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Quality of Life as an Outcome Measure in Nursing Research

"May you have a long and healthy life"

Margaret B. Harrison, Elizabeth F. Juniper, and Alba Mitchell-DiCenso

La qualité de la vie émerge comme un concept et un résultat importants dans les soins de santé. Les décideurs, les chercheurs, les cliniciens et le public en général estiment que la perception que l'on a de la qualité de la vie est une dimension importante de la santé d'une population ou d'une personne. La nature des sciences infirmières est telle que beaucoup de leurs résultats escomptés sont liés à l'amélioration de la qualité de vie des personnes et des populations. Le débat demeure ouvert sur la définition exacte de la qualité de la vie; un concept difficile à définir qui posera naturellement des défis aux moyens de le mesurer. Pourtant, cela n'a pas empêché la prolifération d'instruments de mesure de la qualité de la vie car le concept est reconnu comme un résultat clinique et de recherche de plus en plus important. Des progrès ont été accomplis pour clarifier et opérationnaliser le concept. Nous proposons un point de vue conceptuel qui sépare ce que la qualité de vie est de ce qui contribue à la qualité de vie. Cela permettra aux chercheurs en sciences infirmières d'envisager la qualité de vie comme un résultat dans leur évaluation des interventions en soins infirmiers. Dans les situations cliniques ou de recherche, pour ce qui a trait à la mesure, une définition opérationnelle de la qualité de la vie provient d'une définition de la santé. De là dérive une définition d'une qualité de vie liée à la santé. Pour mesurer les résultats, la définition opérationnelle est liée aux domaines importants pour la population étudiée et à l'intervention sanitaire particulière que l'on étudie. On présente également les questions soulevées concernant la mesure de la qualité de vie liée à la santé.

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Quality of life has emerged as an important concept and outcome in health and health care. Policy-makers, researchers, clinicians, and the public at large consider perceived quality of life to be an important dimension of the health of a population or an individual. The nature of nursing is such that many of its anticipated outcomes relate to improvement in the quality of life of individuals and populations. There continues to be debate about the actual definition of quality of life, and a concept that is difficult to define will naturally pose challenges to measurement. This has not impeded the proliferation of quality-of-life instruments, since the concept is recognized as an increasingly important clinical and research outcome. Progress has been made in clarifying and operationalizing the concept. We propose a conceptual viewpoint that separates what quality of life *is* from what *contributes to* quality of life. This will assist nurse researchers planning to use quality of life as an outcome in evaluating nursing interventions. In clinical or research situations, for the purposes of measurement, an operational definition of quality of life stems from a definition of health. From this is drawn a definition of health-related quality of life (HRQL). For the purpose of outcome measurement, the operational definition relates to the domains important to the study population and the particular health intervention under study. Issues that arise in the measurement of HRQL are also presented.

Quality of life has emerged as an important concept and outcome in health and health care. Policy-makers, researchers, clinicians, and the public at large consider perceived quality of life an important dimension of the health of a population or an individual (Campbell, Converse, & Rodgers, 1976; Kinney, Burfitt, Stullenbarger, Rees, & Read-Debolt, 1996). Nursing is, by its nature, holistic, supportive, and focused on the human response to a state of health (Ferrans & Powers, 1985; Padilla & Grant, 1985). Many of the anticipated outcomes of nursing practice relate to improvement in the quality of life of individuals and populations. As a result, quality of life and its measurement have become an important focus in the evaluation of nursing practice. This paper provides a conceptual viewpoint for quality of life as a nursing research outcome and outlines issues that arise in the measurement of health-related quality of life (HRQL).

Quality of Life as a Concept in Health and in Health Care

Following the deprivations of the Great Depression in the 1930s and the upheaval caused by World War II, the concept of quality of life emerged as a result of society's increased attention to achieving a "good life," rather than merely surviving (Campbell et al., 1976). The increased consumer awareness in North America since the end of World War II has had a significant impact on the health field. By the 1970s it was evident that the perspective of the patient was becoming an important consideration (McDowell & Newell, 1987; Ware, 1984). It is now possible to be biologically alive but socially dead (Edlund & Tandcredi, 1985). Technological and other medical advances have increased our ability to keep people alive longer. Society has put the quality of this extended life under scrutiny, with debates over artificial life supports, euthanasia, and even the meaning and definition of death. Many available therapies offer similar morbidity and mortality outcomes but different effects on quality of life – for example, surgical or medical treatment of ischemic heart disease, chemotherapy or supportive care for advanced lung cancer. Individuals and families are becoming increasingly involved in decisions related to the quality, versus quantity, of life. The "provider paternalism" of the past is no longer widely accepted.

As a result of medical progress, people with chronic or long-term conditions are living longer and more people are surviving serious trauma and accidents (Ontario Ministry of Health, 1993; Strauss, 1984). The goal of their treatment is to maximize quality of life, by alleviating symptoms, maintaining or improving functional capacity, and retarding the progression of the underlying condition or incurable disease (Renwick, Brown, & Nagler, 1996; Stewart et al., 1989). Nursing provides support before, during, and after diagnosis and therapy. In the case of the chronically ill, nursing practice accompanies an individual (and family) on the journey through diagnosis, rehabilitation, and living with the condition day-to-day (Padilla & Grant, 1985; Rideout, 1992). Nursing interventions promote well-being, adjustment, and self-care, and their anticipated outcomes are primarily with improvements in quality of life. Nurses play a vital role in assessing and maintaining "health" for those with chronic or long-term conditions; thus they ultimately influence quality of life.

Quality of life will undoubtedly become an even more important concept in the next few decades. The incidence of chronic or long-term conditions increases as terminal ailments become curable and more individuals survive trauma. A larger aging population further increases the need for quality-of-life assessment. Chronic conditions are more common in the elderly (Kinney et al., 1996; Ontario Ministry of Health, 1993). Demographic data indicate that in Ontario, for example, by the year 2010 the proportion of people over 65 will increase by 68% (Ontario Ministry of Health, 1993, p. 9). The great expectations for technology and science have not been realized. Progress will be characterized by incremental gains in the management of major illnesses, rather than their cure. Thus the need for supportive care will continue to increase, as will its importance. For nursing, the challenge will be to evaluate the effectiveness of such interventions, which will require innovative outcome measurements beyond traditional morbidity and mortality endpoints (Jenkins, Jono, Stanton, & Stroup-Benham, 1990; Kinney et al.; Padilla, Grant, & Ferrell, 1992).

Quality of life offers one approach to this challenge, taking the individual's subjective assessment into account (Oleson, 1990). In a special report, Padilla and colleagues (1992) describe the "vital interest and commitment" of the nursing profession to conceptualizing and measuring quality of life: by actively promoting quality-of-life research (describing quality of life, developing measures, testing interventions); disseminating quality-of-life research through conferences and special issues of journals (for example, *Advances in Nursing Science*, *Seminars in Oncology Nursing*, and *Progress in Cardiovascular Nursing*); establishing pre- and post-doctoral training programs in HRQL; and offering awards for research excellence (Padilla et al.).

Quality of life has already become a major concern in planning, implementing, and evaluating health-care and social policies (see, for example, Spilker, 1990; Ontario's Health Plan in Ontario Ministry of Health, 1993; strategies for cancer care in Ontario Ministry of Health, 1994, and Ortho Biotech, 1993). As the next millennium approaches, decisions concerning quantity versus quality of life will become even more difficult and more prevalent, especially in view of the debt crises facing all levels of government. "Health is generally considered one of the most important determinants of overall quality of life which underscores the relevance of using quality of life as an ultimate outcome of health care" (McDowell & Newell, 1987, p. 205).

For the purposes of outcome measurement in nursing research, a number of practical questions arise: How can HRQL be defined in order to be helpful as a nursing research outcome? How can it best be measured? What are the key considerations in selecting an HRQL instrument?

Definition

The meaning of quality of life is a matter of much debate – even controversy. As yet, there is no agreed upon definition to guide health care and research (Ferrans & Powers, 1985; Gill & Feinstein, 1994; Kinney et al., 1996; McDowell & Newell, 1987; Padilla & Grant, 1985; Schipper, Clinch, & Powell, 1990; Spitzer, 1987). As one researcher bluntly states it, "Quality of life remains more a fashionable idea than a rigorously defined concept in the health sciences" (McDowell & Newell, p. 227).

The debate seems to have divided sociologists and some health researchers into two camps: those who support a broad concept of quality of life (Bergner, 1985; Campbell et al., 1976; Gill & Feinstein, 1994; McDowell & Newell, 1987; Strauss, 1984) and those who take a more pragmatic view, believing the parts can be reduced for purposes related to health-outcome measurement (Aaronson, 1988; Guyatt & Cook, 1994; Jenkins et al., 1990; Stewart & Ware, 1992; Ware, 1984). In the literature, terms such as health status, functional status, well-being, and life satisfaction are sometimes used interchangeably with "quality of life" (Spitzer, 1987), in other instances as components of an overall concept of quality of life.

There is general agreement on several theoretical aspects of quality of life. It is widely acknowledged to be a multidimensional concept (Ferrans & Powers, 1985; Jenkins et al., 1990; McDowell & Newell, 1987; Schipper et al., 1990; Spilker, Molinek, Johnston, Simpson, & Tilson, 1990; Ware, 1984; WHOQOL Group, 1993). Similar domains of quality of life have been identified by various researchers, and there is an emerging consensus toward the acceptance of four broadly identified domains: physical functional status, symptoms and side effects, social functioning, and psychological state (Aaronson, 1988; Schipper et al.). Examples of definitions and domains are found in Table 1. It is agreed that quality of life is a subjective, patient-perceived phenomenon (Gill & Feinstein, 1994; Guyatt, Feeney, & Patrick, 1993; Juniper, Guyatt, Willan, & Griffith, 1994; McDowell & Newell; Oleson, 1990; Strauss, 1984; Ware, 1984) that can change within the same individual over time (Guyatt, Deyo, Charleson, Levine, & Mitchell, 1989; Juniper et al., 1994; Juniper, Guyatt, & Jaeschke, 1990; Schipper et al.). The conceptualization of quality of life has progressed from a nebulous term about subjective feelings to an accepted concept – albeit, in terms of measurement, an evolving one.

Toward Conceptual and Operational Clarity

The challenge for nurse researchers in using quality of life as a primary or secondary outcome will be to achieve conceptual and operational clarity. The qualification of HRQL would facilitate nurses planning to use quality of life as an outcome when evaluating nursing interventions. Conceptually this approach represents a separation of what quality of life *is* from what *contributes to* quality of life (Stewart, 1992). In clinical or research situations, health, for the purposes of outcome measurement, can be viewed as contributing to overall quality of life, and health care as contributing in some way to the person's health. An operational definition of quality of life should stem from a definition of health, and this definition of health should be in philosophical accord with the ethic, standards, and mission of the profession or discipline.

Table 1 *Selected Themes of Quality of Life*

Source	Quality-of-Life Definitions	Domains
Ferrans & Powers (1985, p. 17)	A person's sense of well-being stemming from satisfaction or dissatisfaction with the areas of life that are important to him/her	1. Health and functioning 2. Socio-economic 3. Psychological 4. Family
Gill & Feinstein (1994, p. 619)	Personal perception of health status and/or non-medical aspects of one's life	1. Health-related factors – important clinically – important to patient 2. Non-medical aspects
Guyatt & Jaeschke (1990, p. 37)	The wide variety of subjective experiences related to health	1. Symptoms 2. Physical function 3. Emotional function
Schipper et al. (1990, p.16)	The functional effect of an illness, and its consequent therapy, upon a patient, as perceived by the patient	1. Physical and occupational function 2. Psychological state 3. Social interaction 4. Somatic sensation

(cont'd)

Table 1 (cont'd) *Selected Themes of Quality of Life*

Source	Quality-of-Life Definitions	Domains
Ware (1984); Ware & Shelbourne (1992)	Personal health status and factors such as family life, finances, housing	1. Physical functioning 2. Role functioning – physical 3. Bodily pain 4. General health 5. Vitality 6. Social functioning 7. Role functioning – emotional 8. Mental health 9. Reported health transition
WHOQOL Group (1993, p. 153)	An individual's perception of life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and relationship to salient features of their environment.	1. Physical health (bodily states and functions) 2. Psychological health 3. Level of independence 4. Social relationships 5. Environment

A modification of the broad World Health Organization (WHO) definition, "Health is a resource which permits individuals to achieve their aspirations and cope with or change their environment" (WHO, 1986; personal communication, A.S. Macpherson, McMaster University, Sept. 9, 1996), may be how many nurses would define quality of life. From such a position, one can address the contribution that health-care and nursing interventions might make toward achieving a state of health. A definition of HRQL could then be drawn: a person's "perception of their health status and aspects of their life considered important in relation to their expectations of 'normal' living" (Harrison, 1996). This definition encompasses the notions of a subjective evaluation of one's life against what is normal; an acknowledgement of expectations against natural capacity; and meeting personal goals by narrowing the gap between one's expectations and one's achievements (known as Calman's gap – Calman, 1984). It is recognized that health care and health professionals are limited in what they can change or affect. For the purpose of outcome measurement, the operational definition is more restrictive and situationally specific (Waltz, Strickland, & Lenz, 1991). In the case of HRQL this relates to the domains important to the study population and the health intervention under investigation.

Measurement

Types of HRQL Instrument

There are two types of HRQL instrument, generic and specific. Generic instruments provide a summary of health status, functional status, and/or general quality of life. Specific instruments focus on problems associated with single disease states, patient groups, or areas of function (Guyatt et al., 1993; Guyatt, VanZanten, Feeney, & Patrick, 1989). Generic instruments assess a spectrum of quality-of-life components or domains and are applicable to a variety of populations. Specific measures concentrate on particular conditions or populations. A growing number of researchers have found it necessary to develop specific instruments because the generic measures fail to capture the specific quality-of-life issues associated with the condition of interest – for example, inflammatory bowel disease (Guyatt, Mitchell, et al., 1989) or asthma (Juniper, Guyatt, Ferrie, & Griffith, 1993; Marks, Dunn, & Woolcock, 1992). Additionally, instruments may need to be generated to be developmentally appropriate and specific to a condition – for instance, asthma in children (Juniper et al., 1996).

Another approach is to modify generic instruments for use with particular populations, as Ferrans and colleagues did to create cardiac and cancer versions of their quality-of-life index (Bliley & Ferrans, 1993; Ferrans, 1990; Ferrans & Powers, 1985). However, this approach should be used only with the collaboration of the original developer and with a good understanding of the psychometric issues.

Guyatt and colleagues developed a taxonomy for HRQL measures and evaluated the strengths and weaknesses of each (Guyatt, VanZanten, et al., 1989). A number of authors have systematically catalogued generic and specific quality-of-life measures (Gill & Feinstein, 1994; McDowell & Newell, 1987; Spilker et al., 1990).

Generic measures. These questionnaires are designed for use with patients with any medical condition. Probably the most commonly used and the best validated are the Medical Outcomes Study Short Form 36 (SF-36) (Stewart, Hays, & Ware, 1988; Ware & Shelbourne, 1992), the Sickness Impact Profile (SIP) (Bergner, Bobbitt, Carter, & Gilson, 1981), the Nottingham Health Profile (Hunt et al., 1980), and the McMaster Health Index Questionnaire (Sackett, Chambers, MacPherson, Goldsmith, & McAuley, 1977). Although each health profile is designed to measure all important aspects of HRQL, each does so in a different way. For instance, the SF-36 comprises 36 questions aggregated into two major health attributes (physical health and mental health). In contrast, the 136-question SIP has two domains (physical and psychosocial), which can be combined into one overall score.

The main advantage of generic instruments is that the burden of illness can be compared across medical conditions. However, because they need to be broadly comprehensive to cover all conditions and diseases, they may fail to measure the specific and important impairments associated with any one condition. For instance, the SIP tends to focus on severe impairments (feeding, dressing, etc.) that may not apply to patients with less debilitating illnesses. In addition, there is growing evidence that generic measures may not be responsive to small but important changes when used to assess the effect of an intervention (Hawker, Melfi, Paul, Green, & Bombardier, 1995; Rutten van Molken et al., 1995).

Specific measures. The recognition that generic instruments are often insufficiently responsive to changes or differences in HRQL that are important to individuals has led to the development of specific instruments, for both adults and children. The strength of specific instruments is that they focus on the areas of function that are most important to patients. Their weakness is that the degree of impairment cannot be compared across conditions.

Evaluating the Quality of HRQL Measures

The essential properties of reliability and validity in a high-quality HRQL instrument are well agreed upon (Feinstein, 1987; Fitzpatrick et al., 1992; Fletcher, Gore, & Jones, 1992; Guyatt, VanZanten, et al., 1989; McDowell & Newell, 1987; Ware, 1987). Reliability is the ability of the instrument to consistently provide similar results when used on the same population in similar circumstances. Validity is its ability to accurately measure what it is intended to measure. McDowell and Newell offer detailed methods for generally assessing these key attributes, including the appropriate statistical tests and a rating framework (p. 8). Particular attention must be paid to certain attributes with HRQL instruments, depending on their purpose. A discriminative measure must be reliable and have cross-sectional construct validity. An evaluative instrument must be responsive and have longitudinal validity.

Face and content validity. When selecting an instrument, the researcher must first ensure that it has face and content validity; that is to say, that the instrument appears to measure what it is intended to measure and that the items in a questionnaire have been selected using recognized procedures so that all the areas of function considered important by patients will be captured. Unlike other outcome measures, HRQL questionnaires – particularly specific measures in which items have been selected by clinicians – rarely meet this criterion, because some impairments that patients consider important have been omitted.

In order to address clinically important issues of face and content validity, Feinstein (1987) suggests "sensibility" criteria for the questionnaire: applicability, clarity and simplicity, comprehensiveness, unlikelihood of bias, and elimination of redundant items. Feinstein argues that a sensibility screen judges instruments, rather than mathematically testing them. This would be in addition to empirical appraisals carried out in the selection of HRQL instruments.

Once content validity has been established, the measurement properties are examined to ensure that the instrument is capable of carrying out the intended task. Instruments that are to be used in cross-sectional studies (e.g., surveys) require different measurement properties from those to be used in longitudinal studies (e.g., clinical trials) (Guyatt, Kirshner, & Jaeschke, 1992).

Discriminative Instruments

These instruments are used to distinguish among individuals or among groups of patients – for example, among individuals who do or do not have a chronic condition such as congestive heart failure (CHF), or, within a CHF population, among those who have mild, moderate, or severe impairment. Discriminative instruments are most commonly used in screening and in cross-sectional surveys. Their essential measurement properties are reliability and cross-sectional construct validity (Guyatt et al., 1992).

Reliability. The signal-to-noise ratio is a simple method of deciding which measurement properties will be required in a particular situation. The "signal" is the true difference or change that is to be measured, and the "noise" is the variance, unrelated to the true signal, that will interfere with the detection of the signal. Discriminative instruments must be able to detect differences among individuals or among groups of patients. Therefore, the signal is the between-subject difference at one point in time. The noise that will tend to mask this signal is the within-subject variance. The test statistic usually used to express the relationship between the signal and the noise for discriminative instruments is the intraclass correlation coefficient (ICC), which relates the between-subject variance to the total variance (Cronbach's alpha, which measures the internal consistency, does not give an indication of this property).

Cross-sectional construct validity. Where there is no gold standard against which to determine whether the instrument is actually measuring what it is intended to measure, the developer puts forward hypotheses or constructs, which, if met, provide evidence that the instrument is valid. The most common approach is to demonstrate that the various domains of the new HRQL instrument correlate in a predicted manner with other indices of severity and with other HRQL instruments (see Table 2).

Table 2

Measurement Properties Necessary for Evaluative and Discriminative Instruments

	Discrimination	**Evaluation**
Signal	Between-subject differences	Within-subject differences related to true within-subject change
Noise	Within-subject differences	Within-subject differences unrelated to true within-subject change
Signal-to-noise ratio: descriptive term	Reliability	Responsiveness
Construct validity	Cross-sectional	Longitudinal

Source: Assessment of asthma control: Quality of life. In N.C. Thomson & P.M. O'Bryne, *Manual of asthma control*. London: W.B. Saunders, 1995.

Evaluative Instruments

These instruments are required to measure longitudinal change in an individual or within a group of patients and are often used in clinical trials. The essential measurement properties of evaluative instruments are responsiveness and longitudinal validity (Guyatt et al., 1992).

Responsiveness. Evaluative instruments must be responsive to small but clinically important changes that occur either spontaneously or as the result of an intervention. The signal is the true within-subject change over time, and the noise is the within-subject variance unrelated to the true within-subject change. The relationship between the two represents the responsiveness of the instrument (Guyatt, Walter, & Norman, 1987).

Longitudinal construct validity. Evaluative instruments also require longitudinal validity. Any change in score must reflect a true change in HRQL. Longitudinal validity is usually demonstrated by showing that changes in the various domains of the new HRQL instrument correlate in a predicted manner with changes in other outcome measures, such as disease severity and generic HRQL.

Interpretability

An additional requirement, "interpretability" (Juniper et al., 1994; Juniper et al., 1990; Juniper, Guyatt, & Griffith, 1993), deals with interpreting the clinical importance of a change in a quality-of-life score and the smallest difference in a score that patients would perceive as important. Repeated experience with a wide variety of physiological measures allows clinicians to interpret results meaningfully. For instance, the experienced clinician will have little difficulty interpreting a blood pressure change of 20 mmHg or an increase in respiratory rate of 20 breaths per minute. In contrast, the meaning of a change in score of 1.0 on an HRQL instrument is not obvious, not only because there are no units, but also because health professionals seldom use HRQL measures in clinical practice and each instrument has its own scoring system.

Two approaches have been suggested for interpreting HRQL data (Lydick & Epstein, 1993). The "distribution-based" approach is based entirely on the statistical distribution of the results, the most commonly used being the effect size, which is derived from the magnitude of the change and the variability in stable subjects. The disadvantage of this approach is that there is still no indication of whether the effect is important to the patient. In the "anchor-based" approach, the changes in quality-of-life measures are compared, or anchored, to other clinically meaningful outcomes. A minimal important difference (MID) is defined as "the smallest difference in score in the domain of interest which patients perceive as beneficial and would mandate, in the absence of troublesome side-effects or excessive cost, a change in the patient's management" (Juniper et al., 1994). One method of determining the MID is global rating of changes. Briefly: on a global rating of change questionnaire, a person with asthma, for example, is asked whether he or she has experienced change in HRQL since the last visit. To obtain the MID, the researcher calculates the change in HRQL score that corresponds to the smallest global change that patients consider important. On the St. George's Respiratory Questionnaire the MID was determined by asking patients, at the end of a clinical trial, whether they felt the treatment was effective (Jones & Lasserson, 1994).

Feasibility

Feasibility of the instrument concerns the practical factors that arise in administering the tool and, given the subjective nature of HRQL, are highly consequential in the selection of a quality-of-life instrument. Consideration should be given to the means of administration. Paper-and-pen self-report instruments may be a challenge for older, sight-impaired people. Telephone interviews are difficult for hearing-impaired subjects. Administration of questionnaires by trained interviewers is resource-intensive and therefore costly, but ensures compliance and minimizes errors and the number of missing items (Guyatt et al., 1993). Long surveys or batteries of instruments impose additional risk to recruitment and retention of subjects. Instruments that have been used successfully elsewhere may challenge particularly complex medical populations. A pilot test on the study population is advisable, even with established instruments. Poor instrument feasibility is costly and will endanger successful completion of the study.

On a practical note, many adequately developed and tested instruments (for example, Ware's SF-36 instrument and Ferrans's Quality of Life Index) come with a manual to guide administration, data entry, and analysis, providing detail that is not possible in the published accounts of the measurement. The researcher should ask the developer for full documentation.

When a patient is unable to participate, a surrogate respondent, usually the family member closest to the patient, may be asked to complete the questionnaire on behalf of the patient. Comparison of responses provided by patients and provided by close relatives has shown a correlation of 0.55 between the two sets of responses and a difference greater than 6 on a 100-point scale for 50% of the patients (McCusker & Stoddard, 1984). A relative may not be able to discern the individual's response accurately; therefore, surrogate responses must be interpreted with care. Other research with children has shown that a parent can have a very poor perception of the child's HRQL (Guyatt, Juniper, Feeney, & Griffith, in press).

The Choice: Generic, Specific, or Both Types of HRQL Measure

The choice of a generic or a specific quality-of-life instrument, or both, depends on the question under study. Use of both types is warranted in the following circumstances: to measure the effect of an intervention (specific) *and* the evaluated actual burden of illness experienced by individuals (generic); and to measure the effect of an intervention (specific) when there is uncertainty whether the specific instrument will capture all areas of interest *or* when the specific instrument is fairly new and the measurement properties are not well established. A well-established generic instrument may have poor responsiveness yet still be preferable to a specific measure that proves to have inadequate measurement properties.

Table 3 *Comparison of Use of Generic, Specific, and Multiple HRQP Instruments*

Instruments	Strengths	Limitations
Generic Summary of HRQL (Guyatt, VanZanten, et al., 1989) Capture important differences in health in any adult population (Ware, 1987)	Global/comprehensive: full range of domains relevant to quality of life Applicable to wide variety of populations Comparability, generalizability Established reliability and validity Total and subscale score measures available Single instrument, improves feasibility Short-form versions improve feasibility	May not focus adequately on area of interest May not be responsive Overuse within certain populations Many indices are long, posing feasibility problems
Specific Focus on problems associated with single disease states, patient groups or areas of function (Guyatt, VanZanten, et al., 1989)	Unidimensional: focus on aspects of primary interest – function, age, condition, disease Increased responsiveness Clinically sensible Single instrument, improves feasibility	Application limited No comparability possible across conditions Less established validity and reliability
Multiple Capture information on global and specific aspects for quality of life or multiple specific aspects Greater proportion of conceptual domain of quality of life will be tapped (Jalowiec, 1990)	Triangulation of measurement approaches Enhanced conceptualization of domains Comparability across studies and populations Improved specificity and sensitivity to QL data High responsiveness and reliability	Multiple tools, more variable, larger sample Questionable practicality/feasibility Potential for missing data Difficulty interpreting relationships between variables Redundancy Mixed strengths with reliability and validity

Source: Guyatt et al., 1993; Guyatt & Jaeshke, 1990; Guyatt, VanZanten, et al., 1989; Jalowiec, 1990; Juniper et al., 1990; Ware, 1987.

Some disadvantages of using both a generic and a specific measure are lack of practicality and feasibility; poor reliability of multiple forms due to incomplete or missing data; redundancy or non-comprehension; increased need for sophisticated statistical expertise in interpreting multivariate statistics; and difficulty interpreting complex relationships or contradictory results. The strengths and limitations of the generic, specific, and multiple-instrument approaches are summarized in Table 3.

If both a generic and a specific measure of HRQL are used, the investigator should declare a priori which measure is the primary outcome and what degree of change will be considered a clinically important difference.

Development of New HRQL Measures

The development of any new instrument is a science in itself. The development of an HRQL instrument takes a number of particular steps: identification of all possible suitable items; reduction of this list to the most frequently applicable and most important items; formulation of these items into specific questions or statements; pretesting of the instrument for clarity and completion time; and testing of the instrument for its psychometric properties, including reliability, validity, and responsiveness. While published resources for instrument development may provide guidance (Guyatt et al., 1992; Juniper et al., 1990), the researcher is advised to link up with an expert in measurement development.

Summary

There continues to be debate about the definition and dimensions of quality of life, but there is general agreement that it is a subjective phenomenon that changes over time. With respect to its measurement, significant progress has been made over the past two decades in its acceptance and use in clinical trials as an important outcome measure, and in the development of explicit guidelines for the selection and development of quality-of-life instruments. The decision framework in selecting an instrument is a stepwise one: determining the purpose of the instrument (evaluative or discriminative), identifying the type of instrument (generic or specific), and assessing the instrument's measurement properties and feasibility.

Nursing is by its nature supportive and focused on the human response to a health state. The anticipated outcomes of nursing interventions often relate to elements of quality of life. Because of nursing's broad scope, its evaluation requires the frequent use of quality-of-life measurements. The concept of quality of life as an outcome for nursing studies has been examined from two broad viewpoints: conceptual advancement and measurement progress. HRQL and its components of well-being, adjustment, and functional capacities offer promise as appropriate and sensitive outcomes for evaluating nursing interventions.

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