2002-04-01

A Study of Quality of Life Issues in Community-Dwelling Elders

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Digital USD Citation

McClane, Kimberly S. PhD, "A Study of Quality of Life Issues in Community-Dwelling Elders" (2002). *Dissertations*. 303.
https://digital.sandiego.edu/dissertations/303

UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Sciences
DOCTOR OF PHILOSOPHY IN NURSING

A STUDY OF QUALITY OF LIFE ISSUES IN COMMUNITY-DWELLING ELDERS

by

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A dissertation presented to the

FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE

UNIVERSITY OF SAN DIEGO

In partial fulfillment of the

requirements for the degree

DOCTOR OF PHILOSOPHY IN NURSING

April 2002

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Abstract

In the year 2000, there were approximately 35 million people in the United States who were 65 years of age or older, a ten-fold increase since 1900. The growth of this population has presented opportunities and challenges to American society. Health care needs, physical changes of aging , and the allocation of health care resources are several of the issues that need to be addressed (Federal Interagency Forum on Aging-Related Statistics, 2000).

Quality of life measurement tools have been used to assess the health and social needs of aging people both in the United States and internationally since their conception in the 1960s. (Andreson, Rothenberg, Panzer, Katz, & McDermott, 1998; Johnson, 1998; Katz et al, 1963; Porter, 1995). Data collected from these tools have been used to measure quality of life, to allocate health resources for elderly individuals, and to define aggregate health policy to meet the needs of elderly Americans (O'Connor, 1993)

The purpose of this study is to evaluate the congruence between themes used in quantitative quality of life instruments and the concepts of quality of life as perceived by elderly community residents. Using an interview format, data were gathered from a convenience sample of community-dwelling residents aged 65 years of age and older. Data gathered in face-to-face interviews with subjects were transcribed, and researcher field notes were used to augment the verbal data.

The study population was obtained from a condominium complex in Northern San Diego County, California. The researcher identified twelve subjects; all interviews were complete and utilized as data for this study.

The themes identified in the participant interviews were compared to the themes of several quality of life tools, including the Behavorial Risk Factor Surveillance System (BRFSS), the LEIPAD, and the Medical Outcomes Study Short Form (SF-36).

The LEIPAD tool was found to be the most inclusive of the lived experiences of the subjects. The BRFSS instrument had thematic relevance, but was found to have administrative disadvantages. The SF-36 tool was found to be inconsistent with themes identified by participants and not appropriate as an assessment tool for QOL in a geriatric population.

DEDICATION

This dissertation is dedicated to my parents. My father, William, died at a young age, but shared a deep commitment for education. And my mother, Carol, who recently passed away, making this a bittersweet accomplishment. I would never have accomplished this without their love and support.

Acknowledgments

The path leading to my dissertation may have been lonely at times, but I was never alone. The many who have supported me, bolstered me, and yes, threatened me, deserve more credit than I can give them.

To my mentor, my friend, and my hero JoAnn, I will never be able to express my thanks and love. You introduced me to graduate nursing education, served on my dissertation committee, and continues to be a fellow nursing educator. You are the BEST! I also need to thank Tom, her husband, for sharing her valuable time with me.

My dissertation chairperson, Mary Jo Clark for the hours and hours she has spent making me a successful nursing scholar. Never to preach or mandate, but drawing out my knowledge and reorganizing it. You have made this a challenging and self-fulfilling experience. I doubt I could have completed it with out your guidance.

And Louise Rauckhorst, the last member of my committee. I was thankful for being your graduate fellow for several semesters and the lessons I learned. You input has been helpful and insightful.

To my friends and fellow faculty members, I can only thank you for your support and caring. I would especially like to thank Don and Lee, Cleo, Jill, Sim, Carole, and Kay. Your interest and sustenance has made this journey less lonely.

And Tom and Tom, all I can say is you're the best...you help ground me, and stay focused. For over 30 years, you've been there when I need you....Thanks!

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Chapter 1

Introduction

Aging is an inescapable aspect of life that all must experience, but not all people share the same experiences of aging. Many factors influence the aging process including age itself, quality of life, chronic illness, and the lived experiences of the individual. This dissertation was designed to be a pilot study examining the phenomenological experiences of quality of life in a selected population of community-dwelling elders. A comparison was then made between the themes identified from interview data and themes present in three currently used quality of life (QOL) assessment tools.

By 2030, the size of the population over 65-years of age in the United States will double, reaching 70 million (The Federal Interagency Forum on Aging-Related Statistics, ([FIFARS] 2000). The shift in age of the U. S. population has social and health implications. One such implication is that on reaching the age of 65 years, the average lifespan is predicted to be another 17.6 years, years characterized by needs for increased health care services. A primary cause of increased health care needs is the incidence of chronic diseases associated with the aging process. The increased demand for health care resources by the aging further compromises the already strained Medicare program in the United States (Broyles, McCauley, & Baird-Holmes, 1999; Callahan, 1995; De Leo et al; 1998; Hirshorn & Piercing, 1998).

The "Profile of Older Americans" report (Administration on Aging, 2000) indicated that older individuals accounted for 36% of all hospitalizations and 49% of total hospital days in 1999, with an expected increase of 13% for hospitalizations in the year 2000. As the population of elderly persons ages and grows, these hospital-related expenses will increase.

The FIFARS (2000) described "life expectancy" as a means to evaluate the overall health of a community or nation. Improvement in environmental factors, health practices, and medical care in the United States are major contributors to increased life expectancy and the growth of the elderly population. A consequence of increased life expectancy is the rising prevalence of chronic illnesses, defined as long-term health conditions that rarely involve a cure. Hirshorn and Piercing (1998) observed that individuals over the age of 65 years in the U.S. have an increased risk for developing one or more disabling or chronic diseases. The most frequently diagnosed chronic illnesses in the elderly population are arthritis, hypertension, hearing impairments, heart disease, cataracts, orthopedic impairments, sinusitis, and diabetes (Administration on Aging, 2000).

Physical needs and disabilities caused by chronic illness negatively influence the QOL of older individuals. It is estimated that 7.9 million older Americans have disabilities due to chronic illness or injury (FIFARS, 2000).

The Centers for Disease Control and Prevention ([CDC], 2000a) defined QOL as a general sense of well being with life as a whole. Some identified components of QOL include individual happiness and life satisfaction, achievement of goals, and satisfactory personal environments. An individual's lived experience of aging may be strongly influenced by their physical condition, their perceived health, and their subjective view of their personal QOL.

The availability of life-sustaining medical care has also had a major impact on the concept of QOL. Fry (2001) concluded that QOL for the elderly is no longer an assessment of physical health, disease, and quantity of life, but includes individuals' perceptions of physical, mental, social and emotional health. Longevity, as a primary indicator of QOL, is no longer an appropriate assessment for the population of individuals over the age of 65-years because of the morbidity that is associated with it. In a study of 331 participants between the ages of 60 to 85 years, Fry isolated four "expectations" for present and future QOL of the participants. These included:

1. A QOL that incorporates respect, dignity, and impartial treatment in the community setting.
2. A QOL that provides for economic stability, which may or may not include employment.
3. A QOL that guarantees freedom and control in relevant personal decision-making.
4. A QOL that provides for stimulating activities and the freedom to participate in challenging opportunities within the community.

QOL has become a national health issue. The "Healthy People 2010" governmental health initiative identified a wide range of public health opportunities at the individual and community levels to improve overall national health status (U. S. Department of Health and Human Services [USDHHS], 2000). The two primary goals for Healthy People 2010 were to increase quality and quantity of years in a healthy lifestyle and to eliminate health and health care disparities.

The "years of healthy life" measurement was developed specifically for the "Healthy People 2000/2010" initiatives, and meant to identify the amount of time an individual spends in less than good health because of chronic or acute illnesses. The quantity of years achieved by an individual (longevity) does not equal the QOL of life the individual experiences (USDHHS, 2000).

The U. S. Department of Health and Human Services (2000), in Health People 2010, defined QOL as a sense of overall satisfaction, happiness with life, and lived accomplishments. Components included in QOL are "health, recreation, culture, rights, beliefs, aspirations, and the conditions that support a life containing these elements" (p. 10).

When QOL was established as a valid measurement criterion in the assessment of the elderly, the issue became how to assess QOL. A discussion of seven currently used QOL assessment tools will be presented in Chapter 2.

Fleming, Evans, Weber, and Chutka (1995) concluded that using an age-specific assessment instrument in a primary assessment of the elderly could improve morbidity and mortality rates, reduce length of stay in acute care and extended care facilities, decrease medical costs, and improve function in the elderly client. The unspecified tool would incorporate factors of social and cognitive function.

Stevens and Gillam (1998) identified four purposes for assessing QOL in elderly clients: to promote use of appropriate health resources, to maximize functional abilities, to identify individual risks and need for early intervention, and to gather aggregate data to determine the effects of health status on QOL in the elderly. This type of assessment instrument would be administered in the primary care setting to provide clear and relevant data relating to QOL in the older population.

Fry (2001) discussed QOL as a quantifiable entity related to an individual's health, illness, disease, and functionality. QOL was a factor that could be included in evaluation of an elderly individual's life, medical care or treatments, and satisfaction with health care and resources. Some newly developed QOL assessments have introduced other pertinent factors in an individual's life, such as social, economic or emotional health, and the individual's beliefs about their personal QOL. No specific assessment tool(s) were identified to measure QOL in individuals over 65-years as a baseline assessment. The utilization of a QOL assessment in conjunction with objective physical findings can be a means to increase dialogue and communication between the client and the health care provider.

Zitter (2000) proposed the concept of QOL to measure a patient's perception of their health outcomes and satisfaction with health care in a patient-focused environment. Used in combination with objective clinical data, QOL can reflect the client's access to care, their actual and perceived need for health care, and the effectiveness of medical intervention and function as a basis for examination of the cost-benefit ratio for care.

Wright, Williams, and Wilkinson (1998) noted that most primary care health practitioners conduct a systematic assessment of health needs for individual clients and, at times, their families, related to a specific health concern. The assessment of elderly clients based solely on clinical findings may result in lack of identification of unmet needs in chronically ill clients related to undiagnosed or asymptomatic disease states and aging.

Exacerbation of disease processes can negatively affect an individual's quantity and quality of life, and create safety issues regarding residential decisions and community well-being of older individuals (Administration on Aging, 1998). Broyles et al. (1999) reported that many changes in the elderly are slow to develop and insidious and proposed the need for early and repeated QOL assessment of older clients in the primary care setting.

Morriem (2000) reported that multiple instruments have been developed to measure older individuals' QOL, but often the tools used were developed to meet the criteria of researchers pre-established for a particular study. Traditional methods of measuring QOL in the elderly include functional measurements, improvement or regression of physical health status, use of health care resources, the effectiveness of medical care and treatments in individuals over the age of 65-years, and the extent of disability or impact a chronic illness has on daily activities.

With the inclusion of Fry's (2001) criteria of respect, economic and personal independence, and activities and the USDHHS (2000) elements of satisfaction, happiness with life, and lived accomplishments, it is questionable that currently used QOL instruments effectively measure these subjective components. If these instruments are not sensitive to the subjective components of an elders' life, is QOL research and data collection accurately measuring QOL in the elderly?

A second concern in the utilization of current QOL instruments with the elderly is that many of the tools are not specific to this age group. If the elements measured do not include components specifically relevant to elderly individuals, is the data retrieved from these instruments accurate and applicable to health care resource allocation and policy development for this population?

Purpose of the Study

The purpose of this study was to identify, through researcher-participant interviews, perceptions of community-dwelling individuals age 65 years of age or older regarding QOL and to compare their perceptions to components in selected QOL assessment tools. The study was conducted to address elements of QOL identified by community-dwelling elders using a pre-selected sample from a specific condominium complex. The study was designed as a pilot study to establish a primary database, which the nurse researcher can compare to future cohorts of community-dwelling elderly residents.

The intent is to determine whether there is congruence between the themes identified by the subjects and those in the instruments. If congruence is demonstrated it will validate the use of these tools in developing health care policy. If there is a lack of congruence, it will indicate that further work is needed in developing QOL tools for elderly persons residing in community settings.

This research study includes an overview of seven instruments currently used to measure QOL in the aging population. These instruments were analyzed for content, domain, and theme, ease of administration, and relevance to the aging individual. Three tools were identified from the seven as potential instruments that might be appropriate to or are currently used in a general assessment of an elderly individual. A comparison was made between the data collected in the interviews and the content of the assessment tools.

A phenomenological design used to gain insight and data on the perceived QOL of community-dwelling elders. This approach permitted the researcher to focus on individuals' lived experiences and perceptions relevant to them.

In order to identify congruence or lack of congruence between the lived experiences of the subjects and the assessment tools, thematic analysis techniques were applied to both the interview data and content of the instruments. Lack of congruence between the themes derived from the two data sets would indicate the need for further data collection of the lived experiences of elderly community-dwelling elders and modification of currently used assessment tools.

Chapter Two

Background and Literature Review

Between 1980 and 2000, the United States experienced a moderate rate of growth in the population 65 years of age and older; however a rapid expansion of this population is anticipated prior to 2010 (Anderson & Hussey, 2000). Using FIFARS (2000) data as a baseline, an individual attaining 65 years of age can expect to live another 17.6 years. As the lifespan extends, however, so does the need for medical care. This is primarily associated with the increased prevalence of chronic disease in the elderly population.

The Centers for Disease Control and Prevention ([CDC], 1999a) noted the ten greatest public health achievements from 1900 to 1999. Those that specifically can be related to increasing the lifespan of the elderly include vaccination; motor-vehicle safety; increased workplace safety; the treatment and cure of many infectious diseases; a reduced incidence of death related to coronary heart disease and cerebral vascular accidents; safer drinking water; and healthier and safer food, food preparation, and storage. These accomplishments in health care have had a positive effect on health and shifted the focus of medical care from acute illness and communicable disease to trauma and chronic illness. This shift ushered in an era of caring for older individuals with increased lifespan and increased medical needs.

Fruendenheim (2001) identified improved diet and exercise, an overall decrease in smoking, advances in pharmacological treatment of chronic disease, and improved eye corrective surgery (decreasing injuries related to falls or associated trauma) as major factors in increasing the lifespan and population of the elderly. There has also been a 1.6% decrease in disabilities caused by chronic disease during the 1990's. Whether this trend of decreasing disability will continue is unknown. The decline in disabilities, due primarily to the reduced incidence of chronic disease and improved medical care, may be overshadowed by the rapid expansion of the population over 65-years of age, with an increased demand for services due to a greater total number of consumers.

Chronic Illness, Disability, and Quality of Life

Chronic illness is a major factor in the ability of elderly citizens to live safely and independently in the community. The chronic illnesses causing morbidity and death in individuals 65 years of age or older include heart disease, cancer, cardiovascular disease, cerebral vascular accidents, pulmonary disease, diabetes, cognitive impairments, and depression (Administration on Aging, 1998; Territory Health Service, 1999). These conditions are often asymptomatic or undiagnosed until a physical, emotional or environmental stress occurs. Exacerbation of the disease process negatively affects an individual's quality and quantity of life.

Campbell, Crews, Moriarty, Zack, and Blackman (1999) surveyed a sample of 8,767 individuals over the age of 65 years with a wide variety and severity of chronic illnesses or age-related physiological changes. Eighteen percent of their sample reported visual impairments and 33.2% reported hearing impairments. The levels of disability ranged from visual impairments that were correctable with glasses or minor surgical procedures to complete blindness, and diminished hearing, ranging from mild to total deafness. The resulting impairments negatively affected activities on a daily basis.

Approximately 34% of the subjects reported alteration(s) in health status that negatively influenced their daily functioning and/or QOL. In individuals 85 years of age or older, 61% of the sample reported difficulties in one or more daily activities due to impaired senses or chronic illness that restricted their physical, social or psychological function. In a similar study, Clark, Stump, Hui, and Wolinsky (1998) found that 81% of their sample of 2,857 individuals 70 years of age and over reported decreased functional abilities, loss of independence, and loss of self-esteem.

Porell and Miltiades (2001) used a disablement model developed in the 1990s to identify the course of chronic illness and disability in the elderly. The initial stage, identification of the disease process, is followed by actual or anticipated physical impairments. As these impairments increased, functional limitations occurred, often proceeding to disability prior to death. The period from disease diagnosis to disability is usually prolonged, with the individual often dying before the end-stage disability phase.

Chronic illness has major financial implications for individuals and their families and places increasing financial demands on society, more specifically the Medicare system in the United States. In 1996, the average annual per person cost of health care for the "sickest" elderly was $5,600, with an added $1,200 for medications. This cost does not include medical diagnostics or treatments, skilled nursing care, or institutionalization not approved by Medicare or their Medicare insurance supplement (Bodenheimer et al., 1999). The Administration on Aging (2000) projected out-of-pocket costs for medical care for the average older consumer in the year 1998 at $2,936, a 33% increase since 1990.

Wayne State University (2002) reported that elderly Americans spend from 19% to 32% of their yearly income on prescription drugs alone. According to the Harvard School of Public Health (2000), 16% of Americans spend greater than $100 per month out of pocket to pay for their medications, and within this population, 15% reported not filling all their prescriptions, and 18% had difficulty meeting medical costs.

Chronic illness causes approximately 70% of all deaths, and accounts for at least 60% ($470 billion) of the nation's medical care costs (CDC, 1998a; Factor & Parker, 1998). Effects of chronic illness have been quantified in terms of cost, morbidity, and mortality. The concept of QOL in the elderly has not often been included. To fully understand the impact of chronic disease on the lives of the elderly, research must be conducted on QOL for those affected.

Defining Quality of Life

Padilla and Frank-Stromborg (1997) defined QOL as an individual's perceptions of life derived from one's culture, value systems, and personal environment. It encompasses satisfaction, personal acquisitions, and performance in relation to individual goals, expectations, standards, and concerns. It is dynamic and changes during an individual's life due to personal experiences and environmental conditions.

Zitter (2000) presented the concept of QOL as a measure of an individual's perception of his or her health outcomes and satisfaction with health care in a patient-focused environment. Using a combination of objective and subjective data, QOL reflects the person's access to care pertaining to a specific disease diagnosis, their actual and perceived need for health care, the effectiveness of medical intervention, and the cost-benefit ratio of health care.

Wade, Reimer, Smith, and Lund (1999) identified QOL as an outcome measure in clinical trials, or as an alternative to the traditional medical outcomes measured: duration of illness or remission, morbidity, and observer-rated symptoms. The CDC (2001) supported Wade et al., in defining QOL as an individual's perception of personal physical and mental health over a period of time.

Johnson (1998) derived her definition of health from the World Health Organization Constitution stating that health is a state of well being encompassing physical, mental and social components, not the absence of disease or illness. Johnson identified QOL as the total well being of the individual, encompassing physical and psychosocial health, influenced by an individual's experiences, perceptions of health and illness, and personal beliefs.

QOL has been defined in research in a variety of ways. For the purpose of this study, QOL was defined as the entire complex of biological, social, and mental status; perceived happiness; and personal disabilities of the individual as influenced by their perceived health status.

Quality versus Quantity of Life

Measuring the needs and preferences of the elderly for quality versus quantity of life is difficult. Researchers historically have attempted to calculate or predict quality of life using a variety of measurement terms. The vocabulary includes health expectancy, disability-free life expectancy, quality-adjusted life years (QALY), physical handicaps, functional impairments, functional abilities, and health status (De Bats, Drost, & Hansen, 1995; Mertens, 1994; Richmond, McCorkle, Tulman, & Fawcett, 1997)

One assumption made by early researchers of QOL was homogeneity in the elderly population that implied a shared consensus regarding quantity and quality of life. Oskvig (1999) found that there were few clinical patterns shared by all geriatric patients, and therefore, the elderly population displays nonhomogeneity in relation to their physical needs, personal ideals and goals, and desires.

Proteus (2000) identified a "universal assumption" prevalent in twentieth century society that life is naturally good and should be prolonged; conversely death is naturally bad and should be avoided as long as possible. This belief led to the premise that human life should be extended and death postponed as long as technologically possible. This assumption may not be an accurate reflection of an individual's actual desires.

In a study involving elderly hospitalized individuals, Tsevat el al. (1998) asked participants with a variety of chronic diseases of varying severity if they would give up one year of life in exchange for excellent health. Of the individuals interviewed, 70% indicated they would exchange no more than one month of their lives for excellent health. There were no statistically significant differences in the responses by age, sex, race or level of education. These responses indicate that the elderly individuals in this study preferred quantity to quality of health and QOL.

Sherman (1998), posing a similar question to 414 hospitalized patients 80-years of age or older found 59% of the sample willing to give up quantity for quality. Of this sample, 28% were willing to exchange one-month for their return to health.

Addington-Hall and Kalna (2001) investigated the role of the physician and patient making decisions regarding QOL in "life-threatening" situations. The physician (health-care provider) often makes a decision regarding medical intervention on the basis of his or her opinion of the efficacy of the intervention both immediately and in the future. This decision of whether or not to administer medical treatment, or withdraw an intervention, made by the physician is often not in agreement with the client's. It is imperative at this juncture in medical intervention for the physician to be aware of the client's wishes regarding quantity or quality of life.

The Need for Practical Functional Assessment of the Elderly

In 1995, a Mayo Clinic Symposium was held on the practical functional assessment of elderly persons (Fleming et al., 1995). The objectives of the program were to describe practical measures of psychosocial and physical function of elderly patients that were easily administered and could detect problems in a timely manner to enhance care to elderly clients. Routinely incorporating a functional assessment into the examination of elderly individuals enhances the potential to identify important functional or health deficits in the elderly individual that might be overlooked using only clinical indicators.

Stevens and Gillam (1998) commented that the application of a QOL needs assessment was one means of gathering data to improve the delivery of health care to the elderly population. A health assessment tool in a primary care setting can be applied to all recipients, potential recipients, or specific populations within the practice. Such an assessment could be used as a means to allocate health care resources to appropriate recipients to provide for unmet needs of clients.

Factor and Parker (1998) reported the need to establish an integrated assessment system for chronically ill elders to provide for their needs for medical, rehabilitation, and supportive care services. Mertens (1994) suggested a similar system, but described assessment in the elderly individual as problematic because adaptation to disabilities varies in the older population and objective data do not supply health care providers with enough information to identify the specific needs of elderly individuals.

Broyles et al. (1999) commented on the decreased functional ability of older individuals. Because many changes in the elderly are slow to develop and insidious, they proposed the need for early and repeated assessment of older clients in the primary care setting.

Measurement of Quality of Life in the Elderly

Mertens (1994) recommended the use of a health self-assessment tool for elderly clients in the primary care setting as a method of measuring QOL. This was based on his research and earlier studies that showed a close correlation between self-perceived health and the real or future health status of the individual. Recent research in this area includes studies by Benyamini, Leventhal, and Leventhal (1999), CDC (1998b), Chandola and Jenkinson (2000), and Schecter and Herrmann (1997). The findings of these studies supported the use of a self-assessment tool as a feasible means of measuring QOL and identifying special care needs in the elderly population.

The current literature supports the need for use of a QOL instrument in the diagnosis of elderly clients, either on an as-needed or a routine basis. Unfortunately, no specific instrument has been utilized or recommended for integration into the examination process. It is necessary to evaluate current QOL assessments for their content and fit with the QOL aspects of the elderly client's life.

Function as a Measurement of Quality of Life in the Elderly

When examining the nomenclature used to identify QOL in research literature, De Bats et al. (1995) noted that the majority of the terminology defined QOL both functionally and quantitatively. A historical review of the terminology indicated that empirically-oriented scientists who were uncomfortable or unfamiliar with subjective or lived experience data from research subjects established the vocabulary. The established vocabulary associated with quantitative QOL nomenclature includes morbidity and mortality, severity and length of disease, and functional implications of the disease, which are all objective and measurable.

Functional assessment of the elderly has become a basic measurement approach in evaluating the capabilities of the elderly to provide for physical self-care and independent daily living in the community (Lowenstein & Magowski, 1999). Certain skills relating to function can be replicated in a controlled environment and include social abilities, personal care, or household management skills. This form of testing is proposed to be realistic in measuring an elder's functional skills. The demonstration of these skills by the elder can provide some subjective data, but it is rarely incorporated into quantitative QOL assessment instruments. Rather, this type of environmental skill testing is applied in the rehabilitation setting (Lowenstein & Magowski, 1999).

Gallo, Reichel, and Andresen (1995) identified a prominent theme in gerontology from the mid-1960s, the retention of function as a major goal of health care in the United States. Function and functional assessment embody an aspect of QOL that is not accurately represented by medical diagnosis alone. Health care has shifted from a focus on delaying mortality to decreasing morbidity. Implicit in the concept of decreased morbidity are the preservation of function and an extension of "active" life expectancies.

Gallo et al., (1995) defined function as multi-leveled performance activities that can be assessed, particularly in the elderly population. The first level involves performance of social and occupational roles and daily tasks including transportation (public or private), communication skills, (either in person or by telephone), and handling of personal finances. The second level involves personal care tasks such as bathing, dressing, and self-medicating. Older adults who have deficiencies in these skills can be re-trained to accomplish the specific skill(s) or obtain assistance to remain independent in the community. The maintenance of function and independence is frequently associated with an elder's QOL. Walker (2000) concurred with Gallo et al. in the utilization of a multi-level assessment for elderly clients in order to obtain a pertinent and realistic assessment of an elderly client.

The Role of Activities of Daily Living in Geriatric Assessments

The origins of QOL measurement tools can be traced to the work of Katz et al. (1963) in the development of a functional assessment tool, the Activities of Daily Living Scale (ADLS). Katz et al. designed the ADLS to measure functional abilities relevant to self-care following a change in a client's health status. The functional abilities identified in this scale included bathing, dressing, toileting, transfer, continence, and feeding independently or dependently (an ordinal scale). The ADLS has been applied in both acute and long-term care facilities to assess clients' abilities to function independently (Shelkey & Wallace, 1998).

Salamon (1999) identified the ADLS as the oldest and most widely used of the functional assessment tools. It is primarily utilized in acute, rehabilitation, and extended care environments. Chiriboga, Ottenbacher, and Haber (1999) recommended the use of the ADLS instrument as an outcome measure for elderly patients in the acute care setting. When repeated, the scale identifies a baseline of physical function and comparison for assessment of improvement or regression.

The emergence of a more autonomous elderly population in the latter half of the twentieth century and the early twenty-first century highlighted their desires for independence and residence in community settings. This shift to a more active and functional population created a need to develop assessment tools that measured elderly individuals' daily tasks and abilities to safely interact with their environment and community. Gallo et al. (1995) commented that the ADLS was composed of easily accomplished tasks that could be performed by most elders and was not reflective of the skills that older clients need to remain safely in the community.

Lawton and Brody (1969) utilized some components of the ADLS and an untested Rapid Disability Scale to create a second instrument, the Instrumental Activities of Daily Living Scale (IADLS). The IADLS measured a number of criteria to identify the ability of the older client to function independently and safely within a community environment.

The IADLS is an age-specific tool that assesses an elderly individual's abilities to use the telephone for communication, utilize transportation services (private or public), shop appropriately for personal items and supplies, and safely prepare meals. Additional functions assessed include abilities to maintain a personal dwelling in a safe and healthy manner, perform activities related to cleanliness/laundry, understand medical care plans and self-medicating, and manage personal finances (Stall, 1996). The IADLS was initially designed to be a clinician-administered evaluation tool, but has evolved into a self-administered tool (Villeponteaux, De Croux, & Beardshall, 1998).

Gallo et al. (1995) identified a potential gender bias in the IADLS based on the fact that women traditionally performed many of the tasks measured. The IADLS may be more relevant for female subjects, but has not been limited to gender in current applications. This is due to the importance of the tasks for adequate self-care and independence in the elderly person (male or female) living in the community.

In attempts to find an accurate assessment tool to measure function and self-efficacy of the elderly, a variety of ADL and IADL instruments (a majority based on function), have been developed and implemented in a variety of heath care environments (De Vore, 1994; Sanders, Egger, Donovon, Tallon, & Frankel, 1998). The expansion of geriatric assessment instruments continues to be a major focus in providing health care to the growing elderly population.

Anderson (2001) reported that the results of a National Health Interview Survey indicated there is a need for a means of differentiating between major functional limitations and limitations of self-care and activities of daily living. Relying on a strictly functional level, the NHIS identified an anomaly in its data that can affect health care services and resources of the future. The anomaly was a failure to classify the degree of disability in study participants. It is necessary to identify an instrument that provides a more holistic view of the community-dwelling elder's activities, lifestyles, and independence.

The Transition from Activity of Daily Living Scales to Quality of Life Assessment Tools

Wiener, Hanley, Clark, and Van Nostrand (1990) identified the application of ADL tools as the "standard of practice" or "research tradition" in assessing the elderly for functional abilities and skills relating to self-care and independence. Porter (1995) reviewed the historical evolution of ADLS and various assessment tools to measure the status, abilities, and function of individuals 65 years of age and older. On evaluating several instruments, Porter identified the concepts of independence and competence as conceived by Katz et al. (1963) as the underpinnings of function.

Porter (1995) noted that instrument development in the 1980s was continued based on the concepts of ADL tools and expanded to support the theoretical relationships between functional ability and self-care in the elderly population. The concepts of independence and competence were no longer a priority in the assessment process. During this evolution of geriatric assessment tools, QOL was introduced as a replacement for the "older" concepts.

Henry (1998) viewed QOL in a subjective manner. The definition used was based on an individual's beliefs about characteristics that make his or her "life worth living." An individual's beliefs were considered to be a collection of perceived values specific to physical, spiritual and psychosocial health. This subjective view, therefore, is specific to one's current state, and varies with changes in one's personal health state and needs.

Lawton (1997) was an early researcher in the area of QOL for older clients. His work incorporated a complete assessment of the elderly and used both subjective and objective data. This was a continuation of Lawton's previous research into a "four-segment" QOL model that has evolved into a five-segment model including behavioral competence, objective observation of environment, self-perceived QOL, psychological status, and well being. Lawton's assessment tool was designed for use in institutional settings.

Lawton (1997) presented a multidimensional evaluation of an individual's QOL that included the blending of objective/subjective components for a comprehensive assessment. By identifying the individual as multifaceted and interactive, an assessment could then be made inclusive of intrapersonal and social normative-criteria (subjective–objective) based on and encompassing the individual's personal environment.

The first QOL segment evaluated by Lawton's tool was behavioral competence, often overlooked in earlier QOL assessments. The behavioral competence of the individual was based on responses to the Multilevel Assessment Instrument developed by Lawton in the early 1980s to assess 16 behaviors of the elder. Utilizing this assessment tool allowed Lawton (1997) to assess both specific actions such as personal care and feeding, and frequency of behaviors exhibited by the participant including mobility and the utilization of the facility's resources.

The next segment, the Multidimensional Environmental Assessment Procedure, evaluated the objective environment of the institutional residential setting of the elder. It identified eight dimensions of the residence and residential environment: comfort, security, staffing levels, educational preparation of staff, autonomy, control, rapport between staff, and rapport with residents. This assessment demonstrated Lawton's application of normative and social criteria to the individual's personal environment (Lawton, 1997).

Lawton (1997) measured perceived QOL using three scales. The first, the Friends Quality Index evaluated the satisfaction individuals gain from interactions or communications with friends and other social interactions. The Family Quality Index measures the individual's satisfaction with his or her family relationships. The third tool used in this segment of the overall assessment was the Time Quality Index. The purpose was to evaluate time used by an individual in activities pertaining to personal, business, and social needs. It is interesting to note that there was no evaluation of marital satisfaction, and it was not included in the Family Quality Index. Lawton chose not to include this domain in the assessment because of the overall poor quality of existing instruments in relating to either one or both spouses being institutionalized.

To measure the psychological well being of the elder, Lawton (1997) used the Life Satisfaction Index and Philadelphia Geriatric Center Morale Scale to establish the cognitive attitudes of individuals toward life and their abilities to respond appropriately to "emotion-based judgments." This tool usually results in a stable score over time unless there are cognitive or health status changes in the individual. If changes or treatment interventions occur, the psychological response is often delayed and does not correspond in time with the stimuli.

Finally, Lawton (1997) assessed QOL to identify the effects of health status on the overall QOL of the individual., The scales used to measure this component are the Medical Outcomes Survey Short Form-36 (SF-36), the Quality of Well-Being Scale (QWBS), and the Sickness Impact Scale (SIP). Lawton noted that this assessment was limited to the evaluation of the individual's health-service delivery or physical illness as specifically related to QOL.

Lawton (1997) and Henry (1998) have identified the need for assessment of elderly individuals to include both subjective and objective data. This combination of the data can be used to more accurately and realistically measure the adequacy of abilities and skills required to remain safely in a community-based environment than diagnosis-related objective data alone. Two limitations associated with their research are that the client populations were living in residential facilities and the assessment process utilizing multiple tools was time consuming and required trained clinicians.

QOL Assessment Tools Used to Evaluate the Elderly

A variety of instruments are used to collect data regarding the health and function of elderly individuals. One recognized means of classifying an assessment instrument is to identify the focus of the tool as disease-specific, age-specific, or generic in design (Wright, Williams, & Wilkinson, 1998). Assessment instruments used in populations 65 years of age or older include: the Sickness Impact Profile, the Older Americans Resources and Services Questionnaire, and the Stanford Health Assessment Questionnaire. Other tools examined include the Functional Independence Measure, the Behavioral Risk Factor Surveillance System, the Medical Outcomes Study 36-Item Short Form Survey, and the LEIPAD instrument.

The Sickness Impact Profile. The Sickness Impact Profile (SIP) was developed in 1972 by a social and medical research team headed by Bergner (Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976). This tool was a transition from a functional assessment tool based on abilities to one that incorporates disease, function, and QOL of the client. Based on the continuum of illness and behavior, one end of the scale represents a healthy and fully functional individual, the other end an individual in a disease-state with some impairment related to the illness. It gives a generalized view of function, measured quantitatively and is not sensitive to subtle changes caused by illness or medical treatment, a definite drawback (Padilla & Frank-Stromborg, 1997).

The SIP may be administered by an interviewer or be used as a self-reported instrument. The tool includes the three domains of physical, psychosocial, and independent function, 12 categories, and 136 behavior statements. The categories included in the physical domain are movement, mobility, and gait. Those in the psychosocial domain include intellectual function, communication, social interactions, and emotional behavior. The independent functions domain addresses sleep, nutrition, daily tasks or work, household management, and leisure and recreational activities (Padilla & Frank Stromborg, 1997).

It takes approximately 20 to 30 minutes to complete the SIP. It has been translated from English to 19 other languages and the SIP Advisory Board has evaluated the tool for validity, reliability, and cross-cultural sensitivity and found it appropriate in its translations (Damiano, 1996).

The SIP has been used in disease-specific populations of individuals including those with heart and lung disease, arthritis, and traumatic injuries. It has not specifically been applied to an elderly population (Damiano, 1996). It is mentioned in this review to provide information on currently utilized functional assessments. Teno, Stewart, and Welch (2000) reviewed the instrument and acknowledged that SIP is frequently utilized as a primary assessment instrument measuring QOL.

The Older Americans Resources and Services Questionnaire. The Older Americans Resources and Services Questionnaire (OARS) was developed at Duke

University by a multidisciplinary geriatric research team in 1978 and published by George and Fillenbaum (1985). It is recognized as the first complete functional assessment of elderly individuals to incorporate three elements: personal functional status, a multidimensional analysis of community and medical services used, and the impact of alternative services on the functional status of the elderly subject. The tool evaluates five domains including physical status, mental status, ADLs, social support, and the economic resources available to the participant.

A trained clinician administers the OARS assessment. If the subject does not provide accurate truthful information or is unable to supply the information, a proxy (a family member or caregiver) may be used to complete the assessment. The major drawback of the OARS is that the instrument contains 105 questions and takes a minimum of an hour to administer.

In an attempt to make the OARS a more "user friendly" instrument, several scales have been derived from the original OARS questionnaire: the Social Scale dealing with the client's frequency of social interaction, perceived quality of social network, and the availability of emotional support; a Perception of Personal Economic Status scale; a Mental Health Scale addressing psychiatric symptomology, life satisfaction, quality of sleep, and paranoid ideology; a Perception of ADL Status scale; and the Perceptions of QOL scale (Van Hook, Berkman, & Dunkie, 1996).

The OARS has been used primarily in the research environment rather than in the general elderly population. Some examples of the application of this tool include home care versus institutional care (Ontario Association of Community Care Access Centres, 2000), evaluation of research instruments and the elderly (Burnside & Hertz, 1998), nutritional behaviors of the elderly (Quinn & Johnson, 1997), assessment in general health care of the elderly (Van Hook et al., 1996), resource utilization and urban elderly mortality (Roy & FitzGibbon, 1996), and a comparative study of geriatric assessment instruments (George & Fillenbaum, 1985).

Coyte, Baranek, and Daly (2000) used the data collection components of the OARS instrument and applied them as outcome criteria to evaluate the effectiveness of the Canadian Health System. The OARS was utilized in the home health/home system, reflecting both for-profit and not-for profit home health agencies providing care to the elderly. Using the OARS components for the outcomes of home health care provided the Canadian Health Services with specific and valid data that could be used to analyze cost and outcomes of elder home health care services and providers.

The Stanford Health Assessment Questionnaire. The Stanford Health Assessment Questionnaire (HAQ) developed by Fries in 1980, focused on the client's problems in performing daily activities (Fries, Spitz, Kraines, & Holman, 1980). Initially developed for arthritic clients, the tool has also been applied to other disease-related populations. The HAQ has been expanded for use in a variety of clinical conditions. It is divided into the domains of physical disability and psychological effects of illness, and may be applied to persons with acute, chronic, or terminal disease states (Center to Improve Care of the Dying, 2000).

The HAQ is a 20-question, self-administered instrument that explores the effect of a disease on an individual in terms of disability, discomfort, the side effects of disease treatment, and the costs of medical care. The questions specifically address activities of the last week related to grooming and personal care, nutrition, exercise, range of motion of extremities, and personal activities rated on a four-point scale. The tool also includes a visual analogue scale for pain. The subject must be mentally competent to accurately participate in the HAQ assessment (Teno, 1998).

The HAQ instrument has been used to evaluate QOL in research related to the following diseases: rheumatoid arthritis (Chorus, Miedema, Wevers, & van der Linden, 2000; Strand et al., 1999), total hip replacement (Ridge & Goodson, 2000), change and clinical outcomes from a patient's perspective (Fischer et al., 1999), shoulder pain and disability (Heald, Riddle, & Lamb, 1997), and congestive heart failure (Jenkinson, Jenkinson, Sheppard, Layte, & Petersen, 1997). The focus of these studies has been client disability and rehabilitation rather than QOL per se.

The Functional Independence Measure. The Functional Independence Measure (FIM) was created by Hamilton in 1987 (Hamilton, Laughlin, Granger, & Kayton, 1991), and consists of 18 items related to domains of self-care, bowel control, mobility, locomotion, communication, and social cognition. It is an objective observational instrument requiring a trained observer. No information is required from the client for completion. The FIMS was devised specifically to measure QOL and functional abilities of an individual following a cerebral vascular accident or spinal cord injury. It is administered by a trained clinician and takes approximately 30 minutes to complete (Richmond et al., 1997).

The Center to Improve Care of the Dying (2000) noted that the FIM was designed to assess the physical and cognitive abilities or disabilities of individuals in terms of "burden of care" and as a basis for financial reimbursement. It has been widely accepted in both the United States and Europe and applied to individuals from seven years of age and up.

Bond (1998) discussed the utilization of the FIM instrument with major trauma victims. The conclusion reached in the study indicated that although the FIM could assess overall or global function, it was not discrete enough to reflect the subtle or insidious changes that occur over time. The lack of sensitivity of the FIM to subtle changes indicated that this instrument would not be appropriate to measure QOL in an elderly population.

Balandin and Alexander (1999) researched the domains measured by the FIM, and found them to be consistent with functional changes related to the aging process. Branch and Hoenig (1997) also reported the FIM to be a reliable functional tool in the elderly client, in both acute care and rehabilitation settings, for measurement of baseline function and changes in the older adult's functional status. The FIM can also be a component of a more complex QOL assessment of an elderly client.

Sullivan (1999) confirmed that the data generated from the use of FIM tool in a variety of health care environments were valid and reliable if a trained clinician properly administered the tool. The design of the FIM instrument was research based and not for application in a variety of populations. The FIM has been used to assess QOL and predict rehabilitation outcomes in studies relating to spinal cord and head injuries as well as strokes (Black, 2001; Kelley-Hayes et al., 1998; Sullivan, 1999; Van der Putten, 1999) patient rehabilitational outcomes (Long, 2000), congestive heart failure (Campbell, Konick-McMahon, Banner, & Naylor, 1998), and fall prevention (Morasso, Baratto, Capra, & Spada, 1998).

The Behavioral Risk Factor Surveillance System. The Behavioral Risk Factor Surveillance System (BRFSS) has been used as a data collection tool addressing both health-related behaviors and QOL in public health surveillance efforts. It incorporates both subjective and objective components in assessing health on national, state, and local levels. The data collected are used for decision-making, policy setting, and program development (Teno, 1998).

The BRFSS tool was developed during two workshops convened by the CDC in 1991 and 1992 (Arday et al., 1997). The intent in designing the instrument was to validate and apply this instrument to QOL studies. Data regarding perceived current health status, physical and mental health, and limitations in activities of daily functioning were self-reported by the participants (Hennessey & Moriarty, 1994). In 1993, the initial version of the BRFSS was completed and used in a random inter-state telephone survey with a sample of 44,978 subjects.

The latest published version of the BRFSS tool is from 2000 (CDC, 2000a). There are 12 core sections composed of 89 questions related to health, health care, specific diseases, and health promoting behaviors. Other core sections include mental health, demographics, women's health, and sexually transmitted disease. (Padilla & Frank-Stromborg, 1997). There are 19 optional models, ranging from 2 to 14 questions that can be used with the core sections to create a more specific surveillance of individual or community health.

The BRFSS instrument is generic in design. In addition to the annual BRFSS surveys conducted by the CDC, the BRFSS tool has been used in studies of a variety of chronic diseases including obesity (Mokodad et al., 2000), cardiovascular disease (Karason, Lindros, Stenlof, & Sjostrom, 2000), diabetes management (CDC, 1999b), chronic joint symptoms (CDC, 1998b), and mental distress in adults (CDC, 1997, 1998b). Other studies using the BRFSS have addressed QOL and arthritis (CDC, 2000b), community indicators of QOL (USDHHS, 2000), QOL in older adults relating to sensory impairment and activity limitation (Campbell et al., 1999), and QOL and behavioral risk factors (CDC, 2001).

The Medical Outcomes Study 36-Item Short Form Survey. The SF-36 or Medical Outcomes Study 36-Item Short Form Survey was developed by Stewart and Ware in 1992 (Ware, 1992) to incorporate into one assessment the factors most commonly used in evaluating QOL. The scales included body pain, vigor, social and role function, emotions and mental health, physical abilities, and overall health (Ware, 1992). The 36 responses to the questions can be computer or hand scored, and have been translated or tested in 45 countries other than the U.S. The design of the SF-36 tool is generic, and it can be effectively self-administered by individuals over the age of 14. The SF-36 can be used to monitor general or specific populations for functional status or abilities, to compare the impact of diseases in various populations, to differentiate health care benefits by treatment efficacy, and to screen individuals with a variety of health conditions (Teno, 1998).

In 1994, Lyons, Perry, and Littlepage published a study testing the validity of the SF-36 on 827 senior citizens residing in the community. The purpose of this study was to establish the suitability of the questionnaire for elderly populations. The concern was that the data would be compromised due to inappropriate responses or incomplete questionnaires. The authors concluded that there was 1.2% missing data, a lower percentage than expected, and went on to identify an internal consistency of 0.80 using Crohnbach's alpha.

Despite the findings of the Lyons et al., (1994) study, Gladman (1998) continued to question the appropriateness of the SF-36 in an elderly population. The SF-36 is considered by many physicians and researchers to be one of the better health and functional tools available to measure QOL. Gladman (1998) contended, however, that the concept of "health" in the population being tested should be taken into account. The presence or absence of disability and/or terminal illness, and participants' personal views concerning their state of health may influence the responses and alter the data collected and analyzed. If the SF-36 is utilized, it should be used within a pre-selected disease- or age-specific population that is clearly defined in the study.

Andresen, Rothenberg, Panzer, Katz, and McDermott (1998) verified the limited usefulness of the SF-36 for QOL assessment in community-dwelling elders. Parker (1998) supported Andreson's observations with recommendations that the SF-36 be limited to administration in an elder's home environment with a subject who is not disabled or cognitively impaired. Ferrer (1998) expressed some concern about the ability of older subjects to correctly respond to the SF-36 questions in the answers "grid format." Parker suggested that, when the SF-36 was used with elderly individuals, an interviewer should administer it to provide for accurate data collection, thus eliminating the two concerns relating to the accuracy of the data collected.

The 1997 Balanced Budget Act required the Health Care Financing Administration to monitor and provide data relating to the care elderly clients receive from either a fee-for-service program or coordinated health plans (health maintenance organizations and managed care programs) based on a variety of diseases and medical interventions. The data collection, analysis, and information coordination was termed "HEDIS." HEDIS data collection the elderly population was based on the sample population's responses to the SF-36 assessment instrument. HEDIS is an ongoing surveillance program based on the elderly American population using pre-selected health care or disease oriented care (Health Care Financing Administration, 1999).

The SF-36 continues to be a popular assessment tool in measuring QOL in a populations with various acute and chronic illnesses in a variety of health care environments. QOL research using the SF-36 has focused on individuals with lung diseases (De Vries et al., 2000; Limbos, Joyce, Chan, & Kesten, 2000; Martinez et al., 2000), self-rated health and ethnicity (Chandola & Jenkinson, 2000), functionally limited elderly (Puneillo, McGibbon, & Krebs, 2000), and standardized screening of elderly patients (Berkman et al., 1999). Other studies include individuals with cardiovascular disease (Luderitz, Werner, & Jung, 2000; O'Mahoney, Rodgers, Thomson, Dobson, & James, 1998), QOL in HIV/AIDS in persons under and over 50 years of age (Nokes et al., 2000), and general and disease-specific outcomes and QOL (Enloe & Shields, 1997).

LEIPAD. The LEIPAD, an acronym for LEIden (the Netherlands), PADua (Italy), and Helsinki (Finland) was specifically designed to assess the QOL of elderly individuals in the current world environment. It is a multidimensional instrument and encompasses the domains of physical, social, sexual, and cognitive function; self-care; depression; and life satisfaction addressed in 31 core questions of 49 total questions. The remaining 18 representative questions include a measure of self-perceived personality disorders, an anger scale, a social desirability scale, a self-esteem scale, and a trust in God scale (De Leo et al., 1998).

Other instruments used to develop and assess the LIEPAD instrument include the Older Adult Resource Services (OARS), the SF-36, and the Nottingham Health Profile (NHP). Previously developed tools were limited to concrete measures of the effects of illness, disease, and related therapies on the health-related activities, behaviors, and disposition of the elderly individual. De Leo et al. (1998) found a lack of sensitivity in these tools to many circumstances that are part of the "normal" biopsychosocial aging process and current health and social issues. The LEIPAD instrument, on the other hand, incorporated the natural physical decline of aging, the slowed pharmacological response to treatment, and important life-events that may lead to an increased sense of isolation and loneliness in the elderly individual, including retirement, loss of spouse, loss of income, and the potential for institutionalization (De Leo et al., 1998).

The LIEPAD was designed to provide a means of easily assessing the general needs of the elderly individual in 15 to 20 minutes and to be applicable to a multi-cultural elderly population with a primary (elementary) level of education. The LEIPAD measures QOL in the elderly, incorporating the affects of an individual's health and mental state, medical care plan, and health-related behaviors specific to the community-dwelling elderly population (De Leo et al., 1998).

Developed in conjunction with the European branch of the World Health Organization, LEIPAD has been tested in Italy, Norway, and the Netherlands. Each study was conducted in the native language of the country. LEIPAD has been translated into English, but has not been tested in the United States. Validity and reliability were established in the translated languages, including English, during the testing period. The only published literature regarding the LEIPAD describes the process of formulating the tool and one study of QOL in Italians over the age of 75 years (Urciuoli, & De Leo, 1998).

During trial phases, the LEIPAD was found to have test-retest reliability of 0.81 after 14 days in the Italian sample. Comparing the LEIPAD subscales to the Rotterdam Questionnaire subscales indicated a close convergence of all scales.

Validity of Current QOL Assessment Tools for the Use in the Elderly Population

In reviewing several currently utilized QOL assessment tools, the design and age recommendations were discussed. Each assessment instrument was presented in terms of the strength and merits of the tool, as well as its deficiencies. A major underlying theme in all the instruments discussed is the QOL of the participant.

The concept of functional physical abilities can be identified in its earliest form in the ADLS and has remained the principle component in assessment tools. Porter (1995) reported that Katz et al. (1963) incorporated independence and self-care into the early ADLS, but that the concepts were somehow lost in quantitative researchers' development of QOL assessment tools.

The development of assessment tools to measure function in many age-specific and disease-specific populations was most often associated with the trends and needs of the scientific community. Examining the evolution of the ADLS, IADLS, OARS, and LEIPAD as age-specific instruments provides evidence to support this premise. The IADLS was developed to expand the traditional ADLS assessment to incorporate the community-dwelling elder as a target population. The OARS tool was designed in the late 1970s to meet the scientific and social need to include measurement of mental function and social and financial aspects of an elder's life to provide an accurate and detailed assessment. Finally, the LEIPAD, the newest, and potentially most age-specific assessment tool was developed by De Leo et al. for three purposes: to address the changing needs and lifestyles of the elderly, to respond to the World Health Organization's recognition of the significant and rapid worldwide growth in the number of individuals over 65 years of age, and to meet the specific needs of the elderly (De Leo et al., 1998).

A second concern in the evaluation of QOL tools is the procedure used in the development of assessment tools. The tools developed were designed around researchers' perceptions of QOL in the elderly, not the perceptions of the elderly themselves. Geriatric Medicine (2000) commented on the origins of many QOL assessment tools. Often based on the requirements of the researcher designing the instrument and their criteria of measurement, many instruments were created to meet the objectives of the researcher rather than the generalized elderly population.

Finally, the assessment tools designed to measure function and ability to care for self have now been incorporated into sources for data that influence aggregate health care policy and resource allocation. One example is O'Connor (1993), who, accepting that the data generated were accurate and predictive in nature, used QOL data to recommend modifications to health care systems, including provider services (physical, mental, and supportive), the allocation of number of hospital beds available in a specific health care system, hospital mergers and closures, and forecasting for health systems contracting and service costs.

In 1996, Hornbrook and Goodman designed a "Risk Assessment Paradigm" based on QOL self-reported data designed to facilitate the cost management function of managed care systems. Nanda and Andresen (1998) acknowledged that the data gathered from assessments of elderly individuals have been combined to create statistical databases to guide health care research and outcomes criteria on an aggregate level. Wade et al., (1999) noted that collective data regarding QOL in the elderly are retrospectively and currently being collected to measure the influences of aging on physical and mental activities.

The accuracy and relevance of QOL instruments used to assess the elderly population are of paramount importance in current and future health care environments with respect to allocation of resources. If themes incorporated in current assessment tools are not congruent with perceptions of community-dwelling elderly clients, data gathered may not be representative of the health needs of the aging community-dwelling resident.

Larson (2000) reviewed several methods of integrating QOL assessments and cost analysis at the Harvard Medical School and found that combining cost analysis and QOL data was incongruent. This was based on the availability of accurate cost data that reflects the true overall charges to the patient, often not accurate due to the practice of cost shifting in the managed care environment. Larson reported that the future trend in developing QOL instruments would be more disease-specific, rather than generic or age-specific in design. This is related to the expanding population of individuals over the age of 65-years, the incidence of chronic disease in this population, and the need for increased health care resources.

Carr and Higginson (2001) noted that many of the current QOL assessment tools are not patient-centered in design or in data collection. They defined the major flaw in these tools to be the "disability paradox." This was based on investigating whether individual's who have significant health or functional issues have different perceptions of health and disability than individuals without significant health and functional issues. The central purpose in gathering this data was to explain the influence of health and disability on an individuals' overall QOL. The instruments used in this study were the patient generated index, the World Health Organization QOL 100 and 36 questionnaires, the European QOL measure, the McMaster Index, and the SF-36. The results of this study indicated a discrepancy between a chronically ill individual's objective symptomology in relation to their subjective responses regarding QOL.

QOL Instruments Specific to This Study

Following a summary review of seven assessment tools and supporting literature, three assessment tools were selected for this research. Two of the three, the BRFSS and the SF-36 are generic but widely used with the elderly; the LEIPAD instrument is specifically designed for use with the elderly population. Van Hook et al. (1996), Andresen et al. (1998), Nanda and Andresen (1998), and Berkman et al. (1999) have utilized the SF-36 instrument in various populations of elderly subjects, and it is considered to be a standard for functional assessment tools (Teno, 1998).

The BRFSS instrument has been extensively studied within the research structure of the CDC from inception through continuing research studies of surveillance of community-dwelling populations (CDC, 1999b, 2000b, 2001). The volume of completed and ongoing studies substantiates the inclusion of this instrument in this research study.

The LEIPAD was chosen as an age-specific assessment tool to be included in this study because of its focus on current elderly QOL issues. The lack of testing in the United States provides the researcher an opportunity to determine its applicability by comparing the domains of function assessed by the instrument to the actual QOL issues reported by community elders.

Burnside and Hertz (1998) identified four factors that should be considered when selecting an assessment tool for an elderly population. The first is the length of the assessment tool in either an interview or self-report setting. Results can be negatively skewed when the elderly subject becomes fatigued or confused during the administration of the tool. Rasin (1997) supported Burnside and Hertz in that it takes increased physical and mental energy for the elderly client to participate in assessments and testing. The BRFSS, the LEIPAD, and the SF-36 tools can all be completed in less than 45 minutes.

The second and third factors are methods recommended to diminish the anxiety relating to environment, the "stress" of participation, or confusion during the assessment process leading to inaccurate or incomplete data collection. Burnside and Hertz (1998) discussed the need for the tool's content to be relevant to the participants' lives, experiences, and daily functions and to be culturally sensitive to decrease confusion. Other methods of decreasing anxiety are pertinent to the physical aspects of tool administration. These can include, but are not limited to providing a comfortable environment (e.g., temperature, lighting, noise, seating arrangements) in which the assessment tool is administered in a non-threatening manner (Rasin, 1997). All three of the chosen instruments have been reviewed for personal relevance and cultural sensitivity (CDC, 2000a; De Leo et al., 1998; Ware, 1992)

Finally, Burnside and Hertz (1998) specified that the instrument must be written in a manner that is easily understood by individuals with potentially limited educational experience or literacy. Rasin (1997) noted that, although in the years 1970 through 1990 the number of high school graduates rose from 28% to 55%, there is still concern for the vocabulary used to compose an assessment tool for the elderly. The BRFSS, the LEIPAD, and the SF-36 have been found to be appropriate for individuals educated at the primary (elementary) school level (Burnside & Hertz, 1998; CDC, 2000a De Leo et al; 1998; Ware, 1992).

Conclusion

A rapid increase in the elderly population in America is expected in the coming years. This population shift will increase the strain on health care resources and budgets beyond current levels. There is need for quality assessment tools congruent with the actual lived experience of elderly individuals that will measure, both individually and in the aggregate, elders' QOL.

This chapter has provided a historical perspective on QOL in health care research and a review of seven currently utilized QOL assessment instruments. All share a quantitative approach without evidence of subjective or qualitative input from the target population in their development. This creates a potential gap between the themes incorporated in the instruments and aspects of QOL relevant to the elderly population.

This study was designed to examine the congruence between themes included in QOL instruments and those identified by community-dwelling older adults. The research method used was lifeworld phenomenology. Data were collected from the subjects concerning their lived experiences and personal opinions and were analyzed for common themes and domains. These themes were then compared to currently used QOL tools for congruence. The specifics of the study protocol are discussed in Chapter Three.

Chapter 3

Methodology

This chapter addresses the specific methodological and research design of this study. Areas discussed include lifeworld phenomenology and content and theme analysis. Subject selection criteria, recruitment, and selection; informed consent; and protection of human subjects are presented. Finally, the location of and procedure for the interview process, the schedule of questions used to illicit information from the subjects, and data analysis procedures are discussed.

Lifeworld Phenomenology

This research project employed a phenomenological design. Omery (1983), an early qualitative researcher, identified phenomenology as an alternative to the scientific approach in studying the lived experience of an individual. She identified the need for the nurse researcher to understand the individual's perspective of the "lived experience", and how life events affect the experiences of the person. Phenomenological methodology is relevant to this study because the researcher must understand the individual's perspective of QOL, and how QOL affects his or her experiences of daily life and activities. Dahlberg and Drew (1997) discussed lifeworld phenomenology as a methodology to be applied to nursing research. Borrowing from the work of philosophers, researchers, and sociologists (including Hursserl, Heidegger, Merleau-Ponty, Gadamer, and Satre), Dalhberg and Drew identified five concepts central to lifeworld phenomenology: encounter, openness, meaning, immediacy, and uniqueness.

Encounter

Lifeworld phenomenology deals with the interaction between the researcher and participant. In a clinical nursing environment, the goal of the nurse-client relationship is for clients to gain information or assistance regarding their health or personal growth. In the nursing research environment, encounter refers to nurse-client collaborative interaction that leads to the development of knowledge.

The nurse researcher is accountable for creating an equitable relationship, being respectful of having entered the private life and experiences of the participant (Dahlberg & Drew, 1997). Providing a professional yet comfortable interview environment enables subjects to be forthright and sharing of their lived experiences.

Openness

Openness is a priority among the five concepts in lifeworld phenomenology and provides for the "objectivity" of the nurse researcher. It brings the researcher into the process by searching for his or her involvement and history with the phenomenon to be studied. It provides the researcher with the ability to examine his or her own personal beliefs, preconceptions, and connection with the phenomenon, acknowledging that it is impossible for the researcher to be truly "perspective-free" in relation to the event. Identifying the researcher's perceptions of the event frees the researcher and allows entrance to the participant's world without expectations and with open-mindedness. This allows the individual to teach the researcher what his or her world is about. In other methods of phenomenology this may be referred to as pre-understanding or bracketing (Dahlberg & Drew, 1997).

Open-mindedness leads to open-heartedness, or the ability of the researcher to be self-revealing during the researcher-participant relationship and to serve as a model of self-disclosure. This does not imply full self-disclosure by the researcher and must provide for maintenance of scientific integrity and objectivity. The researcher must focus on the goals of the research project and the lived experience to be studied and incorporate research questions that will assist the participant in a directed self-disclosure process. Open-mindedness brings an ability to be reflective during the study of the phenomenon of interest, particularly during data collection and throughout the research process. Another term used for reflection is scrutiny, the ability of the researcher to critically evaluate the research project and data (Dahlberg & Drew, 1997).

Meaning

The goal of establishing meaning is to find the significance of the lived experience for the participants. It provides a clarification of the experiences that involves the participant and the nurse researcher through the interview process. This differs from the goals of some quantitative methodologies seeking to obtain and identify unique or indisputable data or knowledge (Dahlberg & Drew, 1997).

Immediacy

Dahlberg and Drew (1997) addressed immediacy as placing the nurse researcher in the "here-and-now" of the research process, the client relationship, and the interviewing and data collection processes. The purpose of immediacy is for the nurse researcher to encounter the client as an equal and valued participant, with the sense of open-heartedness. Immediacy is established when the researcher and client are engaged in a trusting relationship that fosters the sharing of the client's lived experiences. The caution in relation to creating immediacy in the researcher-client association is that a professional distance must be maintained and a state of empathy developed. Otherwise, the researcher risks becoming a participant in the client's life experiences in a unprofessional manner and compromises objectivity.

Uniqueness

In lifeworld phenomenology, uniqueness is a term used in place of the nonreductionism described in other phenomenological methods. It promotes the distinctiveness of each participant in the study rather than viewing them as part of the larger sample pool. It diminishes the tendency to generalize the data collected, fostering instead, the generalization of the "essences." The essence, in this methodology is discovered through the depiction of the lived experience by the participant and is understood before any fundamental relationships are derived (Dahlberg & Drew, 1997).

In phenomenology, the uniqueness of the individual is contradictory to the concept of sameness. Drew and Dahlberg (1997) explained this relationship in that we, as humans, all share the sameness of existing, but retain our uniqueness through our choices and the experiences of our lives. This provides the nurse researcher an opportunity to explore and share the lived experience phenomenon with study participants.

The application of the distinct concepts of lifeworld phenomenology provided this researcher the ability to identify the interaction between researcher and subject, a pre-understanding of QOL as a concept, and a means to establish a trusting, open, and sharing relationship with the study participants. The researcher was respectful of the subjects and maintained a curious outlook in the interview setting. Questions were developed to lead the participant to divulge information that clarifies the concept of QOL and its relevant themes. The lifeworld concepts allowed for the participants to be recognized and supported as individuals rather than as members of a larger group, and enabled the researcher to remain critical of the entire research protocol and procedures.

The Concept of Theme in Qualitative Analysis

DeSantis and Ugarriza (2000) noted that the integration of multiple approaches to phenomenology in nursing research has created a variety of definitions for many terms, including "themes." In order to identify a definition of theme common to nursing research, they reviewed 43 nursing research textbooks and 210 qualitative nursing research articles. This significant review of literature could not identify a shared definition of theme in ethnography, grounded theory, or phenomenological nursing studies and textbooks.

De Santis and Ugarriza (2000) defined theme as an abstract entity that conveys meaning and identity to a recurring experience and its variant manifestations. This definition of theme was based on four foundational criteria. These include the emergence of theme from data, the abstract nature of theme, the recurrence of theme, and three levels of thematic identification.

The emergence of themes from data reflects the appearance of concepts as they become apparent from the data, rather than issues inserted or identified by the researcher. Once a theme has emerged, the researcher continues to search through other data for supporting evidence of the emerging theme (De Santis & Ugarriza, 2000).

Themes may be implicit or explicit in data collection. Explicit themes are openly expressed and selected during data collection by the researcher. Most themes in qualitative research, especially phenomenology, are implicit, or inferred during the data analysis process. Implicit themes are subtle, and can be associated with the abstract nature of lived experience data (De Santis & Ugarriza, 2000).

De Santis and Ugarriza (2000) noted that themes are characterized by repetition in gathering qualitative research data, expressed as feelings, thoughts, or actions and repeated by the subjects. More than one participant usually expresses these themes to a point of saturation. At the saturation point, the researcher continues to discover similar patterns and themes in the study participants' descriptions of the lived experiences.

Finally, De Santis and Ugarriza (2000) noted that themes occur hierarchically, ranging from broad to specific. "Category" is the lowest level of data analysis unifying one or more ideas or data elements, and is the first level of organization in thematic formation. Domains unite or explain the relationship between two or more categories. A "taxonomy" represents the unification of two or more domains, and is a level where an actual theme is identified. It is the highest level of theme identification and the most complex and abstract of the three levels.

It is important in qualitative research, and particularly phenomenology, to understand and define theme as a component of the data analysis procedure. Arranging data into categories, uniting them in domains, and identifying taxonomies or themes assists the researcher in organizing and interpreting data. Developing themes from the data assists in organizing dialogue, behaviors, and actions into areas of future discussion and research.

Research Design

Criteria for Subject Selection

Though often perceived as a homogenous group, the elderly are a heterogenous population. Latimer and Sheahan (1998) described some of the variable characteristics of the elderly population as gender, age, income, education, state of health, social interactions, and marital status. This spectrum of characteristics highlights the need for the researcher to define entry criteria for participants in research with the elderly.

Subject selection criteria for this study included persons over 65-years of age residing in a specific condominium community in Southern California. Participants needed to be without cognitive impairments. Characteristics of gender, ethnicity, the presence or absence of chronic disease, and marital status did not affect participant eligibility. A diversity of participants was attempted within the community to provide rich data for the phenomenological process (Porter, 1995). Criteria for excluding individuals from the study included inability to converse in English (English may be their second language), communication impairments, or the inability to complete the interview process.

Site for Subject Recruitment

The condominium community from which subjects were recruited is located in Northern San Diego County, California, and is composed of 155 single-family connecting units in small configurations (six to eight units per grouping). The overall population is multi-generational. The community was established over 20 years ago, and many current residents are the original condominium owners.

This geographic area and community composition was selected for the subject recruitment pool for several reasons. First, this community has approximately 49% of its residents over the age of 65 years, and many chose the area as a retirement location. This provided a sufficient pool of potential subjects to make the study feasible.

Second, there is a wide diversity of community residents. Although primarily Caucasian, there was representation of a variety religious and ethnic groups. With a significant proportion of retirees, there was a diversity of educational and professional experiences. Finally, there was a diversity of family unit composition among the residents.

The community chosen also has a wide range of social, medical, religious, and community resources. These include shopping, medical services, an acute-care hospital, extended care facilities, churches, a public library, and leisure opportunities, and two senior community centers. Community services available to the residents include dial-a ride, Meals-on-Wheels, a Retired Volunteer Service Police program, a daily telephone reassurance service for frail or impaired residents or seniors living alone, and a senior referral service that includes a variety of home and health services to the elderly community members (Rancho Bernardo Senior Services, 2001).

The social, leisure, medical, religious, or community resources are available to all residents 65 years of age or older. This created an "artificially" homogeneous environment for the elderly population regarding available resources, and allowed for a range of personal choice for the residents in using the services, providing a diversity of lived experience data for the researcher (Luborsky & Rubenstein, 1995).

Subject Recruitment Protocol

With the assistance of a 23-year resident of the condominiums who was a past and current president of the condominium's homeowners' association, the researcher identified 25 potential subjects who meet the entry criteria for the research project. This number was projected as necessary in identifying 10 qualified subjects. A letter was sent to potential participants to identify the nurse researcher, the purpose of the study, and the subjects' obligations in participating in the research study (Appendix A). A follow-up telephone call by the researcher was made 3 to 5 days after delivery of the letter to recruit the participant and set up an appointment for the interview. Questions and concerns of the potential subject were addressed. If the subject agreed to participate, an appointment was made for the interview.

Sample Size

Phenomenological methodology does not dictate the number of subjects for a research study (Morse, 2000). This is primarily due to the amount and richness of data that a researcher can obtain regarding the subjects' lived experiences. The quality of both the data collection process and analysis of the data is more relevant than the number of subjects or quantity of data. Foley (2000) supported the concept of in-depth interviews with abundant data collection with a small sample size.

Morse (2000) also recommended a limited sample size with emphasis on the quality of data concerning the subjects' lived experiences during the selection process. When conducting qualitative research with an elderly population, Luborsky and Rubenstein (1995) recommended at least 10 to 12 subjects. If the interviews were properly conducted and analyzed, the data would be sufficient for a QOL study. Their primary concern in working with an elderly population is a higher incidence of attrition due to health issues than in a younger population. That was not a major concern in this project as the interview was a one-time-only occurrence with no follow-up. The initial sample size for this project was 10 subjects, and potentially 12, depending on saturation of data from the interviews.

The Data Collection Process

The data collected for this research were obtained from one-to-one interviews of the participants by the researcher. Interviews took place at the participants' residences to allow the researcher to observe the subjects' home environments. At the time of the interview, the purpose of and criteria for the study were reiterated, and the informed consent form (Appendix B) was signed by the subject prior to the beginning of the interview.

The interview was semi-structured, using a set of questions about the participant's quality of life (See Appendix C). The purpose of using the interview schedule was to obtain consistent QOL lived experiences from all the participants (Britten, 1995). The interview began with general questions and moved to more specific questions about the subject's QOL experiences to promote a trusting and comfortable environment (Bergum, 1991). It was expected that each interview would last 60 to 90 minutes. The author and primary researcher conducted each interview. The interview was tape recorded, and transcribed for analysis. The nurse researcher also took field notes during the interviews regarding observations of subjects' responses to questions and their surroundings.

Following completion of the QOL interview, subjects were asked questions regarding their age, sex, and education. This demographic information was used to provide a general statistical profile of the subject pool.

Data Analysis

Pope, Ziebland, and Mays (2000) noted that the process of data analysis begins during data collection and is an ongoing process throughout the study. If the data collection and analysis processes are not completed in an organized and accurate manner, the outcomes of the study could be flawed.

Discussing lifeworld phenomenology, Dahlberg and Drew (1997) reported that the complexities of the data collected were such that it was necessary to use an analytical procedure for categorizing and organizing data in order to view the whole picture. The goal of the analysis process is to organize and refine the data to allow for clarity and understanding in presentation to the scientific community. Data analysis procedures used in this study included content analysis and thematic analysis. Procedures for both are discussed below.

Content analysis. Content analysis is a broad method of analyzing text documents to identify descriptions, themes, or quantitative references into a organizational pattern that suggests categories for further examination. For the purpose of this study, content analysis involved the analysis of the textual data contained in the interview transcripts.

Schifflett (2000) defined content analysis as any research method that systematically and objectively identifies specific characteristics or messages within a text in a rigorous and structured manner. Though used in phenomenology and other qualitative research methods, content analysis is a method of quantifying data. It is a process that can be done by the researcher or trained associates or assistants and evaluated by computer analytical programs such as QSR NUD*IST. The primary researcher and a committee of two independent nurse researchers analyzed the data from this study.

Thematic analysis. Themes do not spontaneously appear during data analysis. Rather, themes are derived during content analysis through careful observation, mental analysis, and the logical arrangement of data. The three main functions of themes are to (a) unite a body of data that may appear to be unrelated or dissimilar without a thorough analysis process, (b) capture the fundamental nature of the human experience, and (c) identify common behaviors in a variety of situations (De Santis & Ugarriza, 2000).

Synthesizing the process of identifying themes from Aronson (1994), De Santis and Ugarriza (2000), and Schifflett (2000), the researcher utilized the following procedure for identifying themes in this QOL study. As discussed, the data were gathered from tape-recorded interviews, transcriptions of the interviews, and field notes by the researcher.

The first step in organizing and identifying themes was to merge the isolated data into categories of content-specific and related patterns. After organizing the categories into three generic topics, process, experience, and situation, the analysis continued to allow the themes generated during the data gathering process to appear.

The themes that emerged were developed into thematic statements, labels, or domains to provide succinct but thorough meanings in order to explain, expand, or associate the categories of phenomena discovered. This process focused on the unification of two or more categories to identify a domain.

After completing the initial evaluations, the nurse researcher gave a complete packet of interview transcripts to two doctorally-prepared nurse researchers. This was done for three reasons, to assist in validating the categories observed, to seek out personal validation as a researcher, and to increase the credibility of the analysis. This was a content analysis at a deductive level. The return of the interviews with coding and thematic analysis was to facilitate the understanding and analysis of the data gathered during the research project of the author.

Peer debriefing. After communicating with the trio of nurse researchers, a meeting was arranged for a "peer debriefing." Creswell and Miller (2000) identified peer debriefing as an impartial review of the research process and data by someone familiar with the design of the study and qualitative phenomenology. This process not only supports and guides the primary researcher, but also serves to elucidate content not previously observed in the data.

Spall (1998) identified the application of group debriefing during a dissertation process. Depending on the individual researcher, the methodology, and the data collection, an impartial debriefing group may meet to initiate a proposal and throughout the dissertation process. The frequency and utilization of the peer debriefing process depends on the individual doctoral candidate and the identified research project. This nurse researcher chose the peer debriefing process to facilitate clarity in the data analysis process.

The peer-debriefing group utilized in this research consisted of a member-at large from the student's dissertation committee to provide guidance and a doctorally-prepared nurse practitioner who has published qualitative nursing research. The one-time meeting of the group was scheduled for one hour, but continued longer due to the enthusiasm and energy of the debriefing group.

It was during this meeting that the level of content analysis was raised from deductive content analysis to one of inductive content analysis. Russell (2001) identified inductive content analysis as a transition from deductive content analysis to raw data themes. It is used to integrate thoughts, perceptions and incisive abilities of the researcher. On completing the recognition of the raw themes, the development of actual themes was initiated.

The procedure of analyzing interview data for categories, domains, and themes was also used to evaluate three existing QOL assessment tools: the BRFSS, the LEIPAD, and the SF-36. The instruments were analyzed for segments or patterns that could be used to formulate categories. The categories were then evaluated and organized into thematic statements or labels with the goal of identifying thematic domains.

Once the separate analyses for thematic domains of the interview data and the QOL instrument were completed, the two sets of domains were compared. Congruence of domains identified by the community-dwelling elderly with the domains found in the instruments would validate the use of current QOL assessment tools with elderly clients. Lack of congruence would indicate a need for additional instrument development or refinement.

Ethical Considerations Concerning the Elderly and Nursing Research

Ethical concerns regarding the research process and the preservation of human rights are crucial in conducting nursing research. The population in this study was 65 years of age and older, but not classified as vulnerable according to Federal Guidelines in the Belmont Report of 1974 (Department of Health, Education, and Welfare, 1979). In reviewing the literature concerning the conduct of research with the elderly, four areas of concern were identified. These include researcher sensitivity (Burnside & Hertz, 1998), voluntary participation (Alt-White, 1995; Higgins, 1998), informed consent (Higgins, 1998) and vulnerability of the elderly (Callahan, 1995; Kahana & Redmond, 1995; Sorenson & Pinquart, 2000).

Burnside and Hertz (1998) found several potential aspects of research with elderly clients to which researchers must be sensitive. These included increased fatigue during the testing procedure, increased anxiety during participation in a study, and an increased fear of not being educationally or culturally prepared to participate in the study.

This researcher was aware of the concerns of elderly clients through both professional and educational experience. Had a participant become fatigued, anxious, or overly concerned about participation in the study, either as expressed by the subject or perceived by the nurse researcher, the subject would have been given the opportunity to stop the interview.

Concerns regarding voluntary participation in elderly subjects had been expressed by Alt-White (1995) and Higgins (1998). Though their research sites were assisted-living and skilled nursing facilities, their concerns are applicable to a larger segment of the elderly population. Both found participants in their studies to be seeking positive reinforcement from facility staff and fellow residents. The population for this study was independent community-dwelling elderly residents who would not gain positive reinforcement for participation, and the issue was not anticipated or encountered.

Higgins (1998) identified two issues in gaining informed consent from the elderly: understanding the informed consent document and remembering having given informed consent. These barriers regarding informed consent were overcome in this study by selecting an independent community-dwelling elderly population without cognitive impairment. If the nurse researcher perceived the subject to be unable to understand or remember the informed consent, that individual was not interviewed, and another subject was recruited.

Vulnerability of the elderly can be associated with personal neglect, abuse, isolation, institutionalization, and cognitive impairment. Other factors may include the elder's reliance on individuals for personal assistance or a system or source of care to provide for their daily needs (Callahan, 1995). Individuals with these characteristics were not included in the study. Subjects were informed that any identified or suspected abuse during the recruitment, selection, or the interview process, would be reported to Adult Protective Services.

Hirshorn and Piercing (1998) noted that the degree of vulnerability in the elderly cannot be correlated to age. They found that self-reliance and vulnerability were correlated with the high incidence of chronic disease in the elderly and their diminished abilities to provide self-care. The subjects of this study were independent community residents capable of remaining in their residences without personal or community safety issues. Any form of personal assistance was at the convenience, not a necessity, of the clients.

Sorenson and Pinquart (2000) stated that an elderly individual can rapidly decline from independence to vulnerability. They identified a "trigger" that is activated causing this alteration in self-care to occur. Two conditions must be present for this activation to occur. First, there must be a potential, or presence of risk factors associated with a disease or illness in the individual. Second, the elder must be aware of the presence of the risk factors for ill health. Alterations in the balance between awareness of the risk factors and the alteration in risk factors becoming actual health changes can initiate the trigger function. This researcher does not believe this was a relevant concern in conducting this study, as each participant was interviewed only one time.

Protection of Human Subjects

Approval to conduct this research was obtained from the University of San Diego Committee on the Protection of Human Subjects (Appendix D). An informed consent (Appendix B) was obtained from each subject prior to the interview by the nurse researcher. A copy of the consent was left with the subject and one remained with the researcher.

Following completion of the interview, the researcher coded the tape recordings and transcripts to provide for confidentiality of the data. Only the nurse researcher had access to the codes linking the participants to interview tapes and transcripts.

Access to tape recordings and text of the interviews was made available only to the nurse researcher, her dissertation committee, and a panel of two doctorally-prepared nurse researchers. The tape recordings and transcriptions are maintained by the nurse researcher in a secure location.

Summary

The methodology chapter of this dissertation presentation addressed the entry criteria for and recruitment of study subjects, the collection of data, and the analysis process following data collection. Ethical concerns and the protection of human rights have also been addressed.

Chapter 4

Findings

Data for the study were collected in interviews with 12 individuals 65 years of age or older living in a community setting. Each interview was tape recorded, transcribed, and coded to protect the anonymity of the participants. Interpretation of the subjects' lived experiences of QOL began with content analysis of the transcribed interviews followed by thematic analysis.

Following an in-depth initial evaluation of data by the author, a panel of two experts in qualitative data analysis was provided with copies of the transcripts for their independent analysis. The panel consisted of two doctorally-prepared nurse educators and researchers. Both were familiar with coding, content analysis, and thematic analysis of qualitative data. Each member of the panel conducted their coding individually, and a group debriefing was conducted to discuss and compare the coding executed by the researcher.

It is important to note that nurse researchers, not a computer program, conducted the thematic analysis in this study. van Manon (2000) believed that the application of computer analysis to qualitative data becomes mechanical and quantitative in nature by counting terms, codes, or phrases. Researcher-based analysis of the data provides the meanings of the lived experiences of the subjects in a complex and relevant manner, allowing for discovery and disclosure in a less rigid approach.

Participants

Once a potential subject was identified, a letter of intent explaining the study, recruitment procedures and responsibilities of participants in this study was presented to the individual for his or her review. The original plan of sending out 25 recruitment letters to gain twelve subjects was not utilized. When hand delivering the letter, the author frequently met the potential subject, and the recipients were very enthusiastic in their responses. A total of 15 letters were issued, 12 subjects were recruited, and appointments made for the interviews.

The final sample population was five females and seven males. Of the 12, five were married and seven were widows or widowers. The annual household income ranged from $20,000 to $60,000. Further demographic information is found in Appendix E.

The Interview Process

All interviews were conducted in the personal residences of the participants. The purpose of the study and their roles as participants were restated, and informed consent was obtained. In conducting the interview, all subjects were found to meet entry criteria; no potential subject exhibited cognitive dysfunction or was unable to complete the interview process. No evident or suspected abuse or neglect was observed in any participants or family members. All 12 interviews were completed, transcribed, and utilized in the data analysis

The length of interview varied by participant. Some participants were brief and direct in their answers and interviews were completed in 20 minutes. Others lasted over an hour and a half, longer if the time spent with the subjects prior to and at the conclusion of the formal interview is included. Frequently the subjects shared memories, photos, and remembrance books of their family and their personal achievements.

Prior to beginning the specific interview questions (Appendix C), the researcher and participant engaged in small talk to place the subject at ease and to establish rapport with the participant. At this time, the researcher observed the physical surroundings and appearance of the subject. These observations were later recorded as field notes. The identified questions were incorporated in each interview, but the sequence of questions reflected the responses of the individual participants.

Thematic Analysis of the Interview Data

van Manon (2000) described thematic analysis as a process by which structures of information are uncovered, with the meanings rooted in the lived experiences of the participants. Aronson (1994) identified themes as a focus on an individual's patterns of living, behavior, or lived experiences.

DeSantis and Ugarriza (2000) defined theme as a guide, themes emerge from the data derived in both explicit and implicit methodology. A theme is an entity that defines a recurrent experience shared by the research participants that can be identified as a unit of thought or action. Themes create the linkages among the explicit, implied or obscure meanings of dialogues and behaviors. It is through content analysis and the selection of domains that the themes of the data become apparent.

Content Analysis and Identified Domains

In reviewing the interview data, 31 are current categories were identified (see Table 1). This was the first phase in organizing and analyzing the data provided by study participants.

Nine domains were developed that included related categories. These domains were: activities and participation; attitude and enjoying life; health, family health, and quality of care; relationships; independence; lifestyle; aging and knowledge; luck and God; and future expectations (see Table 2).

Table 1:

Categories Derived from Interview Data

Attitude and State of Mind
Being or Staying Active
Comfort
Contributing
Dignity
Doing Things Together
Doing What We/I Want to Do
Enjoying Life, Interests, Having Fun, Live Along the Way," Be Happy
Family Health
Family Relationships
Finances
Getting Out
Growing and Learning
Health Promoting Behaviors
Health Problems
Independence
Keeping Involved
Acquisition of Knowledge
Looking Forward to the Future
Luck or Belief in God or Higher Being
Old Age
Overall Health
Physical Environment/Surroundings
Preparation for Retirement
Quality of Medical Care
Personal Safety
Self-Care
Sleep
Social Relationships
Utilization of Health Care

It was apparent that the participants perceived that QQL was closely related to their ability to participate in and regulate their personal activities. Activities and participation were also components within other domains, but remain independent as a domain. A discussion of the domains follows.

Activities and participation. Activities and participation were identified in every interview as a primary element of QOL. The choice of activities and participation within or outside of their personal dwelling varied in frequency and type, but not in importance. One 73 year-old woman stated it meant that she and her husband had to do something every day to get them out of the house. " I think having places to go and like we always try to get out once a day. Maybe just errands and whatnot, but you are moving around and out and about with people and whatnot. I think that is good for you."

An 81-year-old widower defined his activities around both physical activity and socialization. Three to five days a week he exercised with weights or sit-ups in his condominium. He also walked several miles several days a week. This allowed him time to be out in the fresh air and meet individuals he is acquainted with along his route.
A 69-year old woman reported that she and her husband's travels have been important activities in their retirement. Current limitations on personal travel have not hindered she or her husband's ability to participate in a "rich and fulfilling life." Both have specific activities in the community in which they participate. They have not only increased the quantity of their reading materials, but have also varied the topics.

Table 2:

Domains Derived from the Interview Categories

Domain	Categories Included
Activities and participation	Being and staying active; contributing; doing things together; getting out; growing and learning; keeping involved
Attitude and enjoying life	Attitude and state of mind; enjoying life, interests, having fun, "live along the way", be happy
Health, family health, and quality of health care	Family health; overall health; health problems: quality of health care; utilization of health care; sleep; health promoting behaviors
Relationships	Family relationships; social relationships
Independence	Dignity; independence; doing what we/I want to do; self-care
Lifestyle	Comfort; finances; preparation for retirement; physical environment and surroundings; personal safety
Aging and knowledge	Old age; acquisition of knowledge through aging
Luck and God	Luck; God
Future expectations	Looking forward to the future

Another aspect of activities and participation was personal growth and learning. A major contributor to this domain was the introduction of the personal computer into the lives of elderly community-dwellers. In this study, two of the 12 households had access to and were active on the computer. One couple uses it to communicate with friends and family throughout the United States and to research their family tree. Another 72-year-old widow uses her computer for researching finances, investments, health and varied topics, as well as communication with family and friends. All agree that this is important, especially in times of ill health, to keeping active, involved, and in-touch with their family and friends.

One 81-year-old related how aging can affect your involvement in and contributions to society. Following retirement, he and his wife joined the Sierra Club, took back-packing courses at a junior college, and would sign up for guided tours in California. Both were active environmentalists and involved in cleaning and maintaining both beach and desert environments. Following his wife's death and advancement in years, he now supports their environmentalist activities through donations and instills these beliefs in his grandchildren.

Contributing or helping others or the community was a special instance of activities and participation. A 73-year-old retired military participant included the concept of helping in his definition of QOL. When asked what QOL meant to him, he responded, "Being healthy, happy, doing what I want to do, perhaps helping someone along the way."

A 72-year-old widow associated her lifestyle with QOL and health. "I try to keep myself active both physically and mentally. If nothing, with the volunteer work I do, it's, challenging every day and uh, but it also has it's rewards."

It was interesting to note that of the 12 participants, three identified inability to engage in desired activities as negatively influencing their QOL. Two were a married couple (83 years and 77 years of age); who seldom perform any outside activity without the other. The husband had chronic issues with prostate and bladder cancer and has difficulty controlling his urine. He stated, "I have a urinary problem all the time. Everything is jump up and down. Sometimes I have forty-five minutes to be free, and then what can you do? Can't go out and enjoy a movie. Can't go out and enjoy a dinner, now that's a big one." The concept of "being together" was very important to them. His physical condition negatively affected their ability to do things together.

The other, a 75-year-old woman, felt her physical problems forced her into an almost "housebound" condition. This widowed woman felt that her life was "boring" and felt her overall QOL was poor. She had recently given up driving and, unable to resolve her current medical problems, felt an increased level of depression. This was an example of the reverse and negative impact of keeping involved or "getting out" of their personal residence in community-dwelling elders QOL.

Attitude and enjoyment of life. The study participants frequently identified attitude and the enjoyment of their lives as an element of QOL. One woman felt that each day was a gift, and something to look forward to. She began preparing for her life after 65 years of age when her daughter left for college by taking classes and seminars that interested her (i.e., antiques, oriental flower arranging). To this day, she frequents estate sales and auctions, and studies on the topic. She is currently 72 years of age, and personally maintains her home and garden.

Another couple (84-years and 70+ years of age) felt that some of the expected changes associated with aging did not limit their activities, but allowed them an opportunity to learn and enjoy new activities. Prior to retirement, the husband enjoyed flying and the wife raised and showed horses. They continued these activities for several years, but have since given way to shared interests in golf and bridge. They continue to be open to explore new experiences with their friends and families.

One participant who suffered the loss of a daughter and husband within a seven-month time span was reflective on her loss, but wasn't going to let "life get her down." She has shifted her support system from family to close friends, and continues activities she enjoys such as golf and traveling. She is a very positive person, and states, "I believe you must be positive...I can't believe in living any kind of life without being positive that ah, hey, you're fine, you'll do it, keep doing it and it keeps you younger."

A 75-year-old widow presented her attitude and enjoyment of life in a negative manner. She stated, "(Life) is boring as hell. I don't know what it is to have fun anymore. Um, some days are worse than others. I can't say, depends on how I feel when I awaken in the morning...My mental state is not good."

Health, family health, and quality of care. Health, family health, and quality of care was not a primary issue with many participants, but a strong underlying factor in both the themes of activities and independence, and other themes to be presented. One 83-year-old male defined his QOL as "health and my spouse." Interesting to observe, this is the individual who was somewhat restricted by his chronic urinary problems. He also described a decreased energy level, increased fatigue, and a QOL that has gone "downhill since 1982" when his health problems began.

A 73-year-old married female defined "being healthy" as a major contributor to her "good QOL." She complained of problems sleeping, but feels it is an individual's responsibility to be proactive in their health, to have routine and acute medical care, follow physicians' advice, especially concerning diet and exercise, and to "keep pushing" until you gain your optimal health status." She felt that the basic problem of her insomnia was the medication she was taking for chronic cardiovascular disease. She has discussed this with her physician, and is unwilling to decrease her medication if it will "slow" her down. She will live with the insomnia.

One 69-year-old married female related health to active study of health issues, communication with her health care provider, and a positive attitude. Despite previous health issues, including breast cancer, she stated that she was in "good health" and didn't feel her age. She believes that her health care behavior and activities have done well so far, and will continue in her current practices.

A 75-year-old female "blames" her poor QOL and mental state on her poor health. She feels blessed that she has been able to care for herself until recently, but her diminished health and increasingly uncontrolled pain with movement have decreased her QOL.

One 81-year-old widower was reflecting on his QOL in regards to his wife and family. Presenting the researcher a family portrait, he pointed to his grandchildren, "see how tall and straight they are?...We raised six children, took them all camping, and spent every Friday night at the "Y" exercising." Following the interview, he shared other family pictures and histories. Two of his grandchildren are on scholarships for athletics, though he stated they were smart enough to attend college without the scholarships. He felt that the healthful lifestyles he and his wife participated in were reflected in the health and activities of his children, and now his grandchildren.

All participants of this study were covered by Medicare parts A and B, with supplemental insurance coverage. All reported having a specific primary care physician for their overall health care and medical specialists as needed. All of the individuals utilized the health care system in a knowledgeable and appropriate manner. The participants felt that they received adequate if not better than "average" medical care from their health care providers, but complained of logistical issues such as parking, the pre-determined length of their appointments, and regret at the evolution of medical care in the United States.

One 89-year-old widower provided insight into one of the frustrations encountered in his managed care senior health maintenance organization (HMO). He feels his primary care physician is adequate, and has benefited from both coronary bypass surgery and an aggressive cardiac rehabilitation program. In spring 2001, he had corrective eye surgery (he was vague about the actual surgical procedure) and felt that his surgery was unsuccessful. He was not comfortable with the ophthalmologist, and requested a second opinion. His primary care physician explained that the ophthalmologist was the only specialist within the HMO and referred him back to the doctor. This gentleman was still seeking resolution to this problem as he does not plan return to the ophthalmologist and was still having visual difficulties.

Relationships. Relationships in this sample population were significant contributors to QOL, and were identified in a variety of ways. A 73-year-old male stated he and his wife had a happy family, and "that adds to your QOL." When asked about what kind of loss would most affect his QOL, he responded that "Loss of a dear one, my wife or my son, or probably something like that." His 73-year-old wife stated that "the love of your family and friends" was very important to not only your QOL, but also your health.

One couple, married for 59 years replied that "Everything is lost if we lose one another. Otherwise we do well. We laugh, do our little things, go the grocery store mostly, and the doctors. That's our excitement. Eat lunch out!"

A 75-year-old widow defined her family as her daughter and cats. The loss of this "family" would have the biggest negative affect on her already compromised QOL. This was related to her lack of contact with friends and activities related to her self-imposed "housebound" status.

One couple, 84-years and 70+ years old, stated "It was 50 years ago April 5th, and we have some sayings that we had fun in our marriage. And, ups and downs, of course. It was not all smooth, nothing is. But we always made a joke about it, if you want a divorce, darling, you get the kids!" Both their adult children live in close proximity and frequently visit them and encourage their participation in family activities. They also described family activities prior to their retirement and early in their retirement, indicating that this was not a new facet in their lives. They noted that they also have a social life that is separate from their children and grandchildren. Both social and family relationships were important to this couple.

Interestingly, 11 of the 12 participants had strong bonds with family to form strong support groups; one widower did not. When this 89-year-old man was interviewed and asked about his family, he stated he had one daughter who was married to a man with three children. There had been no further children, and he stated "I have no grandchildren." When asked about his daughter, he responded, "She is very busy with her business and family. I don't want to invade, so I don't go there often."

The identification of friends and support varied in relation to the participants. Two of the married couples identified their friends as "people we've grown old with, shared life experiences, children, and a history." Often, friendships were associated with personal activities such as golf or bridge, social acquaintances that played important roles in the lives of the participants.

One 72-year-old female had frequent contact with her daughter and her son-in-law, but feels that she wants and needs her friends around her. A fear she discussed was being placed in an "institution" and losing her friends. She related this to decreased association with friends because people would eventually stop visiting her, leaving her alone and depressed, and adversely affecting her QOL.

Independence. Independence was an issue raised by many of the participants. The definition varied with individuals, but all supported the concept of being able to decide on what they wanted to do and not being required to do things. One subject, an 89-year-old widower, defined independence as the ability to drive his car despite chronic health issues of cardiovascular disease and "ocular" disease. He passed his last drivers test, but is fearful he cannot pass the next time due to his eye condition. This issue was left unresolved, but he stated he felt his QOL to be "good at age 89," but that the loss of his driver's license would diminish his QOL.

A retired military officer, this 73-year-old man talked about aging and his and his wife's social life, "I don't think we go out as much as we used to years ago, but it is at a stage where we want it, and we are doing what we want to do. We don't do it because we should or anything, we do it because we want to. And that's true of a lot of things I think." This was significant in relation to the mandatory activities his career required.

One 72-year-old widow responded to "What is quality of life for you" with "My QOL I define as my independence. My ability to take care of myself physically, financially, and having support groups around me...I think the most important thing for all of us to do, again, to say, ah, and that's probably an independence thing, it can be ah, involved and contribute something, and ah, ah, grow each day." When asked what would be the greatest negative impact on her QOL, she stated "Oh, not to be independent. I can't tell you how I value my independence." She went on to discuss relying on others for daily care, and believes it is a personal responsibility to maintain one's independence. This had become a major issue in her current QOL as she is one-month postoperative from bilateral knee replacements, two associated hospitalizations, and 10-days in an extended care facility for rehabilitation.

The participants frequently mentioned independence, or the loss of independence in relation to a change in QOL. The participants alluded to at least three individuals in the condominium complex, not included in this study, as examples of loss of independence and diminished QOL (the participant's personal opinions). Two situations were related to dementia and one to a cerebral vascular accident. All three remain in their homes, but require from 12- to 24-hour personal care by a variety of health care providers.

The participants also referred to two couples over the age of 65-years. In both cases, the men were suffering from "Alzheimer's Disease" and the wives were no longer physically able to safely maintain their residence in the community setting. These couples were in the process of selling their condominiums and relocating to senior residential complexes that offer a variety of independent to skilled nursing facility options to meet the needs of their residents. The thought of relocating to a residential community for seniors was not viewed as a "positive" relocation. This loss of independence also evoked issues of diminished personal dignity.

Lifestyle. Several participants mentioned their lifestyle as important to QOL. An 81-year-old widower identified his surroundings as one of the five components of his QOL, "Well, family, health, surroundings (lifestyle), friends, and companionship." A 75-year-old widow felt that her home environment was important not only to her life, but also the family's life. Five of the participants chose their condominiums to provide for their personal comfort, location, and lifestyle following their retirement.

Personal safety was also identified with activities and participation in reference to their activities. This condominium area is located away from major roads or highways, is quiet, and seldom experiences any crime. The most frequent crime reported is malicious mischief or petty theft from yards or patios. In this context, the subjects felt safe when participating in their activities within the community and surrounding areas.

Three males in this study also related their lifestyles to economic resources. All felt there was no problem in their QOL as related to income and that this was a prime consideration in attaining and maintaining their QOL prior to and into their retirement.

Of the 12 participants, only the 77-year-old widow denied making plans for retirement to assure her comfort and security. Identifying their resources prior to retiring, the subjects planned their lives around their homes, expenses, personal activities, and family proximity. All 12 of the participants were born and lived many years of their lives outside the state of California and relocated prior to or at the time of their retirement.

Aging and knowledge. This domain addressed the perceptions of the process of aging and the knowledge an individual gains throughout the life experience. The ages of the participants ranged from 69 to 89-years of age. Except for two women, all participants were open and comfortable with the ages they had attained.

The participants voiced that having reached their current ages, they had experienced a lifetime of personal and professional growth that included achievement of personal and family goals, increased personal knowledge, and the opportunity to share their knowledge with family and friends. These factors have also been instrumental in their retirement and maintenance of the QOL.

A 73-year old man felt that although he is currently "healthy" (with the exceptions of his blood pressure, cholesterol, and allergies), he wished he had taken better care of himself. "I didn't give up smoking until seven years ago, and didn't have a physical for over 25 years. If I'd known how long I was going to live, I would have taken care of myself when I was younger!"

In comparison, an 81-year-old participant realized when he turned 40, he could not "keep up with my son's running or basketball. I was totally out of shape. I quit smoking, started exercising, and watching my diet. I still do today." He is active, very alert mentally, and is involved in several community programs.

Health knowledge is not the only knowledge gained through age. A 72-year-old widow is currently in a precarious financial situation. Funds left to her through her husband's estates were significantly diminished by risky investments. Her current income is derived from Social Security and individual retirement accounts. Having made no plans for retirement, she feels guilty for not learning from prior financial investments and relying on her daughter for support.

One female started learning about and collecting antiques in her 40s. Though she rarely sells any of her collection, she has made some profits on sales. She continues to study (often at the Border's bookstore over coffee) antiques, and is actively involved in collecting. The knowledge she has personally gained she also shares with her friends and family.

Luck and God. The concept of luck or a God intervening in their lives was at times mentioned in both a humorous manner and with reverence. Seven participants identified God or luck as responsible for their current status and achievements in life. Four of them reported belief in God or a higher being as an element of their daily lives and necessary to their QOL.

Although suffering increased depression and reclusiveness, the 75-year-old widow maintained a belief in God. She felt "cheated" in her life by the loss of her husband when he was 42-years-old. She holds tight to the belief and comfort that God will reunite them after her death. One female participant felt that her personal beliefs involving a higher being, a more "Eastern" philosophy, have resulted in life changes (i.e., vegetarianism) that have contributed to the length and quality of her life.

Future expectations. The last domain derived from the interview data categories includes the concepts of dignity, virtue, looking forward to the future, and self-care. An 81-year-old widower described his physician's description of himself as "the poster boy for health." By maintaining his current healthy behavior, activities, and exercises, he will continue to live an independent and health life. He looks forward to spending more vacation and family time with his children and grandchildren. He has also prepared a "memory book" of his wife's life and their family. Sharing this with the researcher, he continues to expand it and leave it as a future legacy to his family in the future.

One male subject 73-years-old related his concerns about the future by stating:

> I see other friends that are older and running into problems and it's always a concern that I might become an Alzheimer's victim, or something like that...My prescription for this is to keep your mind active, read, participate in activities in your life and so forth...I'm 73 now. You know, you get up over that and into your 80s, I think maybe your QOL goes down just because of old age. I'm going to try to keep it up as high as I can for the longest period I can.

Two individuals did not feel positive about the future. A 75-year old female spoke only in present and past tense during the interview. Her recent altered health status and diminished QOL did not provide her with a vision of "future." Of interest, this woman died less than two-months after this interview.

Another subject, an 89-year-old male recounted the activities he has given up due to increasing age and decreased health. These included dancing, golfing, home maintenance or gardening activities, and activities associated with his failing vision. He did not respond directly to the future, but implied that it would not be an improvement over his current lifestyle.

To end on a positive note, a 72-year-old participant stated, "I, I want to grow each day. I want to learn something each day, and I think that's what QOL is all about."

Themes Identified from the Interview Data

The identification of themes in phenomenological research is not a process that can be accomplished from a routine perusal of the data collected, the repetition of words, or the frequency of elicited responses. Rather, themes emerge through the immersion of the researcher into the data, categories, and domains that are revealed during the data collection process. Ryan and Bernard (n.d.) recommended that the nurse researcher concentrate on the search for specific topics that can be the basis for thematic emergence.

This nurse researcher identified two themes (see Table 3). One was defining elements of QOL, comprised of the domains of activities and participation and attitude and enjoyment. QOL as a major characteristic of existence provided a platform that allowed the individual to define their roles, responsibilities, and activities of their daily existence. Two female participants and one male participant reported their diminished daily activities and existence had a negative impact on their QOL

The second theme included determinants of the elders' QOL. This was deduced from the remaining seven domains: health, family health, and quality of health care; relationships; independence; lifestyle; aging and knowledge; luck, and God; and future expectations. Each of these domains are interrelated but separate, and an event that alters any of the seven domains influence on the overall QOL of the individual in either a positive or negative manner (see Table 3).

Table 3:

Themes Derived from the Interview Data

Theme Identified	Associated Domains
Defining elements of quality of life	- Activities and participation - Attitude and enjoyment
Determinants of quality of life	- Health, family health, and quality of health care - Relationships - Independence - Lifestyle - Aging and knowledge - Luck and God - Future expectations

Thematic Analysis of the QOL Instruments

The item content of the three QOL instruments reviewed in this study is presented in Appendix F. The nurse researcher categorized these questions (Table 4), analyzed the categories to identify the central domains (Table 5), and derived themes addressed by the

BRFSS Core Sections, the LEIPAD, and the SF-36 (see Table 6). The process for instrument thematic analysis was identical to that used for thematic analysis of the interview data.

Content Analysis and Identified Domains

Based on the 20 categories derived from the BRFSS, LEIPAD, and SF-36, eight domains were identified. These include health and of health care; memory, cognition, and sleep; relationships; health promoting activities and exercises; personal achievement activities; satisfaction with lifestyle; future expectations; and belief in God (see Table 5).

Health and health care. This domain was created from the categories of overall health, specific health issues, perceptions of health care needs, oral health, mental health, and access to health care. Overall health involved a non-specific overview of a respondent's perception of his or her general health. Specific health issues dealt with detailed inquiries regarding pain, addiction, health screening practices, HIV/AIDS, and use of tobacco products. Specific chronic diseases addressed included diabetes, arthritis, hypertension, cancer, and cardiovascular disease. Clients' perceived needs for health care and access to medical care and oral health were also addressed. The mental health category addressed satisfaction with themselves, their emotional state, their concerns regarding social interactions, and daily worries.

The BRFSS instrument incorporated each of the categories within this domain. The LEIPAD instrument assessed only overall health and mental health. The SF-36 tool identified overall health, specific health issues, and mental health.

Table 4:

Categories Derived from the Assessment Tools

Category	BRFSS	LEIPAD	SF-36
Overall Health	X	X	X
Specific Health Issues	X	-	X
Self-Care	X	X	-
Daily Activities and Exercise	X	X	X
Nutrition & Weight Control	X	-	-
Mental Health	X	X	X
Future Expectations	-	X	X
Sleep	-	X	-
Memory & Cognition	-	X	-
Family Relationships	X	X	-
Social Relationships	X	X	-
Sexual Activities	X	X	-
Hobbies/Personal Activities	X	X	-
Finances	X	X	-
Satisfaction with Lifestyle	-	X	-
Belief in God/Comfort in Belief	-	X	-
Military History	X	-	-
Perception of health care needs	X	-	-
Access to Health Care	X		
Oral Health	X	-	-

Note. X denotes inclusion of a category within a tool; dash reflects lack of inclusion.

Table 5:

Domains Derived from the Assessment Tools

Domain	Category
Health and health care	Overall health; specific health issues; perception of health care needs; access to health care; mental health; oral health
Memory, cognition, and sleep	Memory and cognition; sleep
Relationships	Family relationships; social relationships
Health promoting activities and exercises	Daily activities and exercise; nutrition and weight control
Personal achievement activities	Hobbies and personal interests; sexual activities
Lifestyles	Satisfaction with lifestyle; finances
Future expectations	Looking forward; future expectations
Belief in God	Belief in God; comfort in belief

Memory, cognition, and sleep. Memory and cognition addressed the clients' perceptions of their abilities to concentrate and think clearly or problems associated with confusion in their daily lives.

The category of sleep was included in this domain because the quality of sleep may profoundly influence both memory and cognition (Geriatric Medicine, 2001; Russo, 2002; Wilson, 2002). These categories were specific to the LEIPAD instrument, and not addressed in either the BRFSS or the SF-36.

Relationships. The domain of relationships was constructed from questions related to both family and social interactions. Information on family relationships included marital status, number of offspring, and the availability of family members or caregivers to assist clients in their activities of daily living. The social component of this domain reflected the participant's relationships outside of the family unit, loneliness, ability to trust and communicate with others, and contentment with the individual's self-concept.

Several questions in the mental health domain overlapped issues in personal interactions. These involved satisfaction with individual personality traits or communication with family or friends and were retained in the mental health domain.

The BRFSS focused directly on the availability of family and caregivers in relation to the client. The LEIPAD dealt more closely with the social components of relationships, with few questions relating to family relationships. The SF-36 did not include either family or social relationships in its content.

Health promoting activities and exercise. Health promoting activities and exercise was a domain that shared some content with the health and health care domain, primarily involving health promoting activities, nutritional behaviors, and exercise related to health concerns. For the purpose of this study, the health promoting activities and exercise domain included instrumental activities of daily living and daily activities for health promotion.

All three-assessment tools, the BRFSS, the LEIPAD, and the SF-36 included queries regarding daily health promoting activities. The BRFSS identified exercise, instrumental activities of daily living and health limitations. The LEIPAD addressed instrumental activities of daily living and health limitations.

Personal achievement activities. The domain of personal achievement activities reflects hobbies, personal interests, and sexual activities. Hobbies and personal interests included pursuits in which the individuals participated to provide enjoyment, feeling of accomplishment, and to meet selected personal objectives. Sexual activities identified were not restricted to a marital relationship and included sexual habits and sexually transmitted disease, safe sexual practices, and methods of birth control.

The BRFSS and the LEIPAD instruments have content relating to hobbies and personal activities for self-fulfillment. The BRFSS tool specifically addressed frequency of sexual activity, safe sex, exposure to sexually transmitted diseases, and contraception. The LEIPAD instrument explored interest in sexual activities and the ability to fulfill the individual's needs. The SF-36 did not include sexual activities in its content.

Lifestyles. The lifestyles domain included the categories of finance and the clients' satisfaction with their current lifestyles. Questions relating to satisfaction with current lifestyle in relation to past lifestyles, the ability to manage their current lifestyle, and the effect of their current lifestyle on future expectations were also included in this domain.

The BRFSS and LEIPAD tools directly addressed finances. The LEIPAD alone identified satisfaction pertaining to the current and future lifestyles of the client. The SF-36 contained no questions relating to any of the categories included in the domain of lifestyle.

Future expectations. This domain was limited to identifying expected health changes in the future. LEIPAD asked about expectations of future health. The SF-36 queried the subject on their expected physical and mental health specifically within the next 30 days. The BRFSS did not include future expectations in its content.

Belief in God or a higher being. The LEIPAD was the only assessment tool to address belief in God or a higher being. A second question in the tool addressed whether or not the respondent derived "comfort" from such belief.

Unspecified categories. The BRFSS contains content referring to an individual's military history. This category does not seem to be related to any other categories, and so was not incorporated into a domain. Military history will remain unclassified at present, but may develop into another domain with future research

Themes Derived from the Assessment Tools

Once the categories and the domains of the assessment instruments were identified, a search for the prominent themes was conducted. The nurse researcher discerned three themes from the nine domains (see Table 6).

The first and most prominent theme of the assessment tool content was health status. This was a common thread throughout all three of the assessment instruments.

The domains composing the health status theme were health and health care and memory, cognition, and sleep.

The second theme identified was activities and relationships. The domains of this theme included health promoting activities and exercise, relationships, personal achievement activities, lifestyles, future expectations, and belief in God or a higher being. The domains within this theme are related to the ability of the individual to engage in activities of daily living and other functions that contributed to his or her overall QOL.

Table 6:

Themes Derived from the Assessment Tools

Theme Identified	Associated Domains
Health status	- Health and health care - Memory, cognition, and sleep
Activities and relationships	- Health promoting activities and exercise - Relationships - Personal achievement activities - Lifestyles - Future expectations - Belief in God or a higher being

Comparison of Themes, Domains and Categories Derived from Interview Data and the Assessment Tools

An inductive process was used to compare and contrast the themes, domains and categories from the interviews and assessment tools. This analytical methodology examined congruence or lack of congruence of the lived experiences of the interview participants with the content of the assessment tools (Table 7).

Comparison of Themes Derived from Interview Data and Assessment Tools

Table 7 provides a direct comparison of themes, domains, and categories derived from the lived experiences of the interview participants and the themes from the assessment tools. The first theme of the interviews, defining elements of QOL, reflects a more global view of the concept than the assessment tool theme of health status. The second themes identified from both the interview data and assessment tools appeared more congruent. These themes both reflected activities and factors that influence QOL in the elderly.

Although interview participants frequently mentioned health, it was viewed as an attribute contributing to QOL rather than a defining element of QOL. In fact, some participants in relatively poor health described their QOL as "good." The assessment tools, on the other hand, appear to treat health status and health care as integral elements of QOL, which, if absent, result in diminished QOL.

Table 7:

Comparison of Interview Data to the Assessment Tool Data

Interview Themes, Domains, and Categories	BRFSS	LEIPAD	SF-36	Assessment Tool Themes, Domains, and Categories
* Defining Elements of Quality of Life	-	-	-	-
** Activities and participation	-	-	-	-
Being and staying active	-	-	-	-
Contributing	-	-	-	-
Doing things together	-	-	-	-
Getting out	-	-	-	-
Growing and learning	-	-	-	-
Keeping involved	-	-	-	-
** Attitude and enjoying life	-	-	-	-
Attitude and state of mind	-	-	-	-
Enjoying life, having fun, interests,	-	-	-	-
"Live along the way," be happy				

Table 7:

Comparison of Interview Data to the Assessment Tool Data- continued

* Determinants of Quality of Life	x	x	x	* Health Status
** Health, family health, and quality of health care	x	x	x	**Health and health care
Family health	-	-	-	-
Overall health	X	X	X	Overall health
Quality of health care	x	-	-	Perception of health care needs
Sleep	-	x	-	-
Utilization of health care	x	-	-	Access to health care
Health Problems	x	-	-	Specific health issues
-	X	X	-	Mental health
-	X	-	-	Oral Health
-	-	X	-	** Memory and cognition, sleep
-	-	X	-	Memory and cognition
-	-	X	-	Sleep
-	x	x	x	* Activities and relationships
** Relationships	X	X	-	** Relationships
Family Relationships	X	X	-	Family relationships
Social Relationships	X	X	-	Social Relationships

Table 7:

Comparison of Interview Data to the Assessment Tool Data- continued

** Independence	-	-	-	-
Dignity	-	-	-	-
Independence	-	-	-	-
Doing what we/I want to do	-	-	-	-
Self-care	x	X	-	Self-care
-	X	X	X	**Health promoting activities and exercise
Health promoting behaviors	x	x	x	Daily activities and exercise
-	X	-	-	Nutrition and weight control
** Lifestyle	x	x	-	** Lifestyle
Comfort	-	-	-	-
Preparation for retirement	-	-	-	-
Personal safety	-	-	-	-
Finances	x	x	-	Finances
Physical environment and surroundings	-	X	-	Satisfaction with lifestyle

Table 7:

Comparison of Interview Data to the Assessment Tool Data- continued

** Luck and God	-	-	-	-
Luck	-	-	-	-
Belief in God or higher being	-	X	-	Belief in God or a higher being
-		X	-	Comfort in belief
** Future Expectations	-	X	x	** Future expectations
Looking forward to the future	-	x	-	Expectations of the future
** Aging and knowledge	-	-	-	-
Old age	-	-	-	-
Acquisition of knowledge through aging	-	-	-	-
-	X	X	-	** Personal achievement activities
-	X	X	-	Hobbies and personal interests
-	X	X	-	Sexual activities

Note. The large X indicates congruence, the small x some congruency, and the dash no congruence

Comparison of Domains Derived from Interview Data and Assessment Tools

Further analysis of the domains needed to be completed to support the congruence or non-congruence between interviews and assessment tool data. In Table 7,areas of full congruence are indicated by large Xs and partial congruence with small xs. A dash indicates no congruence between the two data sets.

Activities and participation. The domain of activities and participation from the interview data and the personal activities domain in the assessment tool content appear similar, but are actually somewhat different. The interview domain of activities and participation reflects being and staying active; contributing; and doing things together. It also includes the concepts of "getting out"; growing and learning; and keeping involved. The interview categories are not related to specific activities that give pleasure, rather they indicate the need of the participants to remain physically active and be participative in their chosen activities. The participant's emphasized the importance of activity in their QOL, where the assessment tool domain was focused on the elder's engagement in specific activities.

The BRFSS seeks information to determine if the respondent does or does not have hobbies and activities that fulfill an individual's personal goals. The LEIPAD directly seeks information regarding personal activities that bring satisfaction (e.g., respondent's sexual activities). Neither tool addresses frequency or level of participation or frequency regarding these activities.

Attitude and enjoying life. The interview data content was filled with references to attitude and the enjoyment of life. It reflected both positively and negatively the impact that a positive attitude and personal enjoyment has on QOL. The BRFSS, LEIPAD, and SF-36 instruments did not address this domain in any way.

Health, family health, and quality of health care. The interview domain of health, family health, and quality of health care shared some basic concepts with the assessment tool domain of health and health care. Both data sets contained indications of an individual's perception of their overall health. In the interview data, it was generalized and was a determinant of QOL. The LEIPAD contained a general question regarding an individual's perception of their health status. Both the BRFSS and the SF-36 delved into health of the individual, either by assessing the affects of their health status on QOL or in relation to the existence of specific conditions such as diabetes, cardiovascular disease, and addictive behaviors.

The interview data contained references to the health of the participant's children and grand children. This was not addressed in the BRFSS, LEIPAD, or SF-36.

The interview participants discussed their health care and quality of health care as contributing factors in their health and described their satisfaction with health care and health care providers. The BRFSS contains questions referring to whether an individual is receiving adequate health care, the necessary "amount" of health care related to their health status, participation of the individual in creating a plan of health, and health care resource allocation with their physician or case manager. This is very different from the interview participants' perceptions of health and quality of health care. Neither of the other tools addresses quality of health care in their content.

Relationships. The concept of relationships was present in the interview data, the BRFSS, and the LEIPAD. There was no reference to relationships in the SF-36 content.

Relationships, whether family or social, played a significant role in all of the participant's lived experiences. These were primary determinants of QOL for the study subjects. The BRFSS content was related to family composition and the ability of family members to assist the subject in the instrumental activities of daily living, if needed. The social component was based on loneliness, the ability to trust others, communication, and self-satisfaction with friends. The relevance of the relationship and the personal interaction, and support provided by social relationships addressed in the interview data were not included in the BRFSS. The LEIPAD deals with relationships on a social level. There is no reference to family relationships.

Independence. The topic of independence as perceived by the interview subjects was not congruent with the content of the assessment tools. The assessment tools incorporated the topic of independence into health and self-care content. The interview data reflected a more autonomous perspective of independence through the concepts of personal choice for social or health care issues, diminished ability to provide self-care or remain in the community setting, or mobility. The negative affects of losing personal independence were described as the need for increased personal assistance in the home or relocation to a senior living environment.

Lifestyle. Lifestyle among the interview participants' data was relevant as a contributing factor in individual QOL. The interview participants included their personal surroundings, personal safety, and satisfaction with their pre-retirement planning for their current lifestyles. Several of the subjects also included financial status as an element of lifestyle contributing to their QOL.

The BRFSS and the LEIPAD instruments both had components that reflected lifestyle; the SF-36 tool did not incorporate this concept. Both the BRFSS and the LEIPAD identified satisfaction with personal lifestyle and personal finances. The general reference to lifestyle did not reflect the value of personal comfort that was expressed by the participants in relating their perceptions of QOL.

Aging and knowledge. The domain of aging, the quality of the aging process, and the knowledge gained through lived experiences was reflected in a majority of interviews. This domain was not reflected in any of the assessment instruments.

Luck and God. The only shared category in this domain derived from the interview data and the LEIPAD tool was God. The concept of luck and God were reflected by the participants as contributing factors that enhance QOL, but not defining elements of QOL. The LEIPAD contains two questions regarding personal belief. These are "Do you trust in God or some superior being?" and "Do you find comfort or support in such a belief?" The BRFSS and the SF-36 do not address this domain. There was no content in the BRFSS, the LEIPAD, or the SF-36 that reflected an individual's luck as a factor in determining in his or her QOL, but this was a component found in the interview data.

Future expectations. The last domain identified from the interviews of study participants is future expectations. The BRFSS does not include the future in its content. The LEIPAD included one question on expectations of the future and its influence on doing or initiating things you want to do. The SF-36 queried expectations of physical and emotional function in the next 30 days.

Memory and cognition; and sleep. The LEIPAD instrument contains five questions relating to memory and cognition and one relating to sleep. The BRFSS and the SF-36 instruments have no content in this domain.

Sleep was discussed by one study participant, but related to her medications. Another participant felt that there was an increased issue of memory after the age of 80, but this was not relevant to his current QOL. Other references to memory and cognition in the interview data were related to community residents no longer safe to reside in the community or requiring frequent health care to remain in their condominium.

Comparison of Categories Derived from the Interview Data and Assessment Tools

The final comparison in this study involved specific categories derived from the interview data and those identified in the assessment tools. Table 7 presents overlapping categories in the two data sets as well as information on which tools included which specific categories.

Table 7 reflects a total of 33 categories; 21 (64%) were derived from interview data, three (0.1%) from the BRFSS assessment tool, four (0.12%) from the LEIPAD, and none from the SF-36.The remaining 12 (36%) tool categories were shared with two or more of the instruments. Nine (27%) of the BRFSS categories, 11 (33%) of the LEIPAD categories, and three (0.10%) the SF-36 categories were related to the interview categories. The small percentage of agreement among the categories suggests a definite lack of congruence between assessment tool content and interview data.

The BRFSS instrument had the largest number of total questions, 89, and a small number of (0.1%) of unique categories. This reflects a very low level of congruence between the interview data and the content of the assessment tool. The BRFSS instrument was composed of a significant number of questions that related to health including memory and cognition, emotional and mental health, specific health issues, sexual and reproductive practices, and other health related concepts. The interview data reflected a perceived QOL among the participants related to attitude, activity, and independence. Other interview content reflected personal contributions, choice of activities, dignity, enjoyment of life and future expectations. Commonalities between the two data sources included activities, family and social relationships, finances, quality of medical care, and environments and surroundings.

A discrepancy in focus and content exists between the interview data and BRFSS instrument. The interview data supported personal activity and autonomy, with health being a contributing factor in QOL. The BRFSS focused on health and health-related activities and behaviors that were the components of health as the major theme of QOL. This reflects a lack of congruence between the lived experiences of the study participants and the content of the tool, and suggests that the BRFSS is not a particularly valid assessment in measuring QOL in community-dwelling elders.

The LEIPAD shared 11 categories (33%) with the interview data. The LEIPAD tool is based on 49 questions versus the 89 questions of the BRFSS. The LEIPAD included categories of activity, family and social relationships, overall health, lifestyles, finance and future issues which were included in the interview data. The content of LEIPAD was not based on specific health or health issues and was centered more on the experience of aging and perceptions of QOL. The self-care components of the LIEPAD could be relevant to many elders, but were not present in the interview data as all the participants were living independently within the community. There was some congruence between the interview data and tool content. Unfortunately this instrument is not currently used for assessment of elderly individuals' QOL in the United States.

Finally, the SF-36 instrument was compared to the interview data. The design of this instrument is not age-specific or disease-specific, and reflects a lack of specificity in its content. The content of the interviews incorporated activity, participation, and positive elements of the aging process. The SF-36 was more focused on limitations or restriction of activity experienced by the subject. It shared a basis in health, but the future expectations category was limited to the next 30 days. The concepts of relationships, attitude, and personal components of QOL identified in the interview data were not found in the SF-36. The SF-36 is not particularly congruent with the interview data and is not recommended as an instrument to adequately measure QOL in the elderly population.

Generalizabililty, Reliability, Rigor, and Validity of the Research Study

Early qualitative studies did not apply the historical quantitative guidelines of generalizability, reliability, rigor, and validity. Morse (1999a, 1999b) noted that qualitative studies should be evaluated in a manner similar to quantitative research to support the findings and appropriateness of qualitative research.

Generalizability

Generalizability addresses the ability of the findings of a research study to be applied to a larger population than the cohort studied. It is based on the capacity to share, modify, and transfer knowledge within a similar population (Morse, 1999a). The generalizability of research results to larger populations is enhanced by a pre-selected or purposive sample population (Myers, 2000). It is the author's intention to use this data as a pilot study, and continue to seek out, define, interview, and analyze data from other community-dwelling elders in a variety of environments to determine the generalizability of this study.

One generalizability issue that affects this study is the pre-selected sample population. All subjects were American (by birth) and owners of their residences in an upper middle-class community. The condominiums are surrounded by affluent individual residences and share land with a private championship golf course. This sample was intentionally chosen for the homogenicity of the cohort. The nurse researcher plans to continue to recruit a variety of cohorts sharing similar cultural, religious, birthplace, and economic factors as examples to increase not only the sample size, but also specific subgroups within the overall population of the elderly. The generalizability issues are expected to decrease as more cohorts of elderly individuals are entered into the study.

Reliability

Reliability in qualitative studies can be established in three ways. The first method of establishing reliability of qualitative data is the evaluation of the research protocol, questions, and data by non-participating observers. This resource was applied in four phases of this research project. First, the three-member dissertation committee conducted the initial evaluation of the protocol and interview questions. Following the first two subject interviews, two members of the dissertation committee reviewed the interviews for researcher preparation, conduct, evaluation of the interview process, data gained, and relevance of the data obtained.

The second mechanism for establishing interrater reliability involved reviewing the transcripts of the data gathered. Two doctorally-prepared nurse educators, one a member of the author's dissertation committee and one specializing as a gynecological and community health nurse practitioner participated in this review. Both have conducted and published qualitative research. The purpose of the expert panel and peer debriefing was to confirm the nurse researcher's identification of categories, domains, and themes from the interview data.

The final means of testing reliability will be the presentation and defense of the results of this research to the researcher's dissertation committee and peers. This will be the definitive test of reliability of this study.

Rigor

Rigor in qualitative research depends on the checks, threads, and procedure clarification that are reviewed, analyzed, and maintained throughout the study. One means of supporting this in the research process was frequent review of written transcriptions, audio-tapes, and field notes by the researcher from the initial data collection process to the conclusion.

A second process for establishing rigor is peer debriefing on the data gained through the interviews. The review of all available data by the nurse researcher was begun as soon as it was available and was reviewed throughout the data collection period and numerous times during analysis. A peer debriefing of doctorally-prepared nurse educators and researchers was conducted at the completion of data collection and data analysis by the nurse researcher.

Validity

Validity of qualitative research data is based on the consistency of transcription of the audiotapes, systematic and consistent coding of data, and justification of the data derived (Green, 1999). Trochim (2000) defined qualitative validity to mean that the data and conclusions reached are a basis for explaining the phenomenon studied and are credible to other qualitative researchers. Again, the expert panel and dissertation committee review of the data support its validity. Validity will be strengthened as more cohorts are added to this initial pilot study.

There is controversy in nursing research whether qualitative research must meet the requirements of generalizability, reliability, rigor, and validity (Morse, 1999b). This nurse researcher believes that meeting the identified requirements increases the credibility of findings. It is this nurse researcher's opinion that this study reflects the criteria of generalizability, reliability, rigor, and validity as described.

Chapter 5

Discussion

The initial intent of this study was to identify elements of QOL through the lived experiences of a selected population of community-dwelling elders. Twelve participants were interviewed in their homes regarding their perceptions of QOL and their lived experiences. The results of the interviews, taped and transcribed, and the author's field notes provided a wealth of data for the analysis process. This indicates that the selection of a small, 10 to 12, community-based population of elderly who have access to similar resources can provide rich lived-experience data regarding QOL that permit identification of categories, domains, and themes (Morse, 2000a).

The data gathered in this research indicated that the QOL experiences of community-dwelling elderly individuals constitute a complex phenomenon that incorporates several domains: activities and participation; attitude and enjoyment of life; health, family health, and quality of health care; and relationships. Other domains were independence; personal comfort; aging, knowledge, luck, and God; and future expectations. These are the relevant indicators that were shared by the subject group and that provide a basis for ongoing research on QOL as perceived by community-dwelling elders.

Conclusions

Based on the findings of this study, the following conclusions were reached:

1. The findings of this study were congruent with previous literature on QOL in the elderly.
2. The assessment tools evaluated in this study were not congruent with the study population's perceptions of QOL.
3. Additional research is needed related to elderly community-dwelling residents perceptions of QOL and QOL assessment tools.
4. Simpler more reliable assessment tools might be created for use practice settings.

Congruence with Previous Literature

Glass (1999) studied the association of social, productive, and physical activities with longevity in 2,761 males and females over the age of 65 years. The results indicated that the more active elderly individuals at the beginning of the study were able to maintain their levels of activities and self-care and reflected a longer lifespan. Participation in social, physical, or productive activities including social interactions was included in the domain of activity and participation in this study. Physical activities, especially if fitness-oriented, integrated into the daily routine of longer-lived individuals were very beneficial., Activities that incorporated daily tasks, autonomy, and a sense of accomplishment were associated with increased personal independence and longevity.

The focus of Glass's (1999) study was longevity rather than QOL. The study supports the association between aging, activities, and independence. This association was identified in the domains of activity and participation; aging, and knowledge; luck and God; and independence derived from the interview data.

Ostir (1999) concluded that elderly individuals who chose or were restricted from physical activities and social participation experienced a decline in their functional abilities. Decreased levels of participation were associated with diminished self-care. The decreased self-care led to a loss of "personal lifestyle" by the older individual that was reflected in decreased mobility, increased pain with movement, and increased disability. Interventions in the study to improve and increase levels of activity and participation of the elderly individual slowed the decline of functional abilities including self-care, immobility, pain, and disability. These reflect the domains of activities and participation and independence identified in the study population.

Cardinale (1993) stated that every step in one's lifestyle is different, but generally related. "Old people need money for food, shelter, and clothes; a safe environment and transportation to get there; people around us who care about us and us for them; and most importantly, we need an activity, a reason to get up in the morning." During the interview Cardinale was 68-years old and executive director of the Brookdale Center on Aging (Hunter College) in New York City. Cardinale's views support the domains of relationships, personal comfort, and future expectations in this research.

Going back into the interview data, activities and participation were mentioned in every dialogue, and independence was frequently mentioned when describing activities. The phrases of "Doing what I want to do when I want to do it", "Not doing what I don't want to do", and "choosing the activities we want to do every day" were examples of the data collected. Perrig-Chiello, Perrig, and Staheling (1999) identified similar content in their study of 442 community-dwelling elders. They used the term "control", to identify the activities and behaviors that were reflected in a positive QOL in the sample. Control was identified as a major factor in the elderly individual's internal regulation of cognition, emotion, and motivation, and can be externally observed through activities and participation by the individual. Interestingly, older individuals in the present study who were in fair to poor health relinquished their control to a degree and attributed their poor QOL to poor health and lack of participation in activities within or outside of their personal residence.

These findings support not only the domain of participation and activity by the elderly sample population of this study, but also addressed the domain of attitude and enjoyment of life within the QOL elements theme. Control can also be associated with independence or autonomy, a domain in the contributors to QOL theme.

Grundy and Bowling (1999) identified three major "domains" of quality of life in a study of 630 elders. These were well-being and autonomy, health and activity, and environment. These domains are congruent with three of the five domains in the theme of contributing attributes. These were independence with well-being and autonomy; health, family health, and quality of care with their domain of health, and activity; and environment, identified as personal comfort in this study.

In a study discussing the concept of "aging well," Adams and Blieszner (1995) related that just "having" relationships with family and friends is not adequate in identifying this domain in an elder's life. Rather, the relationships should be substantial and positive. Negative relationships with family and friends may contribute to physical decline in an elder as much as having no relationships might. The interview data reflected a variety of relationships in the elderly sample, but only one indicated a negative relationship within a family unit.

Katz (2000) referred to defining elements of QOL and determinants of QOL themes delineated in this study in his discussion of aging in the current world environment. He described an element of "busyness" comparable to the domain of activities and participation identified in this study.

Issues relating to QOL in aging individuals have also been researched worldwide. Five international studies include those by Matsubayashi, Okumiya, Osaki, Fujisawa, and Doi (1997) with older community-dwelling elders in Japan; Urciuoli and De Leo (1998) in Italy; Fernandez-Ballesteros (1998) Spain; Tobiasz - Adamczyk and Szafraniec (1995) in Poland; Li (1998) in China; and the QOL compendium from Norway by Hanestad and Kalfoss (1999). In each of these studies, participation and attitude were found to be relevant to the aging community-dwelling elder, as elements of QOL and determinants necessary to maintain QOL.

Congruence of Assessment Tools to Interview Data

The second purpose of the study was to examine congruence between the content of currently used QOL assessment instruments and elder's perceptions of QOL. The comparison of the themes, domains, and categories of the interview data and the assessment tools indicated that of the three assessment instruments, the LEIPAD was the most appropriate as a QOL assessment tool in community-dwelling elderly persons. The focus of the LEIPAD questions reflected a greater congruence with the themes and domains from the interview data than the BRFSS and the SF-36.

When designing the LEIPAD instrument, De Leo et al. (1998) attempted to create a general assessment tool that was translatable, culturally sensitive, and relevant in the twenty-first century. It appears to be an instrument that reflects some of the domains of QOL as experienced by the interview participants. There was congruence between activities, attitudes, social, physical, and personal needs derived from interview data and the instruments content.

The LEIPAD instrument is considered to be a European tool and has not been implemented in the United States. Brown University includes the LEIPAD in its' "Toolkit of Instruments to Measure End-of-Life Care" (2000). This may be an instrument that could be useful in assessing community-dwelling elders.

The BRFSS, a second alternative, could be useful in assessing QOL in community-dwelling elders if further research could be done to identify a sub-set of questions specific to elderly individuals. The three major negative aspects of the tool were length of the tool (89 questions); inability to be self-administered; and the minimal inclusion of content irrelevant to QOL in the elderly population. There was congruence between the interview data and the issues of social relationships, individual resources, and family relationships addressed in the BRFSS tool. The BRFSS instrument continues to be used in public health surveillance by both the CDC and individual state health agencies (The Hospital and Health System Association of Pennsylvania, 2000; West Virginia Healthy People 2010; Objectives, 2001).

The SF-36 was found to be deficient in several areas, and is not recommended as a geriatric assessment tool because it excludes several critical domains derived from the in community-dwelling elders' lived experiences. The SF-36 focuses specifically on health, pain, and function, leaving other domains relevant to the survival and safety of community-dwelling residents unexplored. Even if used as a screening tool prior to a physical examination, several needs of the elderly by relating to their abilities to remain in a community-dwelling setting could remain under-diagnosed or misdiagnosed.

The SF-36 continues to be the primary assessment tool associated with the HEDIS surveillance program. HEDIS is no longer a government-based program, but has been used as criteria for the measurement of managed care and primary care health programs, corporate health insurance packages offered to employees, and criteria for accreditation programs (COLA, 2000; Quality Metric Incorporated, 2000; Crozer-Keystone Health System, 2001; The National Committee for Quality Assurance [NCQA], 2002).

The utilization of the SF-36 instrument in measuring and establishing health outcomes in the elderly population is a major concern. The findings of this study do not support the congruence of the instrument and the QOL data collected. Misallocation of health care resources and inaccurate measurement of health outcomes in the elderly American population may easily occur as a result of the extensive use of this intrument.

Future Research

This research is the first of several planned studies of the phenomenon of QOL in community-dwelling elders. Interviews will be conducted with the schedule of questions used in this research (Appendix B) in other pre-selected samples of community-dwelling elders. This will expand the generalizability of the data gathered and the analytical results of the phenomenological study. It is projected that with the addition of future cohorts, the themes in this study may not remain consistent, but may be incorporated into other themes generated from the lived experiences and perceptions of future subjects.

The evaluation of QOL assessment instruments will continue in relation to the themes and lived experiences of future study participants. Related to the findings of this study, the LEIPAD and SF-36 will continue to be utilized as comparisons for future participant cohorts. Though this study finds the SF-36 not to be congruent in assessing QOL in the elderly, it will be included in the next two to three cohorts because of its popularity in clinical settings and policy-making decisions such as HEDIS. The BRFSS will not be investigated due to the lack of congruence in content, length, and a significant lack of relevancy in the content. A third instrument will be chosen for analysis in future study cohorts.

Future Design of Assessment Tools

The findings of this study led to the development of two major themes: defining elements of QOL and the determinants of QOL. These findings suggest that two simple questions might be used by practitioners to assess QOL in elderly clients. These questions are:

1. Can you do what you want to do in your life?
2. If not, why?

These questions may be appropriate at a primary health provider setting, with a one-on-one communication between the patient and physician, but not for aggregate data collection.

The priorities that evolved from this study three -fold. They include continued research into what constitutes QOL for the elderly population, identification or design of an assessment tool that accurately reflects QOL in individuals over the age of 65-years, and education of policy makers on elements of QOL as perceived by the elderly.

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Appendix A

Recruitment Letter

Dear ____________________,

My name is Kim McClane, and I am doctoral student in nursing at the University of San Diego. I am completing my dissertation concerning health issues of community dwelling elderly over the age of 65 years. My reason for contacting you at this time is to request your participation in my research project.

If you choose to be a participant in my study, I will ask you to meet with me for an interview approximately 60 to 90 minutes. The interview will consist of general health questions and beliefs about your quality of life, health, and some basic data concerning your age, gender, education, and so on. For your convenience, this interview will take place in your condominium at a time convenient to you.

The content of the interview will be tape recorded, and transcribed for analysis. As a participant, you will have complete anonymity. I will not be contacting your physician or any other health provider concerning the information discussed at the interview. Presentation of the findings of this study will reflect only coding for identification without your name or other personal information.

Your participation in this study is purely voluntary without financial benefit. The benefit to participating in this study will be in knowing that you are adding to the knowledge of nursing science and gerontology.

I will contact you via telephone in the next few days to discuss this. I thank you in advance for your cooperation.

Sincerely,

Kimberly (Kim) McClane, RN, PhD(c)

Appendix B

Informed Consent Form

You are invited to participate in a study to identify health-related quality of life issues in community-dwelling residents over the age of 65 years in San Diego County, California over the age of 65 years. This study is being conducted by Kimberly S. McClane, R.N. as a dissertation project at the Hahn School of Nursing and Health Science at the University of San Diego.

If you agree to participate in this study, you will be expected to meet with Ms. McClane on one occasion when Ms. McClane will explain the project again, gain your consent to participate, and interview you for 60 - 90 minutes. The topic of this interview will be your beliefs and experiences with your health and how it relates to your quality of life. Each interview will be tape-recorded and transcribed for accuracy.

Ms. McClane will analyze the information gained during the interview for its content and themes to identify factors important to you and your experiences. The results of this research project will be used for completion of her dissertation and for publication and presentation to professional health care programs and journals. All means will be used to maintain your confidentiality and personal rights. Any reference in reporting the findings will reflect only initials and age.

If there is evidence of elder abuse during the interview process, Ms. McClane will report such information to the Adult Protective Services.

Participation in this study is voluntary. Participants will not receive any form of compensation other than personal satisfaction for participation. There are no potential risks to personal safety, harm or discomfort in participating in this study.

For any questions or concerns regarding this research, please contact Ms. McClane at:

Home: (858) 485-6217

E-mail: kmcclane@soh.csudh.edu

Or, you may contact her dissertation chairperson Dr. Mary Jo Clark at:

Office: (619) 260-4574

E-mail: clark@sandiego.edu

I, the undersigned, fully understand the above explanations and, on that basis, I give consent to my voluntary participation in this Health-Related Quality of Life research project.

______________________________ _______________

Signature of Research Participant Date

______________________________ _______________

Signature of Principle Researcher Date

Appendix C

Schedule of Questions

1. When you talk about quality of life, what comes to mind?
2. When you say you have a good quality of life, what do you mean?
3. What would be a bad quality of life?
4. Does your health influence your quality of life? How?
5. Has your quality of life changed related to changes in your health?
6. What else influences quality of life?
7. What is your current age? Marital status? Educational background? Occupation?
8. What is your household yearly income?

Appendix D

Demographic Data on Participant's Age, Sex, Marital Status, and Education

	Males (%)	Females (%)	Total (%)
Number Of Participants	5 (42%)	7 (58%)	12 (100%)
Age of Participants			
Range	73 - 89	69 – 77	69 – 89
Mean	82	72	76.2
Standard Deviation	5.833	3.481	6.801
Marital Status			
Married	3 (60%)	2 (29%)	5 (42%)
Widowed	2 (40%)	5 (60%)	7 (58%)
Education			
Grade School	1 (12%)	---	1 (12%)
High School Degree	2 (16%)	3 (25%)	5 (42%)
Some College/Technical	---	4 (33%)	4 (33%)
Bachelors Degree	2 (16%)	1 (12%)	3 (25%)
Financial Status			
$20,000 – $40,000/yr	3	2	5 (46%0
$40,000 – $60,000/yr	2	3	5 (46%)
<$60,000	0	0	0
Declined		2	2 (8)

Appendix K

Item Content in the Assessment Tools:
BRFSS, LEIPAD, and SF-36

Category of Item	BRFSS	LEIPAD	SF-36
Overall Health:			
- Age	X-2		
- Race	X-3		
- Perceived health status	X	X	X - 2
- Time related (before or after)	X	X	X – 2
- Energy		X	X – 3
- Depression		X – 2	X – 3
- To others			X
- Perception of mental health	X		X
Specific Health Issues:			
- Do you have frequent pain?	X		
- Any physical problems that affect your health	X-2		
- Problems relating to addiction	X-5		
- Treatment for depression			
- Have you/do you currently use tobacco products	X-12 X		
- Frequency/since last use	X-6		
- If you are male, have you ever been exposed to HIV/AIDS	X-3		
- Have you been tested for HIV/AIDS? Why?	X-5		
- Have you ever given/received blood transfusions			
- If you are female, have you ever had a breast exam/mammogram? How often? Your last?	X-4 X-2		
- If female, have you ever had a pap smear? How often? Latest?	X-5		
- If female, have you gone through menopause? Receiving supplemental hormone therapy?	X-5		
- Have you been diagnosed with diabetes? Treatment and results?	X-12		

- Have you been diagnosed/treated for arthritis?	X-6		
- Have you been diagnosed with hypertension? Are you currently being treated for it?	X-3 X-3		
- Have you been diagnoses or treated for elevated cholesterol?	X-4		
- Have you/do you participate in colorectal cancer screening?	X-2		
- Have you been diagnosed/treated for skin cancer? Use sunscreen?	X-7		
- Are you current with all flu and pneumonia immunizations?	X-6		
- Have you been diagnosed/treated for cardiovascular disease?	X		
- Do you have chest pain or shortness of breath?			X
Daily Activities & Exercise:			X
- Planned exercise/Vigorous exercise	X-3		X
- Frequency	X-3		
- Eating/Preparations of meals		X	
- Shop for personal needs		X	
- Use public transportation		X	
- Health limitations doing moderate activity	X	X - 2	X - 10
Nutrition & Weight Control:			
- Use of/how often fruit/juices/vegetables	X-5		
- Are you currently overweight?	X		
- Are you attempting to loose weight/method	X-4		
- What is your current weight? Height?	X		
- Do you take vitamin supplements? What type?	X-4		
Emotional Problems:			
- Interfering with ADLs/sleep?	X-2	X	X
- Time related (before or after)		X	X - 2
- Easily annoyed or irritated	X	X	
- Have outbursts of temper I cannot control		X	
- Become argumentative		X	
- Resentful of others		X	
- Ready to go out of the way to help others		X	
- Jealous of others "good fortune"		X	
- Feel inferior to others/useless		X	

- Have negative feelings/perceptions of self – no one understands me		X	
- Worry about "life" or people plotting against you		X	
Emotional/Health Issues Affecting Social Activities:	X-3	X - 2	X-2
Future Expectations:			
- Worse health			X
- General lifestyle - maintain		X	X
- Initiating/Doing activities you want to do		X	
- Mental/emotional health			
Sleep Patterns:		X	
Memory & Cognition:		X	
- Ability to concentrate		X - 2	
- Think clearly or confused		X	
- Problems associated w/ confusion		X	
Social Ties/Relationships:			
- What is your zip code?	X		
- Currently married	X	X	
- Are any children residing in your home?	X		
- Satisfaction with current social life and relationships/lonely		X X	
- Someone to share thoughts/concerns		X	
- Can most people be trusted?		X	
- Have trouble dealing with others			
- Dissatisfied with the person I have become		X	
- Other people are bothered by the things I say		X	
- Frequently gossip		X	
- Avoid relationships/activities because of feelings of inferiority		X	
- Do you have family members/caregivers who would be willing to assist you?	X-3		
Sexual Activities:			
- Sexually activity/interest	X-5	X – 2	
- Have you been diagnosed/treated for a STD?	X-5		
- Do you currently use protection during sex or practice family planning?	X-9		
Hobbies or Personal Activities:			
- Level of education completed	X		
- Participate/Satisfied with current hobbies or activities		X X	
Financial Considerations:			

- Satisfied with personal financial resources		X	
- How many telephones are in your home?	X-2	X	
- Can/not afford current lifestyle	X		
- Can/not afford health care	X		
- Did your spouse work outside of the household? Type	X		
- Current annual household income	X		
Satisfaction with Current Lifestyle:			
- How satisfied are you with your current lifestyle?		X	
Religion:			
- Do you trust/believe in God or a Superior Being?		X	
- Do you find comfort with this belief		X	
Military History:			
- Have you ever participated in active military service?	X		
- What is your current status	X		
- Do you have/utilize VA benefits	X		
Medical Care:			
- When was your last medical check-up	X		
- Do you have access to health care?	X-5		
- Do you have Medicare	X		
- Do you have access to supplemental insurance coverage?	X		
- Do you need more medical care than you are receiving now	X		
- Do you have all the supportive/assistive devices you need for your ADLs	X		
- Have you (in the last 6 mos.) or do you need personal assistance? Are you receiving it?	X-3		
- In the last 6 mos. have you provided healthcare to a friend or family member?	X		
Oral Health:			
- How long since your last dental care visit?	X		
- Are you being treated for tooth decay, gum disease(s), or orthodontia?	X -3		