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Quality of life as perceived by community dwelling elders

Judith Ann McHale Monahan
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Quality of life as perceived by community dwelling elders

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San Jose State University, 1993

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QUALITY OF LIFE AS PERCEIVED BY COMMUNITY DWELLING ELDERS

A Thesis

Presented to

The Faculty of the Department of Nursing
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

by

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May, 1993

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ABSTRACT

QUALITY OF LIFE AS PERCEIVED BY COMMUNITY DWELLING ELDERS

by Judith Ann McHale Monahan

This study surveyed quality of life in a sample of community dwelling elders ($N=12$; M age=80.9 years). Data were gathered using the 68 item generic version of the Quality of Life Index (Ferrans & Powers, 1985a) and a demographic questionnaire. The QLI consists of four subscales (health and functioning, socioeconomic, psychological/spiritual, and family). Items are measured in two parts each on a 6-point scale: Part I ranges from "very dissatisfied" to "very satisfied," and Part II ranges from "very unimportant" to "very important." Overall scores range from 0 to 30 and are calculated by weighing satisfaction responses with paired importance responses. QLI results for this sample demonstrated a good quality of life ($M=24.18$; $SD=3.71$) overall. However, differences were found in the domains of health and functioning, and psychological/spiritual. The QLI and the four domains may enhance the nursing process by providing individualized data for patient assessment.

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Chapter 1

INTRODUCTION

Quality of life is a complex concept that gained political recognition during the post World War II era that proclaimed the good life in America as something more than material well-being (Campbell, 1981). The concept has been studied and debated by various disciplines in an effort to define and improve the human condition. It has been interpreted as well-being, satisfaction, morale, and happiness. And, it is further delineated by culture, economics, and time-related phenomena such as the effects of age, period, and cohort (Andrews, 1986).

Since the turn of the century, lifespan in the United States and other developed nations has increased dramatically. In the United States, the average life expectancy increased from 49 years in 1900 to 75 years in 1985. Women tend to outlive men so that at age 65 women may expect to live 4.4 more years longer than men (National Center for Health Statistics, 1987).

At the turn of the century, America had 3 million people aged 65 and older, of which 130,000 were 85 years and older (National Center for Health Statistics, 1986). Based on 1989 statistics there were 30.9 million people (12.6 million male and 18.3 million female) aged 65 and

older, of which 3 million (850 thousand male and 2.2 million female) are aged 85 and older (U. S. Bureau of the Census, 1991).

The age structure of the United States reflects the birth history of the nation. Seventy million Americans were born in the postwar era (1946-1960); these babyboomers will reach a mean age of 65 and 85 by 2020 and 2040, respectively. With the advent of oral contraceptives and legalized abortions, this smaller cohort of workers born during the 1970s and 1980s may face a crisis--fewer caregivers for more elderly, and fewer workers to pay into the Social Security system to provide long-term care (Scharlach, Lowe, & Schneider, 1991).

Some estimates suggest that the population is living longer but suffers from more chronic diseases (Longino, Soldo, & Manton, 1990). Therefore, advances in health care have posed questions as to the effectiveness and cost effectiveness of treatments which "must be measured in terms of quality of life" (Katz, 1987, p. 459).

The concept of quality of life is multifaceted, distributed over time, partly subjective, and partly objective (Lawton, Ross, & Glicksman, 1990). Overall, quality of life appears to be conceptualized best by satisfaction with the experiences and conditions of life (Ferrans & Powers, 1985b; George & Bearon, 1980) and, as

stated earlier, integration of objective and subjective elements.

Quality of life is considered by some as a measure of risk factors as well as an outcome measure; however, there is no standard for methodology. Measurement varies from a single item to multiple-item measures (Kempen, 1992). According to Bergner (1989), some instruments produce single scores based on a single dimension while others are multidimensional with a single score that cannot be aggregated. Despite the controversy that surrounds quality of life theory and methodology, assessment of this concept could produce critical data related to decisions on policy and program planning for the elderly. This study addressed the concept of quality of life as perceived by a sample of community dwelling elders.

The Problem and Research Question

Long-term care for the elderly is a social issue of growing importance. The needs of many community dwelling elderly people do not qualify them for traditional home health care or institutional services such as those provided by Medicare. In this respect, community dwelling elders are often ineligible for many health care services. Nursing is challenged to find ways to identify elders who are in need of service, and then, to provide assessment, promotion, and maintenance of health care for this

population. To accomplish this goal, individual values of elders and levels of satisfaction with various aspects of daily life must be delineated.

The question addressed in this study asks: How do community dwelling elderly people perceive their quality of life? Data from this survey could be used in the development of nursing interventions to enhance quality of life for this population.

Purpose and Need

The purpose of this descriptive study was to explore quality of life as perceived by a sample of 12 community dwelling elders who were clients of a Nurse Managed Center. The quality of life of these subjects was assessed according to levels of satisfaction and importance in four domains as described by Ferrans and Powers (1985a): health and functioning, socioeconomics, psychological/spiritual, and family.

Definition of Terms

For purposes of this study, the following definitions apply:

1. Quality of life is a person's sense of well-being that stems from satisfaction/dissatisfaction with the areas of life that are important to him/her.

2. Satisfaction is the cognitive, judgmental experience of the conditions of one's life.

3. Health and functioning is a person's state of wellness and their ability to negotiate life activities.

4. Socioeconomics is a person's access to valued resources including family, friends, finances, health and community services.

5. Psychological/spiritual are the attitudes and beliefs that guide a person's life.

6. Family is a person's network of supportive relatives and/or friends.

Research Design

This descriptive study employed a non-experimental design. A convenience sample was composed of 12 community dwelling elderly people. Each subject completed a 68-item questionnaire, Quality of Life Index (QLI) (Ferrans & Powers, 1985a) and a 9-item demographic questionnaire.

The objectives of the study were (a) to describe characteristics of the population, (b) to describe the perception of quality of life of the sample, and (c) to suggest specific nursing intervention strategies that might enhance the quality of life for the sample. Descriptive statistics were used to analyze the data.

Scope and Limitations

Findings from this study are limited by the size and the demographics of the sample. Though the sample is representative of the population served by the Nurse

Managed Center, results cannot be generalized. In addition, controversy exists regarding the conceptual meaning and measurement of quality of life.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF RELATED LITERATURE

Conceptual Framework

The conceptual framework used for this study was developed by Ferrans and Powers (1992). It defines quality of life in terms of four domains, namely, health and functioning, socioeconomic, psychological/spiritual, and family. It is based on the belief that quality of life is "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her (p. 29)." This definition acknowledges the diversity of individuals and their values. Further, quality of life is conceptualized subjectively as "most meaningful as it is experienced and perceived by individuals," and objectively as "the conditions that influence quality of life" (p. 30).

Ferrans and Powers (1992) chose satisfaction to explain quality of life "because it suggests a cognitive, judgmental experience, which fits conceptually with the notion that judgement and evaluation of life's conditions determine one's experience of quality of life" (p. 29). The related concepts of quality of life and life satisfaction, the Quality of Life Index, and the four domains of health and functioning, socioeconomic,

psychological/ spiritual, and family are discussed in the following review of the literature.

Review of Literature

Quality of Life

Interest in the concept of quality of life in health care grew from the ability to prolong life, and to the realization that patients want to live well and not merely survive (Waltz & Strickland, 1984). There have been problems in rigorously defining and measuring quality of life (Ferrans & Powers, 1985a; George & Bearon, 1980; Medley, 1976). For instance, quality of life was found to be synonymous with (a) well-being (Fillenbaum, 1988), (b) happiness and satisfaction (Neugarten, Havinghurst, & Tobin, 1961), and (c) morale, life satisfaction, adaptation, and mental health (Lawton, 1975). Throughout the literature, the most salient of these concepts appears to be life satisfaction (Conte & Salamon, 1982; Ferrans & Powers, 1985a; George & Bearon, 1980; Neugarten et al., 1961). Globally, the World Health Organization is attempting to identify ways to assess quality of life in old age (Butler, Hermanova, Wertheimer, Evans, & Michel, 1992).

Because the mind influences perceptions of environmental conditions, definitions of quality of life have included both objective and subjective perceptions.

Measures of objective quality of life usually include indicators such as income, housing, and physical function, but these do not tell how people perceive life experience. "Therefore, the concept of subjectively perceived quality of life requires analysis as a discrete entity" (Oleson, 1990, p. 187). The importance of measuring both subjective and objective indicators, or how subjects describe their own experience, and what things influence that experience is widely supported in the literature (Burkhardt, Woods, Schultz, & Ziebarth, 1989; George, & Bearon, 1980; Medley, 1976; Neugarten, et al., 1961).

George and Bearon (1980) recommend that quality of life as a construct could be used to benefit research and service delivery related to the elderly. In addition, they refer to its potential importance in facilitating communication between basic scientists, applied researchers, and service practitioners who work to improve the conditions of life. For example, Pearlman and Uhlmann (1988) studied 126 outpatients with various chronic diseases and their physicians for the purpose of better characterizing quality of life. The findings showed that physicians' and patients' ratings of global quality of life to be significantly different in that the physicians' ratings were lower across all disease conditions. Among the findings of this research was the suggestion that

nonmedical factors (i.e., relationships and finances) are important indicators of quality of life in making health decisions.

Quality of life measures are used with the elderly to explore various aspects of life. Examples include (a) drug treatment (Bulpitt & Fletcher, 1990), (b) general health and functioning as well as specific disease conditions (Bergner, 1989; Ferrans & Powers, 1992), and (c) adaptations for independent living (Reschovsky & Newman, 1990).

Recent reports on the international level (Katz, 1987; Butler et al., 1992) suggest that quality of life among the elderly is a topic of worldwide concern. While there is some focus regarding the need to teach clinicians early in their training about the concepts, methodology, and application of quality of life measures, there remains much to be done in this regard (Radecki & Cowell, 1990).

Information provided by quality of life measures is "theoretically sound and is currently being tested" (Bell, Bombardier, & Tugwell, 1990, p. 596). Research during the 1980s sought to improve the applicability of quality of life instruments, by refining and improving specificity and sensitivity, for the purpose of monitoring disease-specific and patient-specific changes. Until the ideal instrument is developed through comparative testing of current tools

in clinical situations, there can be no standard for quality of life research. However, data gathered from these instruments has and may continue to guide identification of patient problems, treatment priorities and interventions, change over time, and methods for program evaluation and policy planning.

Life Satisfaction

According to Webster (1981), satisfaction refers to the complete fulfillment of needs, expectations, wishes, and desires. Life satisfaction as a construct has been used by various disciplines to examine domain-specific issues. There are studies in psychology and social epidemiology to examine life satisfaction in relation to mental health. Social gerontology has used life satisfaction measures to indicate adjustment to late life (George & Bearon, 1980; Medley, 1976). Increasingly, health professionals who work with the chronically ill have focused on not only the length of life but also on the positive attributes that bring meaning and satisfaction to life (Burkhardt et al., 1989).

Regarding the attitudes of the elderly towards health, Medley (1976) examined the relationship among financial situation, health satisfaction, satisfaction with standard of living, satisfaction with family life, and satisfaction with life as a whole. Findings from this study of 109

males and 192 females (median age was 71 and 71.95, respectively) revealed health satisfaction to be a more important determinant of quality of life than actual health status.

Quality of Life Index (QLI)

The QLI was developed by Ferrans and Powers (1985a) to fill a void in the literature for instruments that would "allow health care professionals to pinpoint problem areas, examine practices, and plan interventions to improve quality of life" (p. 29) for their clients. The instrument was designed for use with healthy individuals as well as those with specific diseases. For example, there is a generic version of the QLI and there are versions specifically for use with oncology patients and renal dialysis patients. According to Ferrans (personal communication, C. Ferrans, October 7, 1992), the QLI has been used successfully with the elderly.

Health and Functioning

The trend towards longevity is due largely to advances in the fields of medicine and public health. Consequently, the focus of health care has changed from infectious disease to chronic disease (Katz, 1987). Reductions in mortality have increased the survival time for persons affected by the major life-threatening chronic diseases: heart disease, cerebrovascular disease, and malignant

neoplasms. Prominent among factors which compromise life expectancy and healthy aging are arthritis, diminished hearing and vision, dementia, hip fracture, incontinence, widowhood, social isolation, symptoms of depression, and institutionalization (Brody, 1989).

Although there is a great deal of variation, for most people there seems to be a point between 80 and 90 years of age when people become "old," and when the fear of becoming helpless is a greater fear than death (Bould, Sanborn, & Reif, 1989). Four times as many elders live in the community as live in nursing homes and most of their care is provided by family and friends (Folden, 1990; Reschovsky & Newman, 1990; Tilson, 1990). The health care needs of the elderly are complex. For instance, most elderly people have at least one chronic condition, and those over 85 are likely to have several (Fulmer, 1991; Morishita, Siu, Wang, Oken, Cadogan, & Schwartzman, 1989).

Data suggest that there exists age-related deficits in health promotion and preventive care for the elderly population (Radecki & Cowell, 1990). For example, Radecki and Cowell cite that people over age 65 are less likely to be aware of the effect of behavioral patterns on health, and that health education and screening examinations are provided less frequently to the elderly.

One goal of the Surgeon General's report (U. S. Department of Health, Education, & Welfare, 1979), was "to improve the health and quality of life for older adults and, by 1990, and to reduce the average number of days of restricted activity due to acute and chronic conditions by 20 percent, to fewer than 30 days per year for people aged 65 and older" (p. 71). However, though an effective national health care strategy needs to include medical care, illness prevention, and health promotion across the lifespan, only in recent years has attention been given to health promotion in the elderly (Walker, 1990).

Rowe and Kahn (1987) explicated bereavement and relocation as two life disrupting events that are common among older people. They reported that these events are studied for their effects on morbidity and mortality but failed to show the connection with losses in social support created by these events. Further, these authors noted a "causal complexity" (p. 237) in that distinction between autonomy-increasing support and constraining care is prevalent in the field of child development but not in gerontological research.

Autonomy and social support are reportedly important variables related to health behavior, morbidity, and mortality (David, 1990). While the elderly are heterogenous, having differing needs and abilities, some

functional losses have been reversed among residents and prospective residents of nursing homes, through even modest increases in autonomy (Rowe & Kahn, 1987).

The World Health Organization (WHO) in 1958 (Fry, 1988) defined health as "a state of complete physical, mental, and social well-being and not merely the absence of disease" (p. 68). Current gerontological and geriatric literature emphasizes a focus on functional integrity rather than on structural deficits in defining health. The elderly are a diverse group with a wide range of health issues for whom, despite age-related changes, the capacity for growth and adaptation remains (Matteson & McConnell, 1988).

Hing and Bloom (1991) reported that functional dependency is higher at older ages: from 20% among those aged 65-74 years, to 66% among those 85 years and older. Further, the average age of the functionally dependent in nursing homes was 83 years, while for those using formal and/or informal services at home averaged age 78 and 77 years, respectively.

The literature suggests that there are age-related deficiencies in health promotion and preventive care directed toward the elderly population. Diagnostic screening declines significantly among patients 75 and older and they are less likely to receive education

counseling (Radecki & Cowell, 1990). "The use of chronological age as a primary criterion in justifying withholding treatments such as chemotherapy and hemodialysis for elderly patients has been cited as evidence that the elderly are at risk for inadequate treatment" (p. 300).

Current research on aging disputes the pathological model of biological aging which is based on notions of inevitable decline in health and function (Dean, 1992). While little is known about the complex interaction of biological, behavioral, and social variables of aging, Dean found that psychological distress directly affected illness episodes and perceived health status, especially in women.

Aging of the body increases the vulnerability to health and functional problems (Fry, 1990). Despite cultural attempts to modify appearance and to deny the gradual effects of aging, it is impossible to halt gradual functional decline. The goal is to find ways to compensate for deterioration in health and function and thereby improve quality of life among the elderly.

Socioeconomics

The population of the United States is aging. Since 1960, the older segment of the population has grown at a rate twice that of the general population with a "recorded average annual net gain of nearly 452,000" (Longino, et

al., 1990, p. 19). Demographically, the elderly population (those 65 and older) of the United States has grown from 4.1% at the turn of the century, to 8.1% in 1950, and to 11.9%, or 1 in 9 in 1985 (p. 21-22).

This expansion of the elderly, and particularly the oldest old, population creates a heightened need for private and public attention to focus on long-term care. Kane and Kane (1981) define long-term care as "a set of health, personal care, and social services delivered over a sustained period of time to persons who have lost or never acquired some degree of functional capacity (capacity in such cases is usually determined by an index of functional ability)" (p. 4).

The number of dependent elderly is projected to more than double by the year 2020 (Tilson, 1990; Dillard, Campbell, & Chisholm, 1984) with the most rapid growth represented by those 85 years of age and over. The 85 and older group is projected to almost triple by the year 2020 and then almost double again by the year 2040; so that 1 in 5 of the elderly will be in the oldest age group (Longino, Soldo, & Manton, 1990). It is further speculated that the number of centenarians will increase from 37,000 in 1982 to over 1 million in 2050 (United States Bureau of the Census, 1987).

As the needs of this population increase, some concerns are that there may be a decrease in social and financial resources. Aging family and friends of the elderly may be less able to fulfill care requirements; and functional losses may result in costly in-home services or institutionalization. Though researchers have identified predictors of long-term institutional versus in-home care, few have examined how the elderly choose among these services. Some obstacles for the elderly in this process include a lack of knowledge regarding available services, and the inability to negotiate receiving services to meet their needs (Dunkle & Kart, 1990).

In a comprehensive analysis of elder care and its implications for corporate America, Scharlach, Lowe, and Schneider (1991) identified several trends that have made elder care an employer issue. The trends include (a) the interrelationship and impact between family life and work responsibilities, (b) the increasing number of dependent elderly, (c) the post 1960 decline in birth rate, and (d) the increased participation of women, the traditional caregivers, in the workplace.

Policy and planning for long-term care fell behind during the 1980s as a result of the federal government shifting responsibility to state and local governments (Torres-Gil & Douglass, 1991). Keeping up with the

demographic reality and the current crisis in health care will require major federal and corporate involvement in order to avoid the "contradictions of a highly developed democracy with atrophied social and health care policies" (p. 25).

Socioeconomic status can be treated as an objective phenomenon or a subjective phenomenon (George, & Bearon, 1980). The former is usually measured by reports of amount and sources of income, occupation, and education; the latter refers to perceived adequacy of, and satisfaction with indicators. Among Medley's (1976) subjective findings, were that family life made the greatest single impact on life satisfaction, and that satisfaction with standard of living may be of greater importance than actual financial condition.

More recently, Reschovsky & Newman (1990) studied how well older frail households cope with the requirements of independent living. The findings showed that among all the indicators for successful adaptation for independent living, the most vulnerable of the frail elderly households fit a common constellation of factors--low income, lack of informal support, and being a renter. Other findings in accord with current literature (Fry, 1990), conclude that health needs of the elderly were largely being met by family members, mainly non-frail spouses, and that family

members also provide housing-related and financial assistance.

There are numerous demographic studies relating to the "old, old," those aged 75 and over, but few relating to their perceptions and needs (Neugarten, 1974). "Many of the oldest old are dependent due not so much to their need for help, as they are dependent due to their limited individual resources and a lack of community resources" (Bould, et al., p. 13). Older people's resources (social, spiritual, intellectual, and family or community property), determine their ability to exchange and to secure services (Fry, 1990).

Lawton et al. (1990) studied by proxy the last year of life of 200 decedents as compared with 150 living persons whose mean age was 77 years. The study found that most deaths occurred among community residents though little attention had been paid to "the quality of community resident older people's last year of life" (p. 1). The authors suggested that such measures could be "used to present the specifics of the individuals who are discussed as statistical or philosophical abstractions" (p. 26).

Further, Lawton et al. (1990) noted that 28% of all Medicare costs occur during the last year of life. This study also points out that there is little documentation of the course of daily life, events, and health over a set

period of time leading to final illness and death. This research attests to the "measurability of quality of life and the central position that individual and aggregate quality of life should play in debates regarding prolongation of life, treatment priorities, and societal health care costs, to name only a few" (p. 25). This study represents the "first estimate of overall quality of the last years of life" (p. 25).

The importance of research on the last year of life is supported by a more recent study (Lentzner, Pamuk, Rhodenhiser, Rothenberg, Powell-Griner, 1992). These authors analyzed the 1986 National Mortality Followback Survey ($N=7,586$) and found an approximately equal distribution among elderly decedents of those who were fully functional versus those who were severely restricted. The goal of this quality of life research was to begin to develop profiles of successful versus unsuccessful agers in order to address the issue of vitality in the prolongation of life and the quality of aging.

Psychological/Spiritual

Frankl (1962) theorized that human beings who possessed spirituality were able to discover the unique meaning in each of life's experiences. He felt that the existential aspects of spirituality permit an individual to tolerate even the intolerable. Though it is generally

agreed that meaning is important to life and health, there is a paucity of research into the topic, particularly as it relates to the elderly (Burbank, 1992).

A theoretical framework of symbolic interactionism guided a study (Burbank, 1992) of 81 subjects aged 62 and older. The purpose of the study was (a) to explore meaning in life, (a) to identify a framework for meaning, and (c) to also identify degree of meaning fulfillment among the participants. Five categories of meaning were identified, according to level of importance: relationships (59.6%), religion (14%), service (10.6%), activities (8.8%), and other (7%). It was not found that one type of meaning tended to foster greater fulfillment in life over others. Rather, the findings suggested that it is important to feel that one is able to contribute something of meaning to life.

In a critique of the literature relating to spirituality as a resource for mental health in the elderly, Reed (1991) notes that there is a dearth of knowledge in this area, and states that science is just beginning to identify the inner resources that augment mental health as adults face the challenges of aging. Further, Reed believes that spirituality is within the realm of nursing practice in dealing with the elderly as they increasingly face events that threaten physical and

emotional well-being. From a developmental perspective of aging, spirituality is broadly defined:

. . . in terms of the human propensity to find meaning in life through self-transcendence; it is evident in perspectives and behaviors that express a sense of relatedness to a transcendent dimension or to something greater than the self, and may or may not include formal religious participation (p. 15).

Simultaneous concept analysis was developed and utilized by Hasse, Britt, Coward, Leidy, and Penn (1992) to create a process model in order to clarify the concepts of self-transcendence, spiritual perspective, hope, and acceptance according to antecedents, critical attributes, and outcomes. The findings revealed (a) that the four concepts studied are dynamic responses to life experiences and that life experiences are antecedents of each concept, (b) the critical attributes impart activity, and (c) growth is associated with outcomes. Common to the four concepts was connectedness which the authors felt had a fuller meaning than social support as is often used in the nursing literature. Self-transcendence was seen as an outcome "attainable through the processes of spiritual perspective, acceptance, and hope" (p. 146). These authors viewed self-transcendence as a significant concept for use by nurses both personally and as an intervention with clients.

In addition to spirituality, self-esteem impacts an individual's sense of well-being and quality of life. Both self-esteem and spirituality gain meaning through relationships in which a person defines and discovers meaning in life situations as a result of the reflected appraisals from people that they trust and respect (Burbank, 1992).

Age related changes that cause negatively perceived alterations in appearance and role performance may disturb a person's self-esteem (Matteson & McConnell, 1988). As a result of such changes, the elderly may experience reduced levels of choice and control. However, even minimal gains in these realms can have positive benefits on physical health, self-concept, and vitality (Birren & Livingston, 1985).

Self-esteem, an important component of quality of life, must be renegotiated as changes occur in the physical and social environment (George & Bearon, 1980). The elderly are at greater risk of losing relationships due to death or otherwise changing circumstances and are, therefore, vulnerable to loneliness (Weiss, 1973). Multiple losses and associated role changes that occur in later life may cause fluctuations in self-esteem (Matteson & McConnell, 1988). Accordingly, professionals need to include the elderly in planning for their own needs in

order to insure their sense of responsibility and personal control (Birren & Livingston, 1985; Conte & Salamon, 1982; Tilson, 1990).

Family

The family, and in particular the relationships between adult children and their aging parents, has undergone many changes because of demographic trends in our society (Mutran & Reitzes, 1990). "People are experiencing more intergenerational roles, and the amount of time and the duration of the roles are increasing" (p. 149).

Subsequently, for the first time in American society, older adults have one or more living parents (natural and/or in-laws) but have no historical role models for managing these relationships. Families, ranging from small nuclear units to large extended units, comprise a significant network of social relationships for the elderly (Fry, 1990). According to Fry, the economy for intergenerational care is based on a system of reciprocity and exchange for services, the balance of which is affected by levels of dependency. The spouse is the main source of support for the homebound invalid and the second source is children, while childless elderly people must depend on other informal supports such as friends, neighbors, and community services (Dunkle & Kart, 1990).

Women, the traditional caregivers of the elderly, have become a significant part of the American work force (Denton, Love, & Slate, 1990; Green, 1991). In 1990, Denton et al. conducted a survey of 20 employers to determine trends in support offered to employees with eldercare responsibilities. They concluded that while employers realize that many workers provide unpaid eldercare, these problems have not been systematically explored nor have policies been developed to help meet these needs. Employers, employees, and government must join together to meet eldercare demands.

Highlighting some fundamental issues and interventions for midlife women in multiple roles, Green (1991) takes issue with the fact that it is the daughter who is socialized to assume most of the responsibility to assist aging parents in maintaining their independence within the community for as long as possible. She cautions that given the context of contemporary women's lives, if this task is not shared by other family members, daughters are at increased risk for burnout and stress-related illnesses.

That the elderly prefer to stay in their own homes is demonstrated by the fact that four times as many elders live in the community as live in nursing homes and most of their care is provided by family and friends (Folden, 1990; Reschovsky & Newman, 1990; Tilson, 1990). Therefore, in

order to maintain frail elders in the community, there is a concurrent need for expanded family support.

Folden (1990) did an ethnographic study of a small sample (N=7) of chronically ill elders to determine what it was like to be homebound. The findings revealed an underlying theme of loss in the realms of independence, social networks, finances, and personal control. Other findings demonstrated that resiliency and creativity relating to lifestyle and environment made it possible for the subjects to stay in their own homes. Among the nursing implications cited was the need to help balance available community resources with family resources in order to reduce family burden.

An analysis was conducted (Reschovsky & Newman, 1990) based on the Census Bureau's Survey of Housing Adjustments along with supplemental data from the Annual Housing Survey of the Department of Housing and Urban development (N=1,070). The purpose was to explore the ability of older frail households to cope with the requirements of daily living related to household operation, housing consumption (adjustments in areas such as size, layout, and/or location), and health-related activities.

Findings from this study indicated that family members, especially spouses, provide all or some of the assistance required in 89.9% of frail households receiving

formal assistance with activities of daily living services, and in 93% where in-home nursing care is provided. Other findings showed that approximately 10% of frail elders have at least made some accommodation to their dwelling. Finally, health-related adjustments were approximately 17% for ADL assistance, and 14% for nursing care.

A homogeneous random sample of 441 women was surveyed (Matthis, 1992) regarding their level of family caregiving involvement and educational needs in this regard. The results found that 86 (19.5%) current caregivers, and 161 (36.5%) future caregivers showed a high motivation to be educated for the caregiving role. Further, a topical guide was developed by home healthcare nurses for caregiver training. The author views home healthcare professionals as experts in preparing families to meet the societal demand to provide the greatest share of care for functionally dependent elderly.

A review of the family caregiver literature by Neundorfer (1991) revealed that most family caregivers cope well, though a significant number experience negative health effects. At risk are those who deal with dementia, those who perceive patient problems as severe, and those who find little gratification or meaning in their roles. The author suggests subgroup specific interventions to help families care for their impaired elderly, as well as

attention to barriers such as lack of transportation, inflexible hours, need for privacy and control, and prohibitive costs.

Summary

While there is no standard for measuring quality of life, the literature demonstrates that quality of life measures can provide important data to guide the development of policies, programs, and services to meet the needs of a rapidly expanding elderly population. Both objective and subjective quality of life data are necessary to provide insight into the values and needs of the elderly. Quality of life assessment can enhance the planning, implementation, and evaluation of nursing care for the elderly population. The four domains of health and functioning, socioeconomic, psychological/spiritual, and family provide the basis for assessing the diverse nature of life among community dwelling elders.

Chapter 3

METHODOLOGY

Research Design

This was a cross-sectional survey that employed descriptive statistics for data analysis. The study was performed concurrent to a larger study by the Department of Nursing at San Jose State University (SJSU), through their Nurse Managed Center (NMC) at the apartment site. The larger project is funded by United States Department of Health and Human Services, Division of Nursing Grant 1D10NU29224-02. The purpose of the present research was to explore quality of life as perceived by community dwelling elders who are clients of the NMC.

Research Question

This study examined how quality of life is perceived by independent elderly people living in the community. The question was addressed by measuring subject levels of satisfaction and importance related to 68 items on a 6-point scale.

Variables

The construct of quality of life was operationalized by four variables--health and functioning, socioeconomics, psychological/spiritual, and family. The variables were distributed throughout a 68-item questionnaire. A weighted

score was established overall and for each of the variables based on the levels of satisfaction and importance.

Setting

The setting for data collection was a 140 unit apartment building for independent senior citizens in northern California. Seventy of the apartments were moderate income units and 70 units were very low income units, subsidized by Section VIII of the Department of Housing and Urban Development. The target population was composed of 131 female and 27 male residents ($\bar{M}$ =79.9 years of age). There were 20 couples in the population. Of the total population, 81.3% of the women and 18.7% of the men were clients of the NMC.

Sample

A convenience sample of 12 volunteers was selected from a group of residents gathered in the dining room of the apartment building. The group consisted of 6 women and 6 men ($\bar{M}$ 80.9 years).

Data Collection

The researcher approached residents of the retirement facility who were gathered in the communal dining room. After being introduced by a staff member from the facility, the researcher made a general announcement to briefly describe the purpose of the study and to recruit volunteers. Initially, it was hoped that 12 people would

volunteer to provide a final sample of 10 subjects. The response was greater than expected and all 12 subjects returned their completed questionnaires.

Each of the 12 volunteers was immediately given a research packet and an explanation of the procedures. The packet contained a consent form with a statement of rights for human subjects, a demographic information sheet, the 68-item QLI, and a return envelope. Each page of the research packet and the envelope were coded to ensure confidentiality.

To assure a reasonable schedule for completion and return of the research packet, the subjects were asked to leave their sealed packets at the main desk within 5 days. Support was provided in the following ways: the researcher (a) was available on site for 1 hour after presenting the packets to answer questions, (b) telephoned those subjects who had not returned their packets 3 days after distribution, and (c) assisted 2 subjects in completing the questionnaire.

Instruments

Two instruments were used for data gathering--a demographic data form developed by the researcher and the generic version of the Quality of Life Index (QLI) (Ferrans & Powers, 1985a). Demographic information included subject

identification code, age, gender, marital status, religion, ethnicity, health insurance, and income level.

The generic QLI consisted of 68 items in two parts (34 items each) that measured four life domains--health and functioning, socioeconomic, psychological/spiritual, and family. Part I examines satisfaction with life domains and Part II examines the importance of these domains to the subject. Each response is gauged on a 6-point scale from "very dissatisfied" to "very satisfied" (Part I), and from "very unimportant" to "very important" (Part II).

Satisfaction and importance responses are weighted by centering the satisfaction items on zero. Each paired satisfaction and importance response is multiplied, and the products of these results are summed and divided by the number of answered items. Finally, negative values are eliminated by adding a constant of 15 to every score producing an overall score range of 0 to 30. A computer program available from the authors was used to calculate scores (Ferrans & Powers, 1992).

Scores for the overall QLI and for each of the variables are derived from a weighted calculation of the two parts which reflects individual values (importance) and satisfaction related to these values (importance). Scores for each item are highest when high satisfaction relates positively to high importance, lowest when high

dissatisfaction relates negatively to high importance, and mid-range for low importance items. This weighing scheme is grounded in the belief that quality of life is related to the degree of satisfaction experienced in important areas of one's life.

QLI Validity and Reliability

The QLI-Generic Version consists of 68 items pertinent to all people. Illness-related versions of the QLI contain items adapted for specific disease conditions (Ferrans, 1990; Ferrans, Cohen, & Smith, 1992; Ferrans & Powers, 1985a). Ferrans and Powers (1985a) developed the QLI based on an extensive review of the quality of life literature, and on patient-identified elements of life satisfaction.

Validity and reliability assessments were originally performed with 88 graduate students and 37 dialysis patients (Ferrans & Powers, 1985a). In the study, the QLI was compared with an overall life satisfaction question ("How satisfied are you with your life in general?"). The results supported:

1. Concurrent validity with correlations of .76 (graduate students) and .65 (dialysis patients).
2. Internal consistency with Cronbach's alphas of .93 (graduate students) and .90 (dialysis patients).

3. Stability with test-retest correlations of .87 at a 2-week interval (graduate students) and .81 at a one-month interval (dialysis patients).

In another study, Ferrans and Powers (1992) examined the psychometric properties of the QLI with a random sample of 349 in-unit hemodialysis patients. Findings from the study further supported the reliability and validity of the QLI.

Analysis of Data

The statistical procedures used to describe and summarize the data include frequency distribution, measures of central tendency, and measures of variability. A description of demographic data includes age, sex, and marital status of the subjects. Also discussed are the overall scores and the individual scores for the QLI and its four components--health/functioning, socioeconomic, psychological/spiritual, and family.

Summary

This descriptive study examined quality of life as perceived by a small sample of community dwelling elders. Data were gathered from 12 volunteer participants who completed the 68-item generic version of the Quality of Life Index (Ferrans & Powers, 1985a) and a brief demographic form.

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

The purpose of this descriptive study was to explore the perception of quality of life among a sample of community dwelling elderly people. The objectives were to describe the characteristics of the sample, to describe the perception of quality of life of the subjects using the QLI, and to suggest some specific nursing intervention strategies to enhance quality of life for the subjects. Twelve subjects, residents of a retirement apartment complex, completed a 68-item quality of life questionnaire (Ferrans & Powers, 1985a) and a demographic information tool. The data were analyzed using descriptive statistics which provided a demographic profile of the subjects, as well as measures of central tendency for age, the overall quality of life, and the four subscales.

Analysis of the Data

Sample and Setting

The 12 participants in this study comprised a convenience sample of elderly persons from a 140 unit retirement apartment building. The participants live independently and they participate in a meal program through which one meal is served 5 days per week in the communal dining room. Of the 12 volunteer participants,

the researcher received no refusals. Two subjects required some assistance in completing the research tools.

Demographics

The subjects (6 male, 6 female) ranged in age from 69.8 years to 88.8 years ($\underline{M}=80.9$, $\underline{SD}=5.2$); 6 were married; 5 (1 male, 4 female) were widowed; and 1 woman was divorced. All participants in the study were Caucasian and all had health insurance. One person had Medicare A and B only, 1 had Medicare/HMO, 2 had Medicare/Medicaid, and 8 had Medicare with private companion coverage. Eleven subjects did name a religious affiliation and 1 did not. Six subjects answered the income level question with a range from \$7,680 to \$29,000 ($\underline{M}=\$17,169$, $\underline{SD}=\$6,792$) annually (Table 1).

Quality of Life Index

The weighted findings between satisfaction and importance of the overall QLI (Figure 1) and the four subscales are reflected in Table 2. Scores for the overall QLI revealed a high of 27.9 and a low of 16.1 ($\underline{M}=24.17$, $\underline{SD}=3.71$) based on a range of 0 to 30. Subscales scores, also based on a range of 0 to 30, were as follows: health and functioning ranged from 12.8 to 28.7 ($\underline{M}=23.25$, $\underline{SD}=4.83$), socioeconomic ranged from 18.4 to 29 ($\underline{M}=24.24$, $\underline{SD}=3.36$), psychological/spiritual ranged from 9 to 29.1

Table 1

Demographic Data

(N=12)

Client	Age	Sex	Marital Status	Insur.	Income	Religion Stated	Overall QLI
1	77.3	Female	M	MC/P	N/A	Y	25.9
2	82.0	Male	M	MC/P	N/A	Y	24.5
3	77.8	Female	W	MC	\$17,500	Y	27.7
4	82.3	Female	W	MC/P	N/A	Y	16.8
5	69.8	Female	D	MC/MD	\$7,680	N	25.5
6	75.7	Female	W	MC/P	\$10,000	Y	16.1
7	86.7	Female	W	MC/P	N/A	Y	23.2
8	81.1	Male	M	MC/P	\$20,000	Y	26.3
9	88.8	Male	W	MC	N/A	Y	26.2
10	78.3	Male	M	MC/P	\$14,000	Y	26.2
11	87.1	Male	M	MC/P	\$29,000	Y	27.9
12	83.5	Male	M	MC/P	\$22,000	Y	23.9

Note.

M= Married

W= Widowed

D= Divorced

N/A= Not Answered

Y= Yes

N= No

MC= Medicare Only

MD= Medicaid

MC/P= Medicare/Private Supplemental

Figure 1. Overall QLI of the Sample (N=12).

Table 2

Quality of Life and Subscales (N=12)

Client	1	2	3	4	5	6	7	8	9	10	11	12
QLI	25.9	24.5	27.7	16.8	25.5	16.1	23.2	26.3	26.2	26.2	27.9	23.9
H/F	24.5	23.1	27.4	12.8	24.1	14.2	21.9	25.4	26.6	27.9	28.7	22.6
S/E	29	23	28.5	21.4	26.3	19.4	18.4	26	26.3	21	27.1	24.7
P/S	24.8	27	26.6	11.5	28.1	9	27.9	29.1	25.4	27.4	26.1	23.8
FAM	27	27	30	28.5	24	18	30	25.5	25.8	28.5	30	27

Note. QLI= Quality of Life Index

H/F= Health/Functioning Subscale

S/E= Socioeconomic Subscale

P/S= Psychological/Spiritual Subscale

FAM= Family Subscale

(M=23.9, SD=6.29), and family ranged from 18 to 30 (M=26.78, SD=3.22).

Interpretation of the Data

Demographics

With a mean age of 80.85 years, this sample represents the old-old segment of the population, those 75 years of age and older (Neugarten, 1974). They are at that point in time between 80 and 90 years of age when people become "old" (Bould et al., 1989), that is, when there is an increased incidence of chronic disease, disability, and dependence. Regarding age and gender, this sample had an equal representation of male and female subjects. However, the resident population (N=158) of the apartment building was 17% male and 83% female with 20 couples, 17 single men, and 121 single women. Though data regarding widow(er) versus divorced status were not gathered from the target population, the higher percentage of women tends to reflect the national statistics for 1989 (U. S. Bureau of the Census, 1991): Of the total population (N=3,728) between age 80-84, there were 1,306 (35%) men and 2,422 (65%) women.

Overall QLI and Subscales

The overall objective for this study was to determine the quality of life as perceived by community dwelling elders as measured by the QLI. Weighted scores, calculated

between paired satisfaction and importance responses, are highest with high satisfaction/high importance scores and lowest with high dissatisfaction/high importance scores. The overall QLI mean for this sample was 24.18 ($SD=3.71$) with a range of 16.05 to 27.94. A difference was found for two subjects who scored below 17 (16.7%) while 10 subjects (83.3%) scored 23.16 and above.

Subscale scores demonstrated a variance for two subjects particularly in the domains of health and functioning, and psychological/spiritual. Subscores revealed the following: health and functioning--two scored below 15, 10 scored more than 21; socioeconomic--two scored below 20, 10 scored 21 and above; psychological/spiritual--two scored below 12, 10 scored more than 23; family--one scored 18, 11 scored 24 and over, of these 3 scored 30.

The overall findings indicate that the sample was satisfied with the domains of life that were most important to them and that they had a relatively good quality of life. The lowest scores were reported in the domains of health/functioning and psychological/spiritual; the highest scores were in the family and socioeconomic domains. Clearly, scores in the health and functioning and psychological/spiritual domains had a dramatic negative impact on the global QLI scores in this sample. Conversely, relative stability in the socioeconomic domain,

along with strongly positive family domain scores had a beneficial impact on the global QLI scores.

Summary

This descriptive study explored quality of life as perceived by 12 community dwelling elderly people who live independently in a retirement apartment building. The characteristics of the subjects were presented along with the descriptive findings that were obtained using the QLI. In this sample, the mean was highest in the family subscore ($\bar{M}=26.78$), followed by socioeconomic ($\bar{M}=24.24$), psychological/spiritual ($\bar{M}=23.9$), and health/functioning ($\bar{M}=23.25$), respectively. The results from this study mirror findings in the literature that demonstrate the important influence and interaction that health and functioning, socioeconomic, psychological/spiritual, and family support have on maintaining quality of life, particularly as health and functioning decline.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

The purpose of this descriptive study was to explore the perception of quality of life among a sample of community dwelling elderly people. The objectives were to describe the characteristics of the sample, to describe the perception of quality of life of the subjects based on the QLI, and to suggest specific nursing intervention strategies to enhance quality of life for the participants.

The subjects lived independently in a retirement apartment building that is served by San Jose State University, Department of Nursing's Nurse Managed Center. The data were analyzed using descriptive statistics which provided a demographic profile of the sample, as well as measures of central tendency for the overall QLI and the four subscales (Ferrans & Powers, 1985a).

Conclusions

All 12 volunteers (6 men, 6 women) for this study were Caucasian. The sample was diverse in that it consisted of both men and women who were either married, widowed, or divorced; whose financial support included social security, government subsidy, family subsidy, and revenue from private investments; all received Medicare benefits, most had private companion insurance coverage, 1 had Medicare only, and 2 had Medicare/Medicaid; all had family support;

and all but one person stated a religious affiliation. The mean age was 80.85 years which represents that time of life between 80 and 90 years when, according to Bould et al. (1989), people become old. This is also the time when there is an increase in the incidence of chronic disease (Fulmer, 1991; Morishita et al., 1989).

Overall, the quality of life for this sample ($\bar{M}=24.18$, $SD=3.71$) was good. Individual differences found among the variables supported the literature by demonstrating the influence and the interrelationship of the variables. For instance, the 2 subjects who scored lowest in the overall QLI ($\bar{M}=16.1$; $\bar{M}=16.8$) also respectively scored lowest in health and functioning ($\bar{M}=14.2$; $\bar{M}=12.8$) and in psychological/spiritual ($\bar{M}=9$; $\bar{M}=11.5$). The highest overall score among the variables was in the family domain ($\bar{M} = 26.78$, $SD=3.22$) advancing findings in the literature (Fry, 1990) that maintain families comprise a significant network of support for the elderly.

Limitations

Interpretation of the findings from this study is limited by the small sample size and demographics. Findings from this study cannot be generalized due to its design, non-random sample, and use of only one quality of life tool. An additional limitation results from the

controversy surrounding the definition and measurement of the concept of quality of life.

Recommendations

Overall, this sample demonstrated strength in the socioeconomic and family domains. While most (83.3%) were found to have good resources in the domains of health and functioning and psychological/spiritual, their mean age (80.9 years) increases their risk for chronic disease and disability. This increased risk warrants ongoing nursing assessment of change in resources over time.

Regarding 2 subjects (16.6%) whose health and functioning and psychological/spiritual scores were low, specific assessment of the factors within these domains revealed strong feelings of loss in the areas of control, independence, personal importance, and general life satisfaction. Nursing interventions could be designed to address deficits in these areas based on the goal of assisting the subjects to improve their quality of life.

The expanding elderly population, particularly in the 85 years and older category, and the higher incidence of disability among this age group requires careful assessment of health care needs and personal resources. Included in such an assessment must be an understanding of clients' perception of their needs and resources. Clinically, it is important for nurses to be aware of how both subjective and

objective factors can interact to influence a person's quality of life. With such knowledge, the nurse can better assist elderly clients in planning for their health care needs.

Future research using the QLI with larger random samples of elderly people from different settings could provide a broader knowledge base related to quality of life among the elderly. This information could enhance the process of nursing assessment, planning, intervention, and evaluation (i.e., outcome measures) in the care of this rapidly expanding segment of the population.

Summary

Longevity and the concomitant potential for increasing disability and decreasing resources require continuous monitoring and enhancement of resources as needs change with advancing age. Since four times as many elders live in the community as live in nursing homes (Folden, 1990; Reschovsky & Newman, 1990; Tilson, 1990), it is incumbent upon health professionals to study and describe this population in order to guide the development of policies and programs for health care that reflect the values and needs of the community dwelling elderly.

The Nurse Managed Center model provides a bridge for services between medical care and community agencies. The holistic domains of nursing, person, health, environment,

and nursing, can inherently interact with the four domains of the QLI, health and functioning, socioeconomic, psychological/spiritual, and family. For example, incorporating the QLI concepts into the assessment, planning, and evaluation of an elderly client's health status might enhance nursing interventions with this population.

Though findings from this study cannot be generalized to the larger elderly population, they are clinically relevant to nursing care of this sample. Quality of life data contributes knowledge that assists the nurse in differentiating normal from pathological changes of aging. Appropriate interventions and referrals can be made to provide support and/or treatment for domains that compromise an elderly client's quality of life.

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APPENDIX A
Human Subjects
Institutional Review Board
Permission to Conduct Research

A campus of The California State University

Office of the Academic Vice President • Associate Academic Vice President • Graduate Studies and Research
One Washington Square • San Jose, California 95192-0025 • 408/924-2480

To: Judith Monahan
1684 Everett St.
San Jose, CA 95125

From: Serena W. Stanford *Serena W. Stanford*
AAVP, Graduate Studies and Research

Date: January 20, 1993

The Human Subjects-Institutional Review Board has reviewed and approved your request for exemption from Human Subjects Review for the proposed study entitled:

"Quality of Life as Perceived by Elders Living in the Community"

Provided that there are no changes in the procedure proposed, you may proceed with this study without further review by the Human Subjects-Institutional Review Board. You must notify the Human Subjects-Institutional Review Board of any changes in the subject population or procedure for this study

I do caution you, however, that Federal and State statutes and University policy require investigators conducting research under exempt categories to be knowledgeable of and comply with Federal and State regulations for the protection of human subjects in research. This includes providing necessary information to enable people to make an informed decision regarding participation in your study. Further, whenever people participate in your research as human subjects, they should be appropriately protected from risk. This includes the protection of the confidentiality of all data that may be collected from the subjects. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

If you have questions, please contact me at 408-924-2480.

CC: Jayne Cohen

APPENDIX B

Permission to Administer the
Quality of Life Index

Department of Medical-Surgical Nursing (M/C 802)
College of Nursing
845 South Damen Avenue, 7th Floor
Chicago, Illinois 60612
(312) 996-7900

October 15, 1992

Ms. Judith Monahan
1684 Everett Street
San Jose, CA 95125

Dear Ms. Monahan:

Thank you for your interest in the Quality of Life Index (QLI). There is no charge for use of the QLI. You have my permission to use the generic version of the QLI for your study. In return, I ask that you send me any publications of your findings using the QLI. Such reports are extremely important to me.

If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research.

Sincerely,

Carol Estwing Ferrans, PhD, RN
Assistant Professor

APPENDIX C
Subject Consent Form

A campus of The California State University

College of Applied Sciences and Arts • Department of Nursing
One Washington Square • San Jose, California 95192-0057 • 408/924-3130 • FAX 408/924-3135

Agreement to Participate in Research

Thesis: Quality of Life as Perceived by Community Dwelling Elders.

I have been asked to participate in a research study pertaining to my perception of quality of life. I understand the following:

1. I will meet with the investigator on one occasion for approximately 15-30 minutes to receive instructions for completing the questionnaire;
2. Benefits of my participation may be that study results will help the nurses in the care that they provide to me;
3. Possible risk may be fatigue from the exertion of completing the questionnaire;
4. Confidentiality will be protected by a system of number coding (to replace name); and, data will be kept secure within the Department of Nursing;
5. The interviewer will ask for demographic information and I will complete a questionnaire that contains 68 questions; upon completion, I will return the questionnaire to the investigator in the accompanying envelope;
6. There are no alternative procedures;
7. The results of the study may be published but no information that could identify me will be included;
8. Questions about participation in this study may be directed to me, Judith Monahan, 445-1901; complaints about procedures may be directed to Bobbye Gorenberg, R.N., D.N.Sc., Graduate Coordinator for the Department of Nursing, 924-3134; and concerns regarding my rights may be directed to Serena Stanford, Ph.D., Associate Academic Vice President for Graduate Studies, 924-2480.
9. Refusal to participate will not affect my relationship with SJSU of the nurse managed center;
10. Consent to participate is given voluntarily. I may refuse to participate in the study or in any part of the study. I am free to withdraw from the study at any time without prejudice to the subject's relationship with San Jose State University.
11. I have read/or have had read to me this form and agree to participate in this study. I have received a signed and dated copy of this consent form.

Subject's Signature _____

Date _____

Interviewer's Signature _____

Date _____