

THE CONCEPTUAL AND OPERATIONAL DEFINITION OF QUALITY OF LIFE:

A SYSTEMATIC REVIEW OF THE LITERATURE

A Thesis

by

MARVEL CLARK CHURCH

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

August 2004

Major Subject: Health Education

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ABSTRACT

The Conceptual and Operational Definition of Quality of Life:

A Systematic Review of the Literature. (August 2004)

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Quality of life (QOL) has been chosen as an outcome measure by various agencies of the United States federal government and has been employed to an increasing extent by healthcare researchers when evaluating various courses of treatment or health promotion interventions. In light of the increasing ubiquitousness of QOL, one can conclude there exists a commonly employed and accepted conceptual understanding of its meaning. A systematic review of the literature focusing on quality of life published between January 1990 and January 2004 was conducted in an effort to discover this definition. Based on inclusion and exclusion criteria outlined in the study, a population of 503 articles was identified for potential inclusion. From this population a random sample of 50 articles was selected for further review, with an emphasis placed on the conceptual and operational definitions of quality of life employed in the various studies. Twenty of the articles contained some conceptual discussion of quality of life and 38 contained some operational discussion. Although many articles contained some discussion of the term, little agreement with regard to its meaning and measurement was found. The only acknowledged fact in the majority of the articles concerns the subjective, multi-faceted nature of quality of life and its inherent measurement

difficulties. As a result of this work, and because of this lack of cohesion in the understanding of the conceptual issues involved, the following conceptual definition has been proposed. Quality of life is a measure of an individual's ability to function physically, emotionally and socially within his/her environment at a level consistent with his/her own expectations.

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INTRODUCTION AND BACKGROUND

The “primary objective of any health care intervention is the enhancement of quality of life and well-being.”¹ If this is true, the first question one must ask is, simply, what is quality of life? With quality of life as the outcome measure, it is important for a researcher or allied health care provider to be able to conceptualize and operationalize the term quality of life. Conceptually, what is the meaning of this term? Varying schools of thought exist as to its understanding. Is it defined in the context of disability prevention or preservation of functional capacity as it was in *Healthy People 2000*,^{2,3} or is it a broader concept involving domains such as position in life, environmental and spiritual well-being, and a general sense of happiness and satisfaction?^{4,5} Does the concept rest solely in the domain of patient perception,^{6,7} or is it something more objective? Other considerations include the extent to which factors such as locus of control, societal values and personal expectations contribute when determining the quality of a person’s life?^{4,7} Instead of one all encompassing view, should conceptual thinking concerning quality of life be limited in scope by specific diseases, disabilities or population groups⁸?

Measurement of this concept raises many interesting questions. How can you effectively and reliably measure a person’s satisfaction? How do you standardize findings in order to compare samples? Is quality of life something to be measured through a macro approach—comparison of different societies—trying to quantify how

This thesis follows the style and format of *Quality of Life Research*.

someone would ideally function within a society, or does it require a micro approach utilizing an intense look one's attainment versus one's expectation? Spilker and his colleagues in the second edition of their book *Quality of Life and Pharmacoeconomics in Clinical Trials*⁹ cataloged more than 200 separate instruments that were currently available to assess quality of life as it related to a multitude of specific diseases, disabilities or disorders. With this number of instruments measuring countless constructs specific to a multitude of conditions, the questions become, "does any common ground exist?", and if so, "to what extent can this common ground be explored to reach a shared understanding of the definition of quality of life?"

PURPOSE

The purpose of this thesis was to systematically review the conceptual and operational definitions of the term quality of life in studies published between January, 1990 and January, 2004. The goal of the work was to propose a shared conceptual definition of quality of life, to examine current operational definitions, and to provide some direction for future work.

This study examined how the term is defined by the researchers in different fields of study such as public health, medicine, social science, and urban studies. Specific areas of interest that were examined when looking for differences in the conceptual or operational use of the term included date of publication and academic appointment of the lead authors.

METHODS

Systematic Literature Reviews

A systematic literature review is an organized search through literature in an effort to answer a focused question with inclusion and exclusion criteria for research papers defined *a priori* and data extracted and analyzed in a consistent manner.^{10,11,12,13} The importance of systematic reviews can be summed up in their ability to analyze previous research and further disseminate research findings.¹¹ The reviews provide an opportunity to capture and consolidate published research concerning a focused question or topic.

Sampling

A two step process was employed when selecting articles for inclusion in this review. First, the journal of publication was required to meet specific criteria for inclusion. Inclusion criteria for journals were as follows:

- Must be listed in the Institute for Scientific Information – Web of Knowledge Database 2002 Journal Citation Report in any of the following categories
 - Education & Educational Research
 - Family Studies
 - Gerontology
 - Health Policy & Services
 - Nursing
 - Social Psychology

- Public, Environmental & Occupational Health
- Social Sciences, Biomedical
- Sociology
- Urban Studies
- Women's Studies
- Must have an impact factor of 1.0 or greater.

The impact factor is a calculation performed by Thompson ISI.¹⁴ A full description of the calculation of the impact factor is available online from the Thompson ISI. The choice of 1.0 as the threshold for inclusion is one of simple convenience in an effort to be somewhat exclusionary but still result in a large population from which to draw the review sample.

Journals were excluded for the following reasons:

- Publication not in English, and
- Journal not available in some form through the Texas A&M University Library System.

One exception was made to these criteria. The journal *Quality of Life Research*, which does not meet the impact factor criteria in the 2002 Journal Citation Report¹⁴, was included due to its focus on relevant content. The selection of categories from which the journals were taken is supported by statements from the Centers for Disease Control and Prevention in their report, *Measuring Healthy Days: Population Assessment of Health-related Quality of Life*.¹⁵

A list of 87 journals having an impact factor of 1.0 or greater resulted from a review of the 11 identified subject areas.¹⁴ After reviewing TAMU Library System holdings and the removal of 1 publication not in English, a final list of 66 journals was available for review. TAMU System library holdings had limited access to some of the qualifying journals. As a result, only those time periods in which library holdings were available were included in the review.

Once study inclusion criteria were met for journal inclusion, selection of articles proceeded. To be considered for review an article:

- Must have included either of the following terms in either the title or keyword list,
 - Quality of Life or its abbreviation QOL,
 - Health-related Quality of Life or its abbreviation HRQOL
- Must have been published between January 1990 through January 2004,
- Must have been a research study, not an opinion piece or editorial.

The publication dates selected are important to note. On September 6, 1990, the United States Department of Health and Human Services published *Healthy People 2000*.² Included in the publication was the thematic focus improvement of the “quality of life“ for all Americans.¹⁶ This marks the first time quality of life was identified by the federal government as a goal for the nation.

Article selection proceeded, first by searching the electronic archives of the available journals. When an electronic archive was not available, the table of contents was scanned visually. If an article met the first two inclusion criteria, a full-text copy

was obtained. This resulted in a compilation of 738 qualifying articles. After removal of book reviews, editorials and opinion pieces 503 articles remained. A discrete identification number was assigned to each resulting article. A sample of 50 articles was randomly selected through the use of the random number generator packaged within Microsoft Excel. The resulting sample of 50 articles (see Appendix A) was then reviewed using the attached data extraction form. The number 50 was chosen for manageability and in an effort to achieve a sample representative of the published literature meeting the required criteria.

Data Analysis

From the articles selected for inclusion, information was recorded systematically in a data extraction form developed for this review. A copy is attached in Appendix B. Specific information that was noted for each article included the definition/conceptualization of the term quality of life as well as any information regarding the inclusion/exclusion of constructs used to measure quality of life, date of publication, underlying theories guiding development of the study instrument (if present), academic appointment of the lead author(s), content focus of the journal publishing the material, and a brief description of the study's sample. Analysis of the data was carried out with a review of the definitions found and measurement constructs employed with frequencies reported for each.

A content analysis of the definition from the qualifying articles was conducted with the goal of arriving at some understanding of how quality of life was conceptually and operationally defined conceptualized by the researcher.

RESULTS

Conceptual Definition

A conceptual definition is a definition outlining the basic principals underlying a term. For the purposes of this review, a conceptual definition was defined as some explanation of the author's intended meaning through the use of quality of life, or some abstract discussion of how one might measure quality of life. Twenty articles in the sample stated some form of a conceptual description or understanding of quality of life.

The following are some of the definitions found during the course of this review that, in whole or in part, represent the important constructs included by the remaining 17 articles.

- An individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns; ^{17, 4}
- Patient's subjective satisfaction with one's life; ¹⁸
- The presence of poverty, malnutrition, isolation, neglect, lack of health care services. ¹⁹

The first definition is the definition developed by the World Health Organization (WHO) to comply with the WHO definition of health as being more than just the absence of disease.⁴ All of the identified conceptual definitions include domains beyond those of absence of disease.

Fifteen of the conceptual discussions found included domains relying heavily on the patient's satisfaction and happiness with either their life as a whole, or specific domains of their life. The idea of satisfaction or patient perception of life quality is included by the authors in their conceptual definitions to highlight the generally accepted importance of items other than health status that are viewed as integral to the idea of quality of life.^{17, 18, 20}

The final definition represents domains outside of health status or patient satisfaction that also contribute to the quality of one's life.¹⁹ Socio-economic status, education level, employment status, marital status and living conditions were factors also cited when conceptual discussions of quality of life are reviewed.

It is important to note the relative homogeneity of the definitions found. The idea of a highly subjective measure of health status and/or patient perceptions was constant across the time frame and varied subject areas examined with only a few exceptions.

Operational Definition

An operational definition outlines a metric for quantifying something of interest. For the purposes of this review, an operational definition is one that denotes specific domains measured in the qualifying articles. Thirty-nine of the articles in the sample articulated some operational definition of quality of life, often simply by citing the instrument to be employed in the study. Of those, 37 used some published instrument in the measurement of the construct. When possible, the instrument employed in the study also was consulted to better understand the domains measured, their associated

definitions and their relevance to the topic. Table 1 lists the instruments or techniques employed in the reviewed studies along with the frequency with which they were employed.

The SF-36 was, by a large margin, the most frequently employed questionnaire in this sample. The SF-36, developed by Stewart and Ware²¹, “as a short form standardized questionnaire to assess health status and quality of life and allow comparison of the data by satisfying minimum psychometric standards necessary for group comparisons”. The SF-36 grew from standard measures of health status, and was developed by inclusion of the 8 most frequently included health concepts selected from the Medical Outcomes Survey: physical functioning, role limitation due to physical functioning, bodily pain, general health, vitality, social functioning, role limitation due to emotional functioning, & mental health.²¹

Once the domains of all cited instruments were reviewed, along with their associated definitions, categories were constructed to group as many similar domains together and to consolidate the varied vocabulary employed by the multitude of researchers. Table 2 lists the resulting categories and the frequency with which a domain belonging to that category was employed when quantifying quality of life within this sample.

Table 1. Quality of life instruments employed in reviewed studies.

Quality of Life Instruments	
Instrument	# of Occurrences
Asthma Quality of Life Questionnaire	1
Cancer Quality Of Life – Cystic Fibrosis	1
Dementia Care Mapping	1
Dementia Quality of Life Scale	1
FACIT	2
Functional Independence Measure	1
General Social Survey	1
German KINDL	1
Lancashire Quality of Life Profile	1
McGill QOL Questionnaire	1
MOS-HIV	3
MUDI & MUSIQ	1
QLQ-C30	2
QOL-CS	1
QOLRAD	1
Quality of Life Index	2
SF-36	10
Spitzer Uniscale Quality of Life Index	1
WHOQOL-100 & WHOQOL-BREF	1
WHOQOL-HIV	3
Wisconsin Quality of Life Index - Canadian Version	1

Table 2. Factors included in operational definitions of reviewed articles.

Quality of Life Factors	
Factors Identified	# of Occurrences
Social Functioning/ Social Support	30
Physical Functioning/Capacity	29
Psychological / Mental Health	21
Role Functioning / Independence	21
General Health/ Health Status	19
Vitality / Fatigue / Energy	17
Emotional Functioning / Distress	15
Bodily pain	15
Neurologic / Cognitive Functioning	10
Spirituality / Existential Beliefs	9
Life Satisfaction & Happiness	7
Self Assessed QOL	7

Inclusion in the above categories was rather straight forward and was based in large part on similar vocabularies used to describe the associated domains or similar constructs measured within the associated domains.

CONCLUSION

Quality of life is recognized, throughout the sample reviewed for this thesis, as a highly subjective measure without a clearly articulated definition, either conceptual or operational. Many of the reviewed works make mention of this fact when discussing the problems associated with measurement,^{17, 18, 22, 23, 24, 20, 25, 26, 27, 28, 29, 30, 31, 32, 33} yet all still portend to quantify the construct.

The discussions regarding the definitions, both conceptual and operational, center on two underlying pillars: health status measurement and health utility measurement.³⁴ Health Status is defined as the measure of one's health through objective, quantifiable measures; health utility is defined as a "subjective preference a person assigns to his or her health state."³⁴ The large majority of quality of life measures in this sample rely primarily on health status measurement, often with the inclusion of a token item to assess health utility. Health utility is most often captured by asking individuals to rate their global quality of life on some numerical scale. Other measures employed operate solely in the realm of health utility measurement. With the conceptual definitions most often employed including aspects of both health status and health utility and the operational metrics often employed not fully quantifying both broad conceptual themes outlined by the authors, significant room for improvement exists.

As a result of this thesis, it can be said quality of life is an important concept to consider when evaluating efficacy of health promotion programs. The satisfaction and subjectively self-identified changes in the participants quality of life merits capture of the information and discussion. However, change in quality of life should not be the

ultimate outcome measure when evaluating health promotion programs at this time. Lack of a clearly articulated, and generally accepted, conceptual definition currently precludes the development of a widely used, easily employable, and adequately validated operational metric to allow for comparison of data.

This is not to say that once a definition is agreed upon, all problems will be addressed. Jansen et al²⁷ cite a significant problem with using the patient to subjectively evaluate the quality of their life, response shift. Response shift “refers to the change—as the result of an event such as therapy—in the meaning of one’s self-evaluation of quality of life.”²⁷ Citing response shift as a problem associated with the measure of quality of life is not to say the quality of one’s life must be static; in fact, one hopes quality of life is improved with therapy or other interventions. The problem is a lack of sensitivity to what caused the change and the shifting internal standard by which quality of life is judged. Until problems such as these can be better understood and characterized, it would be unwise to place too much stock in the outcome of these measures.

When attempting to objectively measure health status, another set of problems exists: how to determine which domains warrant inclusion in quantifying the quality of an individual’s life? Many instruments have been developed over the years to perform this assessment. The SF-36, for example, was developed by simply extracting the 8 most frequently used health outcomes from the Medical Outcomes Survey.²¹ Other instruments have been developed by examining, through multiple regression or factor analysis, the relationships that exist between objective measures, and an individual’s

perception of his/her quality of life, defined independently and subjectively by each respondent.^{35, 23, 36, 26, 17, 33}

Proposed Conceptual Definition of Quality of Life

As a result of this work, one can see the clear need for a shared conceptual understanding of quality of life in order to focus future research. The following proposed definition is a starting point in the development of that conceptual definition:

Quality of life is a measure of an individual's ability to function physically, emotionally and socially within his/her environment at a level consistent with his/her own expectations.

Functioning and role fulfillment are part of the SF-36 instrument and have been shown to be associated with patient's self-assessment of quality of life.^{37, 38, 27, 30, 39, 40, 41,}

^{25, 21, 29, 33} Physical functioning should include, at a minimum, an individual's disease status, independence and ability to fulfill his/her expected physical role in life.

Emotional functioning should include, at a minimum, an individual's mental health status, cognitive ability and ability to fulfill his/her expected emotional role in life.

Social functioning should include, at minimum, an individual's available social support and ability to fulfill his/her expected social role in life.

Environmental factors can also contribute to an individual's perception of his/her quality of life.^{4, 42, 17} Environmental factors include anything affecting an individual's construction of reality and the surroundings in which he/she lives. Some examples of domains to be considered for inclusion are one's culture, physical safety, work status, financial resources, housing and availability of necessary health and social services.

Many of the conceptual definitions from the reviewed sample fail to discuss all of the domains included in the proposed definition. Figure 1 is a collection of the conceptual definitions from the review along with the proposed definition. Also included in Figure 1 is a comparison of the domains included in all of the definitions. The proposed definition is the only definition to take into account the domains of physical, emotional and social functioning and coupling them with environmental factors while framing the discussion in terms of personal expectation and satisfaction. From this review of the literature, these are the minimum necessary domains for understanding quality of life. The definition proposed is the first to include reference to both of the necessary constructs affecting quality of life, health status and health utility.

Figure 1. Comparison of conceptual definitions of quality of life found in the reviewed sample and the domains included in the proposed definition.

Study Authors	Conceptual Definitions of Quality of Life	Physical Functioning	Emotional Functioning	Social Functioning	Environmental Factors	Individual Perception
Boling, Macrina & Clancy 2003	Subjective paradigm comprised of social/family, emotional, physical and functional domains	X	X	X		
Brady, Peterman, Fitchett & Cella 1999	Subjective multi-dimensional construct, dimensions usually considered to be core include physical, emotional, social, and functional well-being	X	X	X		
Frick et al 2004	The difference or gap between the current hopes and expectation of the individual and that individual's present experiences					X
Hunter & Arbona 1995	Reduced QOL exists in "the presence of poverty, malnutrition, isolation, neglect, lack of health care services"				X	
Jenkins, Bono, Stanton & Stroup-Benham 1990	Denotes a wide range of capabilities, limitations, symptoms, and psycho-social characteristics that describe and individual's ability to function and derive satisfaction from a variety of roles	X	X			X
Kimmmer et al 1997	A person's satisfaction with various life domains					X
Kulich, Wiklund & Junghard 2003	Patient's subjective perceptions of ...symptoms of pain or discomfort impacting everyday life	X				

Figure 1 continued		Physical Functioning	Emotional Functioning	Social Functioning	Environmental Factors	Individual Perception
Lam, Phong, Lauder & Lam 2002	Patient perceived global health					X
Lamb, 1996	Conceptual Definitions of Quality of Life QOL is composed of mediating factors associated with total well being					X
Lin et al 2002	A multi-dimensional construct that includes at least such domains as physical capacity, psychological well-being, social relationships and environment	X	X	X	X	
Montgomery, Pocock, Titley & Lloyd 2002	A patient's quality of life is what he or she determines it to be and the best judge of gauging how important areas of life are affected by illness is the patient					X
Mytko & Knight 1999	A multi-dimensional construct that includes the patient's perspective of their overall quality of life and their assessment of specific components of quality of life					X
Rannestad et al 2000	Subjective satisfaction with one's life					X
Ravens-Sieberer & Bullinger 1998	HRQOL can be viewed as a psychosocial construct which describes the physical, mental, social, psychological and functional aspects of well-being and function from the patient perspective	X	X	X		X

Figure 1 continued		Conceptual Definitions of Quality of Life	Physical Functioning	Emotional Functioning	Social Functioning	Environmental Factors	Individual Perception
Study Authors							
Ready, Ott & Grace 2004	Important components of QOL include mood, affect, perceived ability to experience positive emotion, belonging, enjoyment, absence of negative emotion		X		X		X
Starace et al 2002	Individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns					X	X
Schmeuli 1998	A subjective view of one's health						X
Thumboo et al 2003	A subjective perception of [patient's] physical, emotional and social functioning	X	X		X		X
Tovbin et al 2003	Health status and psychological factors such as hostility, social support, family, work, etc...	X	X		X		
Wolinsky et al 2004	"HRQOL encompasses... the notion that health is not simply the absence of disease but also includes physical, social, and role functions, as well as mental health and general health perceptions"	X	X		X		X

Figure 1 continued

Study Authors	Conceptual Definitions of Quality of Life	Physical Functioning	Emotional Functioning	Social Functioning	Environmental Factors	Individual Perception
Proposed Definition	Quality of life is a measure of an individual's ability to function physically, emotionally and socially within their environment at a level consistent with his/her own expectations.	X	X	X	X	X

Significance

The significance of this thesis lies in its providing, through a systematic review of many years of literature, a collection, across many disciplines, of the conceptual and operational definitions of a term that is becoming more important as a means of outcome measure for federally funded projects.^{15,5} In 2003, health-related quality of life was selected by the Centers for Medicine and Medicaid Services as a primary outcome measure for evaluating managed care delivery programs.³³ In order to assess this concept, one must have a definition that is clearly articulated and generally accepted by those conducting the evaluations and relevant research. The development and acceptance of a conceptual definition can then lead researchers to collectively develop and validate an instrument or metric to quantify the phenomenon and to accurately and consistently compare data across populations and over time.

Definitions are vital in research. Without a tightly crafted conceptual definition, the linear progression from conceptual understanding to a well developed operational definition cannot take place. This can result in the situation currently surrounding much of quality of life research, lack of a clearly articulated conceptual definition but many varied operational definitions. As shown in ongoing work by the National Cancer Institute, even with a tightly constructed, coherent definition, measurement difficulties are near impossible to overcome in health studies.⁴³ This thesis, even if the proposed definition is not accepted, at the very least has focused the discussion surrounding the definition and measurement of “quality of life” by reviewing the literature from the previous 14 years.

Limitations

Several limitations of this work exist. The use of a random sample of articles to be included in the review narrows the discussion by means of restricting the sample and by limiting inclusion of articles appearing in the reference lists of included works. The exclusion of all studies not published in English possibly excludes potentially valuable research from inclusion. Finally, inclusion of only empirical studies at the expense of including philosophical and opinion/discussion pieces written on the subject and its inherent connection to the existentialism of Kierkegaard and Sartre force the discussion to be more limited than is necessary.

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APPENDIX A
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APPENDIX B
DATA EXTRACTION FORM

Conceptual Definition:

Operational Definition:

Name of Instrument Tested:

Theory Used/Cited: _____

Sample Size: _____

Reliability Measure: _____ Validity Measure: _____

Focal Variable tested in Study: _____

VITA

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| 2004 | M.S. | Health Education
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PROFESSIONAL EXPERIENCE

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| 2001-2002 | Undergraduate Research Assistant
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Previous Published Material

Reitz, J, McGivern, S, Church, Wilson, M, & North, S. The fate of the hydroxyalkoxy radical in the OH-initiated oxidation of isoprene. *International Journal of Chemical Kinetics* 2002; **34**: 255-261.

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