in three substantive ways: (a) adding arrows to show that biological function is influenced by characteristics of both individuals and environments, (b) deleting nonmedical factors, and (c) deleting the labels on the arrows because they tended to restrict characterization of the relationships. We also provided theoretical background for each of the major components of the model and examples of instruments for measuring them. The result is a revised model to advance knowledge and use of the concept of HRQoL in nursing and health care.

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