RESIDENTS' PERCEPTIONS OF QUALITY OF LIFE IN A CULTURALLY DIVERSE LONG-TERM CARE ENVIRONMENT

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RESIDENTS' PERCEPTIONS OF QUALITY OF LIFE IN A CULTURALLY
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Dissertation

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ABSTRACT

What factors may contribute to residents’ perceptions of Quality of Life and sense of community in culturally diverse long-term care environments? The purpose of this study is to offer a new lens with which to view the lived experience of those in long term care.

Quality of Life in long term care environments has been explored for decades. Most studies address regulatory mandates and utilize quantitative data from regulatory agencies, and are not derived from the residents utilizing a qualitative component. Long term care environments are now corporate faces rendering services to the elderly based on regulatory dictates and the ability to gauge satisfaction with results from current quantitative satisfaction instruments. The results of this study indicate that this methodology is inadequate for capturing the desires of the residents.

This exploratory study employed survey and interview techniques to harvest data from residents that are living in long term care. The disparity in responses between the
techniques indicates that delivery of services are based on assumptions from quantitative data rather than qualitative data derived from those living the experience.

Existing research has not thoroughly explored if “community” within this environment is important. This exploratory study indicates that is important to residents. We need to redefine what “community” looks like to residents in long term care. What does it mean to them? How must community be modified to reflect the reality of the nursing home environment? The onslaught of baby boomers into long term care is likely to impact the organizational/corporate rules on experience for determining Quality of Life indicators.
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Finally I would like to say that the late Dr. Douglas Shaw was an inspiration to me and will be forever in my memory.
DEDICATION

To my husband, Bill Busson.
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CHAPTER I

It is precisely because life so often fails our expectations that we need one another. It is precisely because moral demands to give self can be so outrageous, so utterly devastating, that we need to know others are prepared to do the same for us...Vulnerability is understood to be part of the human condition, some being visited with greater needs than others, but others being blessed with greater strength...A good society is one that finds ways to match needs and strengths, one that cares for not only public injustice visited on minority and other weak groups, but also for private injustices that nature and life visit upon individual people.

--Daniel Callahan, in Nancy Jecker, Aging and Ethics, 1995, pp. 167-169

INTRODUCTION

This dissertation is an exploratory analysis utilizing a phenomenological perspective of residents’ perceptions of quality of life in culturally diverse long-term care facilities. Exploratory research in this area is sparse as access to facilities is difficult. By exploring cultural diversity and defining the phenomenon in these “accidental communities,” as defined by Kane & Kane (1987), a better understanding of the effects on quality of life for residents will be illuminated. Subtleties will be noted in the behaviors, attitudes, and language of the participants;
as it pertains to “others” and reciprocal impacts on individuals.

Long-term care for elders in a culturally diverse nursing home environment is scant. Studies addressing the ethnic elderly are also minimal in numbers. In order to understand the purpose of this research, one must be able to draw distinctions between various definitions and research to understand their meanings as they relate to aging of the elderly, and more specifically, culturally diverse elderly populations. It is also important to understand the nursing home is an “accidental community,” (Kane & Kane, 1987) comprised of many different types of persons even when race/ethnicity is excluded. Although Kane’s description of this community seems plausible, further inquiry reveals there is a method and public policy influence as to the construction of such aggregations of persons.

While these people receive a variety of care, it is important to note that all residents are not necessarily patients and all patients are not necessarily residents. This is determined by the length of stay. Patients generally stay a fixed amount of time determined by an illness, usually not to exceed six to nine months. Patients become residents when the stay becomes, or has been
determined, to be indefinite. Again, while the community may be accidental in ways, it is also controlled much like redlining of housing. Redlining in public administration literature refers to geographic areas where people live based on demographics such as race and income, stratifying the social structure of living environments (i.e. African-American areas, Caucasian areas, lower economic areas, etc.). A nursing home is an institution that provides the resident with healthcare in a place they may call “home.”

This research project will explore the phenomena of values and attitudes of those utilizing these services that are socially constructed to enhance the experience of aging with the loss of control of decision-making in daily living. This loss has disrupted and eliminated choices such as where one lives, who one associates with and living with virtual strangers. Those now living in these environments are being taken care of by people that may not have been a part of one’s historical choices of association. An exploration of this change affecting the quality of life for these individuals who once were free to live in their own culturally defined communities that defined who they once were is an area that is ripe for study.
AGING AND DIVERSITY

Characteristics of nursing home residents illustrate changes in who is using these facilities, when and for what purpose. In 1997, the average age at admission among nursing home residents was 82.6 years with most of the residents being Caucasian women. Current changes are occurring with regard to ethnicity. In 1985 Caucasian residents comprised 93 percent of the nursing home population, but by 1997, this proportion had decreased to 89 percent due to an increase in other races utilizing this resource. Additionally, in 1997, 30 percent of nursing home residents were discharged into the community because they had recuperated or stabilized, representing a 12 percent increase since 1985. The mean length of stay for this group dropped from 89 days in 1985 to 45 days in 1997. Mortality also declined over this period from 25 percent in 1985 to three percent in 1997 (CDC Report, 2005).

The older population (65+) numbered 35.6 million in 2002, an increase of 3.3 million or 10.2 percent since 1992. By the year 2030, the older populations will more than double to about 71.5 million. The number of people aged 85 and over is expected to triple. Hispanic
populations are also living longer. Members of minority groups are projected to represent 26.4 percent of the older population in 2030, up from 16.4 percent (AoA, 2004). Theoretically speaking, if one lives to be in the group of the old or the oldest old, he/she will at some point in their lives spend time in a long-term facility, either short term on a Skilled Nursing Unit (SNU) or long term until death.

Cultural diversity has become an issue in all American organizations. There is a need for the workplace to be more reflective of the population it serves. In the nursing home industry, products of the more culturally insensitive eras are now entering en masse. Due to the welfare reform of recent years, many filling the positions of nurse's aides are coming off of the welfare rolls transitioning into facilities. The two could present conflict and affect the quality of life of both resident and worker. An important point about the immigrant European population in long-term care is that they cannot be considered as Caucasian (one group) because they have different values, attitudes and beliefs (Kane & Kane, 1987). Many of the immigrants regress to their original language and cannot be understood. What is not known is if it is feasible to accommodate all this variety or if prior attempts have been successful.
Academics are starting to publish in this area but it has not been thoroughly assessed.

Cortese (in Fusco Johnson, 1999) observed that

It is not surprising that the exploding field of gerontology during the 1970s placed great emphasis on minority status. However, the de-emphasis of cultural diversity in aging among European American scholars and policymakers reflects our society's assimilationist ideology that defines all people as having similar traits, aspirations and problems (p.56).

For many years, the dominant ethnic perspective of the United States-this "nation of immigrants"—was that cultural differences eventually dissipate through the assimilationist forces of the American melting pot (Gordon, 1964). However, this view has been challenged during the past three to four decades as some authors (Greeley, 1969; McGoldrick, 1982; Noelker & Harel, 2001) maintain ethnic and cultural characteristics may persist across many decades of family life. Many Caucasian-Americans view themselves as part of an ethnic minority or an undervalued culture with special needs: Jewish-Americans, Arab-Americans, Eastern European immigrants, Appalachians, Cajuns and others experience prejudice without being "people of color" (Stoll, 2000).

Personnel issues are interesting in that they will be tied to cultural diversity. This will also be related to the organizations' structures. At this point, there is much
research on the “welfare to work” personnel, as well as, the immigrants and citizens that do not speak English. Conclusions drawn are to create facilities specifically for particular groups. Training is an important issue. Guttman (1987) suggests staff must be aware of the history of their clients (i.e. holocaust victims have special needs, etc.). Some literature suggests because of monetary constraints, the staff does not have time to interact with the families of the residents.

Pertinent literature uses the terms cultural diversity, culturally competent care, quality of care and quality of life. It is important to understand the distinctions between the terms used in the literature to better understand the dual role of the nursing home (Monaghan, 2002). This study will utilize the following terms: cultural diversity, culturally competent care, quality of care, and quality of life. Definitions of these terms are as follows:

*Cultural diversity:* Variations among cultural groups. As a community concept culture describes shared values, beliefs, customs, language, and behavior by a distinct group of persons.

*Culturally competent care* is using knowledge that has been learned about a specific culture and applying
it in sensitive, creative, and meaningful ways when providing care to individuals from diverse backgrounds” (Leininger, 1999, p. 1).

Quality of Care for this study will be defined by the residents as far as their needs, as they perceive their relative importance, to be (i.e., toileting, bathing, bandage changes, etc.), not regulatory dictates.

Quality of Caring will be examined in this study as to the nature of staff/resident, resident/staff, resident/staff/family interactions deemed as important to quality of life as the quality of care is received.

Quality of Life is measured in “terms of minutes of life during which one's affect state may be positive, neutral, or negative” (Noelker & Harel, 2001, p.157).

The theory that will provide the framework for this exploratory study is Community Theory. Community Theory holds there are social relations within and between groups that affect a person’s quality of life (Tinder, 1995).

these distinct populations there were generational differences between resident and caregivers. This begs the question of whether or not one’s own culture delivers care that is congruent within cultures due to the maturation of younger generations within the global economy and their attitudes towards the elderly.

Other authors have viewed cultural diversity in long-term care environments with some trepidation regarding cultural diversity (Maldonado, 1977; Schafft, 1979; Cyr & Schafft, 1980; Belgrave, Wykle & Choi, 1993; Salive, Collins, Foley, & George, 1993; Mui, Choi & Monk, 1998; Johnson, 1999; Chin, 2000; Drevdahl, Taylor & Phillips, 2001; Krakauer, 2002). Most of the aforementioned studies have looked through a dichotomous lens: Caucasian/African-American, Hispanic/African-American, and Caucasian/Asian.

Current studies in academic literature have investigated utilization by minorities and public policy issues surrounding utilization. “The differences that have existed historically in the United States in terms of distribution of power, wealth, and access: treatment by medical establishments and acceptance by others are still present today” (Werth, Blevins, Toussaint, & Durham et al., 2002, p. 208). This study investigates cultural diversity and its effect on quality of life issues in long-term care
with the underlying premise that “Culture permeates our existence, touching every aspect of our lives individually and collectively, including the end of life” (Krakauer et al., 2002, p. 188). This is a presentation of the views of those living the experience and not an aggregation of numbers that leave no room for the human element essential in attempting to understand the trials and tribulations of communal living at the end of life.

RESEARCH QUESTION

The research question for this study is: What factors may contribute to residents’ perceptions of Quality of Life and sense of community in culturally diverse long-term care environments?

In addition to a questionnaire, the phenomena and underlying concepts to be explored will be guided by asking residents the following questions:

1. How does your life here compare to the world that you once were a part of?
2. What is the best experience that you have had while living here?
3. What is the most disturbing (worst) experience that you have had while living here?
4. Tell me about your friends and those that you interact with.

This study aims to see how residents currently in nursing homes and from relatively the same cohort (pre-Civil Rights) view "others" as members of their "community" or as outsiders and whether this affects the quality of life for the resident. The purpose of this phenomenological perspective is to expand the knowledge base of the lived experience of those in long term care.

Limitations of this study will include answering truthfully due to fear of retribution and replication with the same group because they are in the end stages of life. However, this study may be replicated in other facilities. Due to the fact the researcher has been imbedded in the environment(s) both as a volunteer ombudsman and as a registered nurse, it is believed trust and familiarity with the interviewer will help foment the quality of responses. This also affords the researcher the opportunity to observe the residents as they exist in this environment. Without this advantage, replication may be difficult for another researcher. Having relationships with the residents affords more passionate responses. The trust that has been built equally supports the expectation of frank and honest answers.
Investigating the impact of cultural diversity in long term care should reveal some of reasons why society is constructed on the “outside.” In a society, these individuals chose to live where they were comfortable and interacted with whom they chose to engage. When moving into an institution they are accepted based on their level of insurance benefits and their choices are not as diverse as when making decisions they once were able to make. What has been socially constructed on the outside is of no value for placement in the “new inside” living arrangement. What bothers this generation of elders may not be relevant to the generation making the decisions of replicating a culture they believe will be desirable.

The broader, ever-increasing graying population of American Society is composed of a mosaic picture of discrete cultural groups existing with the context of their own values and identities. Those distinct cultures are embedded in the thinking of each resident, affecting his or her perceptions of quality of life in long-term care (Suh, 2004, p. 100).

METHODS

An exploratory study is appropriate in this case because the researcher is interested in the outcomes as defined by Babbie (2001):
• to satisfy the researcher’s curiosity and desire for better understanding;
• to test the feasibility of undertaking a more extensive study; and,
• to develop the methods to be employed in any subsequent study (p. 92).

An exploratory design in this study will allow the researcher an approach to study and uncover meanings of the participants’ experiences. In this case, exploring the nature of the community formed within the nursing home relating to cultural diversity. Does cultural diversity, as academics have explained through definition, transcend from the outside world to the facilities that are socially constructed by both public and private entities? Does this positively or negatively affect the quality of life for those individuals?

A phenomenological perspective will allow the researcher to uncover the perceptions of the participants; seeing how they experience, live and cope with the phenomenon of life in long-term care. Concurrent nested methodology will be employed to gather relevant data.
The importance of this study is that it fills gaps in both the nursing literature and public administration literature concerning aging, cultural diversity, and future living arrangements. It will add knowledge about issues for caring for an aging population in need of an acceptable quality of life from their point of view.
CHAPTER II

The tolerance, the room for great differences among neighbors - differences that often go far deeper than differences in color - which are possible and normal...but which are so foreign...are possible and normal only when...allowing strangers to dwell in peace together on civilized but essentially dignified and reserved terms.


LITERATURE REVIEW

A brief discussion of the theoretical foundation that will guide this study will be followed by an overview of the evolution of the nursing home. This will be followed by terms that are used in the literature. It is important to understand the distinctions between the terms in order to better understand the dual role of the nursing home (Monaghan, 2002). The following terms from the literature to be expanded on are: cultural diversity, culturally competent care, quality of care, and quality of life previously identified in Chapter I. The theoretical paradigm that will be used to guide this study is Community Theory.
Community Theory.

The idea of community has many definitions. Scholars refer to nursing homes as communities (Kane, 1987, Monoghan, 2002). The application of this theory warrants further analysis and further investigation. In the late 1800s, Ferdinand Tönnies observed a change in the process of community formation. The changes he observed were being brought about by the Industrial Revolution. In what scholars refer to as his seminal work, Gemeinschaft and Gesellschaft, Tönnies (1887/1964) uses these terms “to mark the ends of a continuum of social life” (Tönnies 1887/1964; Phillips, 1996, p.124). This book was later translated into English in 1957 as Community and Society. Ferdinand Tönnies (1855-1936) was a German sociologist who identified two contrasting types of society and mentality: Gemeinschaft (community) and Gesellschaft (society).

“Tönnies followed the Marx tradition and traced social development and an evolutionary transition from primitive communism and village-town individualism to capitalist urban individualism, and the future to state socialism” (Tönnies, 1887/1964 ; Phillips, 1996, p. 124). Tylor (1891) interprets Gemeinschaft as “being based on an affective
solidarity and an attachment to place which overrides other
loyalties” (p. 1).

In Tönnies’ Gemeinschaft social organization, people
are bound together by common values, sacred traditions, and
blood ties. He considers the family as the primary social
unit. This primary social unit consists of close-knit
families and close social ties (Tönnies, 1887/1964, 1964;
Phillips, 1996). “Because there is very little change in
Gemeinschaft; the lives of members of one generation may be
quite similar to that of their parents or grandparents”
(Phillips, 1996). This is eminent French sociologist Emile
Durkheim’s (1964) "mechanical solidarity."

The social structure in Gesellschaft is compromised by
outward forces pushing into the close-knit circles of
trust. “Society is governed by rational will and is an
ideal type. Self-interest dominates and there is little
consensus concerning values and commitment to the group.
Social control relies on more formal techniques such as
laws and legally defined punishments” (Phillips, 1996, p.
124). This is Durkheim's (1964) "organic solidarity."

The descriptions and explanations of these theories
polarize the two constructs which is, in fact, not what
Tönnies (1964) intended. Tönnies (1964) philosophical
overview was the variables in the dichotomy were neither
good nor bad, but only an observation of the phenomenon taking place. In fact, he advocated for a balance of both.

Tinder (1995) argues in order for a community to be a true community, the individuals must be tolerant. This means the individuals must be tolerant of the ideas of others. He argues tolerance leads to order and peace. Community brings with it the qualities such as cohesion, uniformity, and discipline. Community to Tinder (1995) is the unity of two or more persons in their essential being. As is the case with the “accidental community,” Tinder (1995) argues “forced relationships cannot possibly be communal” (p.101). “Community is an insecure and incomplete conquest of estrangement, and men and women can only pursue if like partisan fighters trying to gain possession of their homeland” (Tinder, 1995, p.177).

Relating to long-term care environment and cultural diversity: “Pluralism is favorable to communication and thus to a communal and inquiring tolerance...Community is the positive goal of pluralism” (Tinder, 1995, p. 221). He argues to be communal, you must accept your status as one individual among many; this is to accept your finitude, a condition requiring you to be a determinate being, excluding many possibilities and occupying a certain position... (p. 235).
It is evident to readers both Kikoyeda (2000) and Monaghan (2002) think of the nursing homes they studied as communities using the definition of likeness, shared beliefs, values and traditions. Kikoyeda's (2000) study included Japanese-American women and Monaghan studied the Pueblo Indian Reservation's nursing home. Both of these studies dealt with one sliver of the ethnic diversity in this country. Even Kane's (1987) accidental community should be placed under this umbrella since most of the studies of nursing homes conducted are on the Anglo population. Young (1990) argues "the ideal of community denies and represses social difference...the ideal community denies difference in the form of the temporal and spatial distancing that characterizes social process" (p. 227).

The ideal of community is what Foucault (1980) calls the Rousseauist's dream of

a transparent society, visible and legible in each of its parts the dream of there no longer existing any zones of darkness, zones established by the privileges of royal power or the prerogative of some corporation, zones of disorder. It was the dream that each individual, whatever position he occupied, might be able to see the whole of society, that men's hearts should communicate, their vision be unobstructed by obstacles, and that the opinion of all reign over each (p. 152).

Any conception of community in nursing homes needs to recognize the diversity of its residents, as well as, the
common experience of aging. Monaghan (2002) and Kikoyeda (2000) imply there is a need for nursing homes that will cater specifically to culture rather than integrating all.

Nursing Home Evolution

Prior to the twentieth century, homes for the aged were not needed due to diseases, plague, infant mortality, and war which reduced life expectancy (Sherwood, 1975). During the late 1700s to 1920, government played a small role in nursing care as the political view was communities would take care of those destitute and without families, and families should take care of their own (Bohm, 2001). Quality of care at that time is hard to access as records are rare or nonexistent.

Individuals and/or families rather than the government cared for the poor and elderly based on the culture and bureaucratic regulations of that time (Bohm, 2001). Dependent elderly people who could not be cared for directly by their own families were "boarded out" with surrogate families (Haber, 1983). Adult children of elderly people were considered financially responsible for paying the costs of such care. If there were no adult children, work was often exchanged for board or churches or
municipalities took on the responsibility (Teaford, 1975; Haber, 1983; Bohm, 2001).

The creation of "indoor relief" institutions was the response of government to alleviate poverty and dependency (Trattner, 1974; Teaford, 1975; Haber, 1983). As American society evolved from 1820 to 1865, institutions such as "almshouses" developed and effectively separated the ill, the indigent and the criminal from the rest of society, with almost no measures to ensure quality (Bohm, 2001; Teaford, 1975). These "indoor relief" institutions where people age 60 and older constituted about one fourth to one third of the inmate population were run by the city or county (Trattner, 1974). Older persons were often housed in almshouses as an act of charity, being viewed as too sick and weak to survive outside.

Buhler-Wilkerson (2001) identified the Ladies Benevolent Society of Charleston as the first organization in the United States to provide home care to the sick and poor in 1814. Around the same time, the Charitable Organization Society of New York also became an important influence in dealing with the aged and the poor. The society's goal was to provide assistance to the poor and elderly and eliminate the need for public assistance (Sherwood, 1974; Holstein & Cole, 1996). The women involved
in this movement would become one group of Stivers’ (2000) "settlement women" of the Progressive Era.

Charitable organizations and groups such as Little Sisters of the Poor constructed programs to keep the "able-bodied" poor out of almshouses and restore them to self-sufficiency. Alternatives to the almshouses began to develop when American culture was shocked "to find that white, native born women were ending up in these almshouses at no fault of their own for being poor" (Holstein & Cole, 1995, p.327). Public institutions had a stigma attached paving the way for religious and other benevolent organizations to establish "old age" homes of their own. In an effort to get their own elders out of the punitive environment of the almshouses minority groups followed by opening additional private homes (Bohm, 1995,). At this point in time there were no federal or state regulatory bodies to monitor the quality of care in these homes.

During the Depression many people found their large homes could be converted into boarding houses thus joining the mix of private institutions caring for the elderly (Regan, pp. 1975-76). The New Deal promoted the idea that elderly citizens should receive federal benefits on the basis of need. The Social Security Act (SSA) of 1935 and the creation of the Old Age Assistance (OAA) program
started a long history of governmental regulation of nursing homes at the federal level (U. S. Dept. of Human Services, 1996). This funding spawned the era of "specialized care" homes. "This was the beginning of the for profit elderly care business contributing to the demise of almshouses that had served the elderly as public nursing institutions" (Armour, 1994, pp.217, 238). For the majority of the minority population they did not qualify for this benefit, due to lack of job history and paying "into the system," hence, care for the Caucasian elderly.

The Hill-Burton Act of 1946 was an amendment to the SSA providing funding to encourage hospital construction so that the acutely ill could be cared for (Bohm, 2001). In 1954, Hill-Burton funds became available for the construction of skilled nursing facilities creating more alternatives for elderly patients in need of health care. The nursing homes were modeled after hospitals. This was the transformation of nursing homes from being part of the welfare system to being part of the health care system (Kane & Kane, 1987).

Throughout the 1970s, nursing homes went through transition. Throughout this period scandalous occurrences of poor provider fraud and poor care emerged and were brought into the political arena. Still few changes were enacted.
The largest overhaul of the system was to occur with the Omnibus Reconciliation Act (OBRA) in 1987. Yet this too was slow to effect change in the nursing home industry.

Misery, chronic neglect, humiliation and physical abuse—the barbaric treatment of America's elderly population—this was the nursing home culture in Texas shown to the television viewing audience October 25, 1991. The events were recorded by an ABC 20/20 undercover (October 25, 1991) investigator. One cannot watch the episode without being deeply moved. The video showed repeated scenes of residents tied to their beds or chairs, unwashed, uncared for. The residents' gowns are stained in fecal material, incontinent patients lying in waste for hours on end, covered with bedsores, roaches crawling under their bedclothes, suffering from hunger, and in agonizing pain. One of the facilities had razor barb wire surrounding it.

Federal Medicaid money was arguably sufficient to provide adequate care for the residents ($20,000.00/yr. per resident). Administrators, institutions, and profiteering on the part of the owners leads to maximizing profits (some over hundreds of thousands of dollars) by cutting patient services, chronic understaffing, reducing the number of qualified and adequately trained staff, providing patients substandard or watered-down food, and giving them
unnecessary drugs to keep them quiet and submissive. As a result of these actions residents frequently suffered from malnutrition, severe dehydration and illness from lack of good hygiene (ABC 20/20, 1991; Bates, 1999).

Deficiencies in the oversight of the quality of care provided by the government agencies responsible for monitoring nursing home compliance issues also contribute to the problem. Some critics charge the system is fundamentally flawed. The facilities are aware of the dates when they will be visited so they are able to clean and schedule adequate staff. It is the policy of the oversight agencies to investigate only specific complaints made and not beyond. When citations are issued for serious deficiencies, three months are permitted for remedying the problem. This is discouraging to investigators trying to make a difference. Even when death or serious injuries occur in situations of institutional abuse or neglect, it is difficult to prosecute the offenders. In the case of the Texas nursing homes, the owner of many of the homes investigated also sits on the state board.

Congress began recognizing the problem of elder abuse over twenty years ago. The House Select Committee on Aging published its report entitled "Elder Abuse: An Examination of a Hidden Problem" in 1981 which compared statistical
evidence of the prevalence of elder abuse with child abuse and recommended increased federal dollars for protective services and federal legislation. Thirty years later not much has been accomplished. A follow-up report on nursing homes in Texas, "Nursing Home Conditions in Texas: Many Nursing Homes Fail to Meet Federal Standards for Adequate Care" reveals that even the action of airing an investigation on national television fell far short of its goal for reform. This report was issued October 28, 2002 (eleven years after the broadcast) with the following conclusion:

The 1987 nursing home law was intended to stop abuses in nursing homes by establishing stringent federal standards of care. Although the law and its implementing regulations require appropriate standards of care, compliance by the nursing homes in Texas has been poor. This report reviewed the OSCAR and complaint databases and found that many nursing homes in Texas are failing to provide the care that the law requires and that families expect. Furthermore, this report found that most nursing homes in Texas did not meet the minimum staffing levels identified by HHS (Health and Human Services) as necessary to provide adequate care to residents (Nursing Home Conditions, 1981, p. 17).

A survey of nursing home personnel in one U.S. state disclosed that 36 percent of the nursing and aide staff reported having seen at least one incident of physical abuse by other staff members in the preceding year, and 10
percent admitted having committed at least one act of physical abuse themselves. At least one incident of psychological abuse against a resident had been observed by 81 percent of the sample in the preceding year, and 40 percent admitted to having committed such an act (Pillemer & Moore, 1990).

The nursing home industry is a lucrative business. When nursing homes moved away from smaller, family-run operations to large, for-profit enterprises, the players were more interested in real estate transactions than healthcare. Charles Phillips, director of the Myers Research Institute in Beachwood, Ohio charges our current long-term care system is a creature of government policy and these real estate ventures (Real Estate Investment Trusts or REITS) became corporate empires (Bates, 1999).

Currently mechanisms have been put in place to monitor for this type of situation and it is more heavily scrutinized. New quality measures have been implemented in the hopes of eliminating deficiencies. With the onslaught of “Baby-Boomers” about to enter, there is sure to be a large population involved in effecting change. The path of the future of this evolution will be predominantly based on public policy and legislation fueled by the entering generation.
Demographic Overview

Characteristics of nursing home residents illustrate changes in who is using these facilities, when and for what purpose. In 1997, the average age at admission among nursing home residents was 82.6 years with most of the residents Caucasian women. Current changes are occurring with regard to ethnicity. In 1985, Caucasian residents comprised 93 percent of the nursing home population, but by 1997, this proportion had decreased to 89 percent. Additionally, in 1997, 30 percent of nursing home residents were discharged into the community because they had recuperated or stabilized, representing a 12 percent increase since 1985. The mean length of stay for this group dropped from 89 days in 1985 to 45 days in 1997. Mortality also declined over this period from 25 percent in 1985 to three percent in 1997 (CDC Report, 2001).

The older population (65+) numbered 35.6 million in 2002, an increase of 3.3 million or 10.2 percent since 1992. By the year 2030, the older populations will more than double to about 71.5 million. The number of people aged 85 is expected to triple. Hispanic populations are living longer. Members of minority groups are projected to
represent 26.4 percent of the older population in 2030, up from 16.4 percent (AoA, 2004).

The older Hispanic population was 2.0 million in 2002 and is projected to grow to over 13 million by 2050. In percentage terms, the 2002 Hispanic person made up 5.5 percent of the older population. By 2050, the percentage of the older population that is Hispanic is projected to account for 16 percent of the older population aged 65 and older and is projected to be the largest racial/ethnic minority (AoA, 2004; U. S. Census Bureau, 2004).

The nursing home industry has flourished and facilities are found in nearly every city. The privately-owned nursing homes of the 1980s and 1990s are now being purchased by huge investment ventures and have corporate faces. Currently there are approximately 17,000 nursing homes in the United States that house over 1.9 million individuals (AoA, 2004). In 1997, only 4.3 percent of the population 65 years of age and over was in a nursing home (CDC Report 2005). However, almost one-quarter of all the aged will reside in a nursing home at one point or another.
According to the U. S. Census (2000), more than 30 percent of the total population is composed of various ethnic minorities other than non-Hispanic Caucasians. Approximately one out of every three persons in the United States distinguishes him or herself as a "minority." By 2050, it is expected this minority population will comprise almost 50 percent of the whole population (U.S. Department of Commerce, 2000). With life expectancy increasing an unprecedented 30-years within the last one hundred years, it is almost certain people will die at an advanced age, following a period of chronic illness and decline which will require some version of long-term care (Rao et al, 2002).

Projected growth of the older population guarantees understanding the organization, financing, and human interaction dimensions of long-term care will assume increasing importance. Within this context, the ethnic elderly will make up a proportionately larger segment of the population needing long-term care. Ethnicity has been defined by Holzberg (1982) as follows:

Social differentiation based on such cultural criteria as a sense of people hood, shared history, a common place of origin, language, dress, and free preferences, and participation in particular clubs or voluntary associations, engenders a sense
of exclusiveness and self-awareness that one is a member of a distinct and bounded social group. But it is not the ethnic content (marker) per se that constitutes the diacritica of social differentiation. More important for the purposes of social distance are the feelings of shared particularity, self-identification and membership in ethnic-exclusive associations (p. 252).

“Delivery and organization of quality long-term care services to culturally different groups has policy, practice, and scientific implications” (Barresi & Stull, 1993, p. xvii).

People of common European ancestry, Arabs, Jews, Native Americans, African-Americans, and different nationality groups of Hispanics and Asian-Americans, make up the varied ethnic/racial groups in this country. Because of the United States’ history of according differential treatment to different ethnic/racial groups, not all of them have been allowed equal economic, political, and social opportunity. Some groups have become more dominant in their economic, political and social status and have enjoyed greater privileges than others, with some of the latter having become the object of collective discrimination from the dominant groups (Gordon, 1964; Fox, 1985; Wilson, 1987; Barresi & Stull, 1993; Massey & Denton, 1993; Waldinger, 1996; Mui et al, 1998, pp. 5-6).
“Hence, there is the need for differentiating minority from ethnic groups because ‘minority’ status carries with it the exclusion from full participation in the life of the society” (Wirth, 1945, p.348).

Wirth’s observation in 1945 still applies today: “In the United States, the primary markers for unequal treatment of and discrimination against an ethnic/racial group have been their physical (notably skin pigmentation) and cultural characteristics” (Wirth, 1945, p. 350). Some argue that unlike the Caucasian majority counterpart, minority elders are thus likely to bear the stresses and burdens of being a minority person, on top of those being associated with being elderly (double jeopardy hypothesis), which derives from the devaluation of the old age found in most modern societies (Dowd & Bengtson, 1978; Mui et al, 1998, p. 6).

facilities were included in the study is not stated. It is reasonable to assume this interface carries through the entire healthcare system based on the usage of minorities and nursing homes (Belgrave et al., 1993; Brooks, 1996; Mui et al., 1998; Howard et al. 2002).

The American ways of class and race separation are often mirrored in nursing homes. In many cities, the majority of nursing assistants are people of color caught in the cycle of poverty. Residents are overwhelmingly European Americans who have been cast what should be deemed a better lot in life filled with opportunities to succeed financially, socially and politically (Noelker & Harel, 2001, p. 196) (see also Mui, Choi, & Monk, 1998 for statistical analysis of care delivery to Caucasians vs. minorities). This will be explored further in sections of this work examining delivery of services, i.e. care, caring, and quality of life.

Although racial disparities in the rates of utilization of nursing homes have been closing over the past 30 years, it is still estimated African-Americans are admitted to nursing homes between one-half and three-fourths of the rate of Caucasian elders (Belgrave, Wykle, & Choi, 1993; Mui et al., 1998). Other ethnicities enter at even lower rates. Some studies have shown that usage of
long-term care services are less utilized due to extended familial support systems in some minority groups (Aschenbrenner, 1975; Cantor, 1979; Gratton, 1987; Maldonado, 1977; Mindel & Wright, 1982; Rogler, 1978). Mui et al (1998) provide studies investigating usage of long-term care, service needs and service use among African-American, Hispanic (primarily Mexican-Americans, Puerto Rican, and Cuban-American), and Caucasian elders. Asian-American and American Indians were not included in this study due to lack of data sets. Most of the chapters explore in-home use of long-term care and use of community-based services. Chapters five and six (Mui et al, 1998) deal more specifically with nursing home placement.

Chapter five utilized an expanded Anderson-Newman Model (Anderson & Newman, 1973) identifying frail elderly who applied for nursing home admission and those who had not. These two groups were compared to examine factors associated with such applications. Mui et al (1998) found Caucasian elders were 73 percent more likely than African-Americans and Hispanic frail elderly to have applied for admission. The study indicated there were other factors for determining whether an application for admission was made: advanced age, cognitive and functional impairments, low income, number of formal services used, living alone, and
number of unmet needs. The availability of informal support was not a significant factor (Mui et al, 1998, pp. 72-73).


Using a survey of a stratified sample of 181 residential care/assisted living (RC/AL) facilities and 39 nursing homes in four states, they found African-Americans tended to be concentrated in a few predominately African-American facilities and the vast majority of Caucasians resided in predominately Caucasian facilities (Howard et al, 2002). They concluded there were racial disparities and these may be the result of economic factors, exclusionary practices, or resident choice. Smith (1999) presents an explanation by arguing long-term care facilities are influenced by both social and economic forces to admit primarily Caucasian (i.e. private pay) patients. In this context, "having one African-American resident may be
innocuous, but having many might adversely influence the number of white residents who choose to reside in a facility” (Smith, 1999, p. 1975).

The results of the Howard et al (2002) study concur with those of prior studies (Schafft, 1979; Cyr, et al, 1980; Morgan et al, 1995; Mutran et al, 2001). The findings of these studies concur with findings in the public administration literature identifying racial, economic, and social polarization as well as segregation in our society on the whole in choices or forces of living arrangements (Fox, 1985; Wilson, 1987; Sassen, 1991; Massey & Denton, 1993; Phillips, 1996; Waldinger, 1996; Mohl, 1997; Rusk, 1999).

Nursing research on race, ethnicity and culture (REC) has been examined by Jacobson et al (2004). The review gathered studies dealing with race, ethnicity or culture from major nursing research journals for the period 1992-2000. The study reviewed literature from a database consisting of all issues of IMAGE: JOURNAL OF NURSING SCHOLARSHIP (in 2000, The Journal of Nursing Scholarship), Nursing Research, Research in Nursing & Health, and the Western Journal of Nursing Research published between 1992 and 2000. The sample size of the research articles was 167.
Of the analysis conducted, ninety-four reports (56.3 percent) contained participants from more than one racial or ethnic group. Of the 73 reports (43.4 percent) devoted to single groups, 17 (10.2 percent) each focused on African-Americans and Hispanics or Mexican-Americans. Fourteen studies (8.4 percent) focused on people from Asian countries, 13 (7.8 percent) studied immigrants or refugees, and 6 each (3.6 percent) studied Native Americans and rural residents. “Other” (40, 23.6 percent) refers to named groups like Afghans, Arabs, Lebanese, Ethiopians, Africans from African nations, and Pacific Islanders regardless of race (Jacobson et al, 2004, pp.9-10). These findings focus on non-Caucasian samples in the review (32.4 percent) over three times as high as the previously reported findings in Drevdahl, Taylor and Phillips (2001) for the years 1952-2000 (9.1 percent). This dramatic increase could be due to the increasing amount of international research graduates. While these two research studies investigated REC in published nursing journals, there was no indication of how many were directed to issues of long-term care in the nursing home environment.

“The differences that have existed historically in the United States in terms of distribution of power, wealth, and access: treatment by medical establishments and
acceptance by others are still present today” (Werth et al., 2002, p. 208). These experiences shape the perspectives of residents and their loved ones. In addition, the values, beliefs, attitudes, rituals, and dynamics that have been important and adaptive in the past continue to shape the thoughts and actions of individuals today (Werth et al., 2002). “Culture permeates our existence, touching every aspect of our lives individually and collectively, including the end of life” (Krakauer et al., 2002, p. 188).

Cultural Diversity

Frusti, Niesen, and Campion (2003) state diversity competence is "an individual's ability to respect each person's uniqueness" (Frusti, Niesen, and Campion, 2003, p. 31). Diversity not only includes sexual orientation, age, gender, ethnic backgrounds, race, and mental and physical characteristics, but also communication skills, educational background, religion, primary language, work experience, income level, geographic locale, experience in the military, and family status.

Culture, as the social scientist uses the term, refers to “the social heritage of man—the ways of acting and the ways of doing things which are passed down from one
generation to the next, not through genetic inheritance but by formal and informal methods of teaching and demonstration" (Tylor, 1891, p. 3). The classic definition of culture is attributed to anthropologist, E. B. Tylor (1891), who described it as "that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society" (p. 3). Sociologists use the term subculture to refer to the cultural patterns of any type of subgroup within the national society (Gordon, 1964). The ethnic group, however, rests on ancestry and family connection and is involuntary: "For each man or woman is the intersection of a line of ancestry and a line of social and cultural patterns and institutions, and it is what we are by heredity and early family influence that comes nearest to being inalienable and unalterable" (Kallen, 1924, p.60). Or, as he had put it even more succinctly in his early essay: "Men may change their clothes, their politics, their wives, their religions, their philosophies, to a greater or lesser extent: they cannot change their grandfathers" Kallen (1924, p. 122).

Culture in this paper refers to more than ethnicity, using the definition provided by Krakauer, Crenner, and Fox (2002): It is "a constellation of shared meanings, values,
rituals, and modes of interacting with others that determines how people view and make sense of the world" (p.184). The first fact about nursing home residents is heterogeneity.

Heterogeneity is not confined to disabilities and lengths of stay. The focus of minority aging is related to an increasing emphasis on minority groups that began with the civil rights movement. As ethnic minorities became politically empowered, older people too began to view themselves and began to be viewed by others as a political base with which to be reckoned. Gray power piggybacked on the success of the civil rights, Chicano, and feminist movements (Kane & Kane, 1987).

Cultural diversity is addressed in the nursing literature as far as workers in an organization representing the clients that it serves. Cultural diversity in long-term care has also been explored, although not extensively. Most researchers are reluctant to address this topic when discussing cultural diversity's impact in the nursing home whether it is staff or residents (Maldonado, 1977; Schafft, 1979; Cyr et al, 1980; Belgrave, et al 1993; Salive et al, 1993; Mui et al, 1998; Johnson, 1999; Chin, 2000; Drevdahl et al, 2001; Krakauer, 2002). These studies rely on dichotomous populations i.e. Black/Caucasian, Caucasian/Hispanic, and Caucasian/Asian. This leaves an area in need of exploration.
Culturally Competent Care

There has been extensive discussion in the nursing literature regarding cultural competence. The literature brings with it a number of definitions. The monograph, Toward a Culturally Competent System of Care (1989), defined cultural competence as a set of behaviors, attitudes, and policies that enable a system, agency, or group or professionals to work effectively in cross-cultural situations.

The California Cultural Competency Task Force, established in 1994 by the state's Department of Mental Health, defined "cultural competency" as "appropriate and effective communication which requires the willingness to listen to and learn from members of diverse cultures, and the provision of services and information in appropriate languages, at appropriate comprehension and literacy levels, and in the context of an individual's cultural health beliefs and practices" (Task Force, 1993).

Leininger (1999) stated

culturally competent care is using knowledge that has been learned about a specific culture and applying it in sensitive, creative, and meaningful ways when providing care to individuals from diverse backgrounds. The goal is to provide culturally competent care to patients and their families (Leininger, 1999, p. 1).
Alexander (2002) defined cultural competence as a set of congruent behaviors, attitudes and policies that come together in a system, agency, or among professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations (p. 30).

Alexander advocates for cultural competence training at every level within a healthcare organization.

Burcham (2002) described cultural competence as “an ongoing developmental process based on increased knowledge and skills specific to cultural sensitivity, understanding, interaction, and awareness” (p. 6). This means care is individualized and appropriate in regard to the patient's cultural values, beliefs, and practices. Diversity and cultural competence have become buzzwords for maintaining a competitive edge while satisfying affirmative action objectives (Chin, 2000).

Quality of Care

Perceptions of quality of care is a component of the quality of life for those involved in this environment and is a critical consideration in international health care policies and health care decisions. There have been relatively few studies addressing the quality of care issue surrounding the interaction of staff, family members and patients (Duncan & Morgan 1994; Hertzberg & Ekman 1996).
Some studies have addressed the need for autonomy for chronically ill, but cognitively competent, residents (Mattiasson & Andersson, 1997) while others have addressed the interaction of staff with family members of cognitively incompetent residents (Hertzberg & Ekman 2000; Hertzberg, Ekman & Axelsson 2003). Most studies on the quality of care and interactions have looked through the perspective of the nursing staff only (Mattiasson & Andersson 1997, pp. 1118).

Research has shown family involvement in nursing homes may influence the quality of life for residents (Ekman & Norberg 1988) as well as the quality of visits for relatives (Linsk et al 1988; Grau et al, 1995; Hertzberg & Ekman 1996). Interaction between nursing staff and residents is also used as an indicator of quality of care (Taylor et al 1991; Vuori 1991; Bond & Thomas 1992; Zinn et al 1993). Most respondents in the studies indicated interactions were deemed very important but due to staff downsizing and mounting responsibilities the opportunities for such interaction becomes limited. As downsizing continues, the quality of life of the residents and the quality of life for the nursing staff is greatly impaired (Bediako, 2002).

The opportunity to gather information relating to the perceptions of interactions of quality of care from nursing
staff, residents and their families may lead to identification of obstacles and promoters of positive feelings between the groups. Perceptions are unique to individuals and interactions may not be interpreted as others think they are. While some studies have indicated nurse's aides sometimes are the object of verbal assault, interactions in culturally diverse environments has not been studied and is an area ripe for investigation.

Articles on quality of care for diverse populations abound in the literature surrounding healthcare from providers in mainstream society. The literature on quality of care in nursing homes is usually looked at through studies of quality form nursing documentation (Wan, T. T. H., 2003; Voutilainen et al, 2004), state surveys, or through the eyes of third parties (caregivers, regulators) and often measured in terms of inputs and processes (Davis, 1991; Burgio et al, 2004). In recent years there has been an increased focus on output and outcome measures of quality (Shaughnessy, et al, 1991).

Currently efforts to evaluate quality of care are taking into consideration perceptions of the quality by customers of nursing home care. Kane (1988) argues more attention be given to resident evaluation of quality of care has in some cases been followed (Bleismer & Earle,
Pearson et al's (1993) study on staff mix and resident quality of care reached disappointing results. The instrument in the study was difficult to use and a high percentage of positive responses by residents did not correlate with the observations of the research assistants. There was also concern while residents were able to assess care, they were reluctant to criticize the staff or their behavior.

Another cause of negative interaction in residential care facilities is racism expressed as racial slurs and stereotypes (Tellis-Nyak & Tellis-Nyak, 1989; Dougherty et al, 1992; Holmes, Ramirez, & Fairchild, 1994). Research by Ramirez (1998) and her colleagues found significant predictors of nursing assistant job burnout included stress related to ethnic and racial conflict. This source of stress refers to nursing assistants' perceptions residents were biased toward them based on the nursing assistant's ethnic background. For example; nursing assistants who perceived the residents thought they would not do a good job or unjustly accuse them of things because of the nursing assistant's race were more likely to report burnout. Their work underscores previous findings by Grau
and Wellin (1992) that nursing home subcultures develop based on differences in occupational status and ethnic background, and “the subcultures cause tensions in the facility's interpersonal climate when administration fails to address them” (Noelker & Harel, 2001, p.21).

More research needs to be conducted in these areas of interactions between nursing staff, residents and family members to try and find ways that will benefit all of the players in maintaining a high quality of life for everyone involved in the nursing home environment. These groups can learn to assist one another in the caring and it allows for intimacy for the resident. Mattiasson & Andersson (1997) argue the "staff in the caring professions should have a moral obligation to actively create opportunities for and uphold the humanizing element in nursing homes-human relationships" (p. 1123).

Quality of Caring

Caring has been subjected to considerable attempts of defining and theorizing in order to adequately specify the term quality of care (see previous discussion). Because caring involves meeting human needs, it is logical that
theories of caring are based on needs theories (Maslow, 1954) and modified in accordance with healthcare situations (Mattiasson et al, 1997).

Glass (1991) however, distinguishes quality of caring from quality of care as key to quality of life in nursing homes. Traditional quality of care approaches focus on the skill levels of staff, the appropriateness of medical and physical care, and adherence to standard guidelines and procedures for providing this care. Quality of caring in contrast refers to

the nature of staff and resident interaction that is as important to quality of life as the quality of care that is received. The traditional emphasis on technical proficiencies in care as they relate to health and functional outcomes stands in contrast to the fact that most chronic care involves routine, nontechnical, and time-consuming assistance with personal care tasks and activities of daily living (ADL)” (Noelker & Harel, 2001, p. 12).

The personal care that residents receive is not part of routine care, i.e. dressing, bathing, and feeding, and it is consequently left undone when there is an insufficient number of staff. Lack of time for personal caring is a major concern for staff and residents in the results of Jackson's (1997) study. This study found sometimes it was the special relationships that had evolved that prompted personal caring. Jackson (1997) noted
Yet personal caring was rendered invisible by virtue of the fact that these care acts had few and insignificant consequences that could be linked directly to the omission of a single care activity. Evidence of neglect of these actions could be easily hidden...Personal caring is assumed and is only sometimes reinforced in service or staff development programs. However it is neither scheduled, rewarded, nor compensated (pp. 198-199).

Discussions of caring evolved out of the feminist literature (Gilligan, 1982; Noddings, 1984) and is often discussed in the realm of ethics of caring. In order for nursing home patients to remain healthier and care less costly nursing home patients need the entire scope of care, including routine caring and personal caring.

Quality of Life

One of the issues in quality of life research is the concept itself. Quality of life encompasses all areas of human life: environmental and material components, and physical, mental, social and spiritual well-being. The highly individualistic, subjective and multidimensional nature of the concept of quality of life makes it difficult to define and measure” (Wood-Dauphine & Williams, 1987; Fletcher et al, 1992, p. 45).
Quality of life is measured in terms of minutes of life during which one's affect state may be positive, neutral, or negative. If our focus is on the individual, only that person can tell us (either in words or nonverbally) the quality of life for residents in general, then aspects of the care environment known to be statistically associated with the most favorable balance of positive and negative for the group of people receiving care must be thought of as elements of quality of life (Noelker & Harel, 2001, p. 157).

This will be the definition for this study.

Guse and Masesar (1999) conducted a study of quality of life in long-term care. Thirty-two residents were asked to rate factors related to quality of life. They identified the following factors as important to a good quality of life: interaction with family and friends, personal qualities, "room and board" items, and aspects of well-being. Two factors not usually identified in studies became evident: enjoying nature and being helpful to others. The previously mentioned constructs in this paper are all contributors to the residents' quality of life. Quality of life is investigated by researchers in regard to those with diseases such as dementia, diabetes mellitus, and cancer. Quality of life is a significant factor for all studies within the nursing home realm. Though the findings are subjective, they unveil some discrepancies in care that may be addressed by the staff.
The broader, ever-increasing graying population of American Society is composed of a mosaic picture of discrete cultural groups existing with the context of their own values and identities. Those distinct cultures are embedded in the thinking of each resident, affecting his or her perceptions of quality of life in long-term care (Suh, 2004, p. 100).

This study will help fill the gap in both the nursing and public administration literature in the lived experience of individuals in culturally diverse long-term care facilities. Health, aging and housing will continue to be areas of great interest to academic disciplines as society continues to age.
CHAPTER III

METHODOLOGY

A phenomenological approach for this study utilizing concurrent nested methodology (quantitative and qualitative) will be employed. Social workers of the facilities will provide the demographic data of the residents by way of face sheets. Face sheets contain data such as name, date of birth, country of birth, race, religion, occupation, marital status and number of children. Social workers will also identify those residents who are cognitively able to participate based on assessments such as the MMSE (Mini-Mental Sate Exam) where participants must score 24 and higher. By providing this information, the task of recruiting the eligible population will be made much easier, as these individuals interact with the residents on a daily basis and are able to provide valuable information as to changes in mental status from the onset of selection for participation and actual participation.

A mixed methodology (concurrent nested) approach should yield data that is richer in content than
simple quantitative or qualitative study. Residents' perceptions of positive living experiences are based on the life experiences of the individuals: when they grew up, where they grew up, and personal events (Werth et al., 2002). The oldest old of the respondents would have lived through the Depression and before civil rights. This could affect their life views.

Concurrent nested methodology is appropriate for this study by permitting both quantitative and qualitative data to be simultaneously harvested from the participants. This methodology saves time and reduces the wear and tear on the elderly participants who often become tired or experience discomfort from a long interview process.

For the qualitative portion of the study a phenomenological approach will be employed.

Phenomenology has its roots in the philosophical perspectives of Edmund Husserl (1859-1938) and philosophical discussions to follow by Heidegger, Sartre, and Merleau-Ponty” (Creswell, 1999, pp. 51-52). In essence, it is the understanding of the lived experience of people and how they make sense of it. The phenomenological approach is primarily an attempt to understand empirical matters from the perspective of those being studied (Creswell, 1998, p. 275).

The healing professions, particularly nursing, seem to be deeply imbued with a phenomenological focus on the provision of care based on a rigorous emphasis on the patient’s subjective experience” (Benner, 1995).
In phenomenological analysis,

the researcher is required to state her assumptions regarding the phenomenon being investigated and then suspend those preconceptions so that the experience of the subject can be fully understood and the researcher does not impose an a priori hypothesis on the experience” (Creswell, 1998, p.277).

There are various approaches within this tradition (Spiegelberg, 1982), but it is typically divided into two different types, descriptive and hermeneutic or interpretive phenomenology (Cohen & Omery, 1994; Walters, 1995; Morse & Field, 1996). Descriptive phenomenology refers to the pure description of the phenomena under study, involving as little interpretation as possible. Hermeneutic phenomenology aims for a phenomenological interpretation to uncover the meanings of the phenomenon studied (Colaizzi, 1978; Benner, 1991; Astedt-Kurki & Nieminen, 1997). In this study, descriptive phenomenology will be used.

Both approaches share a common view of the individual's experiential relationship to the phenomenon in question (Colaizzi, 1978; Benner, 1994, Astedt-Kurki & Nieminen, 1997). The task for the researcher is to try and gain as genuine and a possible in-depth understanding of the subject's life-world. This requires self-reflection on the part of the researcher and a conscious effort to put
aside any preconceptions he or she may hold about the subject. However, previous knowledge is important for any analysis and for clarifying and justifying the research task (Colaizzi, 1978; Patton, 1987; Astedt-Kurki & Nieminen, 1997). Colaizzi's (1978) phenomenological method emphasizes the discovery of both explicit and implicit meanings in the research material. The analysis of implicit meanings (or latent content) necessarily involves interpretation which has been the subject of some disagreement in the research tradition (Colaizzi, 1978; Patton, 1987; Cohen & Omery, 1994; Walters, 1995; Morse & Field, 1996). According to Colaizzi (1978), the researcher has to try to spell out the meaning of each significant statement, in other words, she must leap from what they say to what they mean. However, the researcher must not formulate meanings and clusters of themes which have no connection with data.

In this study, the data will be collected by questionnaire with space provided after each question for the resident to add comments (see Appendix A). Additional unstructured interviews with volunteer residents will be conducted. The purpose of this is not to have simple question-and-answer sequences but rather to encourage participants to reflect upon their own experiences in a
conversational manner. The participants will be asked if they understand the terms cultural diversity and quality of life and to describe their own experiences of living in long-term care, with each other, and specific situations that they liked and or disliked (best-worst).

It is desirable to study life in long-term care as a form of “living” from a philosophical and phenomenological perspective in order to analyze the essential concepts of cultural diversity, culturally competent care, quality of care, quality of caring and quality of life from the residents' perspectives. The concept of long-term care viewed as a community is equally essential. Development of contacts between residents and others largely depends on a person's perception of the other person and the self (Dimbleby & Burton, 1998). All of above-mentioned concepts will impact the residents’ perceptions of their quality of life.

Having been imbedded in this environment of long-term care in multiple capacities it is anticipated that familiarity and trust with the researcher will help to foment the quality of the responses. Incorporating a participant-observation component to the study will capture body language and behavior of participants and the environment in which they live. The “lived experience” will
be richer if participants are able to describe their experiences in their own words while the researcher documents behaviors, attitudes, body language and events associated with the respondents.

Participants and Procedures

After some small modifications and clarifications of questions, permission to conduct this study was granted by the University of Akron’s Internal Review Board (APPENDIX A).

The study will be carried out in three long-term nursing facilities in two Ohio counties. Quantitative data with an option to add qualitative data will be collected by a survey administered in the facilities' activity room. Qualitative data will be collected in semi-structured interviews with a purposive volunteer sample of residents recruited by posting invitations to participate in the study on the bulletin boards.

Parameters for the resident population in this study are: age 60 years or older, able to provide informed consent, able to participate in the study, and having resided in the facility for at least one year (Appendix B). According to Patton (1987) there are no guidelines for determining the size of a purposeful sample. Sample size
depends on what you want to know, what will be useful, credible, and the availability of time and resources (p. 184). Twenty participants will be selected from this sample of those willing to participate in the interview portion of the study for the interview sessions. This selection will be based on the initial participation in the survey. Those that seem to be interested in participating further will be asked to be interviewed more extensively. In qualitative research the size of the sample is determined by attainment of saturation point in data collection (Morse & Field, 1996). Lincoln & Guba (1985:202) recommend sample selection to the point of redundancy...In purposeful sampling the size of the sample is determined by informational considerations. If the purpose is to maximize information, the sampling is terminated when no new information is forthcoming from new sampled units; thus redundancy is the primary criterion. (emphasis in original)

In this study it is expected saturation should be reached at 10 interviews.

Data will be collected by questionnaire that will be conducted in the activity rooms of the facilities. The researcher will be present to explain, or assist the participant in filling out the questionnaire. The instrument that will be used is a combination of Satisfaction with Life Scale (SWLS), Cultural Competence Assessment Instrument (CCAI), and Resident Satisfaction
Index (RSI). The first two instruments are in the public domain. Permission for adaptation of the Resident Satisfaction Index (RSI) was granted from the author, Elzbieta Sikorska-Simmons.

There are five questions in the SWLS section of the questionnaire. A likert scale is used for the participant to circle their perception from 1=strongly disagree to 7=strongly agree. The RSI portion consists of fifteen questions using a likert scale ranging from 3=always to 0=never. The CCAI portion consists of 13 dichotomous (yes, no) questions (see Appendix C for a copy of the adapted instrument).

The qualitative portion consists of questions and areas to be explored as follows:

1. Tell me about your life in this facility. How does it compare to the world that you once were a part of?
2. What is the best experience that you have had while living here?
3. What is the most disturbing (worst) experience that you have had while living here?
4. Tell me about your friends and those that you interact with.

These are in addition to the qualitative additions to the survey questions. Attributes of community will be explored
as the answers to these questions unfold. A tape recorder will be used to collect this data so as not to distract the subject during the process and for accuracy of answers. The following will be discussed with the participants:

I’d like to tape record what you have to say so that I don’t miss any of it. I don’t want to take the chance of relying on my notes and thereby miss something that you say or inadvertently change your wording somehow. So, if you don’t mind, I’d very much like to use the recorder. If at any time during the interview you would like to turn the tape recorder off, all you have is tell me and I will stop the recorder (Patton, 1987).

It is desirable in this type of study to also utilize a participant observer component. The purpose of this type of data is to describe the setting, the activities taking place in this setting, who participates and the meaning of what was observed from the perspective of those observed (Patton, 2002, p. 202). Notes will be taken while in the field or immediately after the interview. The term participant observation “refers to the circumstance of being in or around an on-going social setting for the purpose of making a qualitative analysis of that setting” (Loftland, 1971, p. 93, in Patton, 1990, p. 202).

The data collected will be stored in a locked filing cabinet in the researcher’s home. The answers will be coded to preserve anonymity of the participants.
Data Analysis

SPSS (Statistical Package for Social Sciences) will be used to analyze quantitative data for descriptive statistics and regression models will be used to determine significant relationships between variables.

Files will be created and organized from the qualitative data collected. This data will be read and initial codes will be formed. The data will illustrate the meaning of the experience and the researcher will find and list statements of meanings for individuals. The data will then be grouped into meaning units. The data will then be developed into a structural description of “how” the phenomenon was experienced. The analysis will be presented using tables or figures of statements.

The interpretation of the qualitative data from the final interviews will be analyzed utilizing the four-step phenomenological analysis taken from Moustakas (1994) and further described by Patton (2002). According to Patton (2002), “phenomenological analysis seeks to grasp and elucidate the meaning, structure, and essence of the lived experience of a phenomenon for a person or group of people” (p. 482). Following are the four steps:
Step 1 – Epoche. In the Epoche, the everyday understanding of judgments, and knowing are set aside in order to allow a wide-open sense of the phenomenon. The Epoche is “the process of removing, or at least becoming aware of prejudices, viewpoints, or at least assumptions regarding the phenomenon, or at least assumptions regarding the phenomenon under investigation” (Katz, 1987, p. 36). The purpose of this step is to allow for the noema and noesis of the situation to emerge. The noema as described by Patton (2002) is the process of “discerning the features of consciousness that are essential for the individuation of objects (real or imaginary) that are before us in the consciousness.” While the noesis “is explicitly how beliefs about such objects (real or imaginary) may be acquired, how it is that we are experiencing what we are experiencing” (Patton, 2002, p. 484).

Step 2 – Phenomenological Reduction. Bracketing “holds a phenomenon up for serious inspection” (Patton, 2002, p. 485). Denzin (1989) applies bracketing involving the following steps:

1. Locate within the personal experience, or self story, key phrases and statements that speak directly to the phenomenon in question.
2. Interpret the meanings of phrases, as an informed reader.

3. Obtain the subject’s interpretation of these phrases, if possible.

4. Inspect these meanings for what they reveal about essential, recurring features of the phenomenon being studied.

5. Offer a tentative statement, or definition, of the phenomenon in terms of essential recurring features identified in step 4 (Denzin, 1989).

Step 3 – Imaginative Variation. Once the data are bracketed, they are assembled into meaningful clusters. Then a delimitation process takes place to eliminate irrelevant, repetitive, or overlapping data. Then data are then assembled into themes to perform an “imaginative variation” on each theme. The process of imaginative variation is to work around the theme to see it from different views in order to develop an enhanced or expanded version of the theme (Patton, 2002).

Step 4 – Synthesis of Texture and Structure. Once the themes have been determined a textual portrayal of that theme was developed. According to Patton (2002), the textual portrayal is an abstraction of the experience that provides content and illustration, but not
yet essence. The structural synthesis looks beneath the affect inherent in the experience to deeper meanings for participants (p. 485).

Data from interviews that are recorded will be transcribed completely with names of those involved being changed to protect the identities of those observed. These will also be coded to appropriate facility for further analysis.

The findings from both data sources will be presented using tables, figures and/or charts in Chapter IV. This mixed methodology (concurrent nested) approach should yield data that is much richer in content than a simple quantitative or qualitative study.

Qualitative studies are limited to the participants involved and does not allow for generalization. Limitations of this study include lack of participation by residents due to fear of retribution.
CHAPTER IV
RESULTS AND ANALYSIS

This study explores the phenomena of residents’ perceptions of quality of life in culturally diverse long-term care facilities which utilizes a phenomenological perspective. Concurrent nested methodology (quantitative and qualitative) was employed for this study. Demographic data was derived from the “face sheets” (admission forms) supplied by the social workers of the facilities. Surveys completed by selected residents provided quantitative data for analysis. Qualitative data was collected from interviews and observations of the lived experience in these facilities.

The research question for this study is: What factors may contribute to residents’ perceptions of Quality of Life and sense of community in culturally diverse long-term care environments?

The results will be presented in this chapter in two sections. Quantitative data will be presented in the first section followed by qualitative in the second section.
Participants

Seventy four residents were surveyed in the three facilities participating in the study. Four of those were eliminated before data collection due to a significant event occurring compromising cognition. Three of the selected subjects died before the survey data was collected, two did not meet a MMSE (Mini-Mental State Exam) score of 24 (surveyed at request of resident and facility) and four were younger than the starting age parameter of 60 (also surveyed at resident and facility request).

Demographics

Sixty-one survey eligible residents from three facilities participated in this study. Facility one comprised 24 percent, facility two 26 percent, and the largest facility provided 50 percent of the participants. The age range of the participants was 61 years old as the youngest and 97 years old as the oldest. Females represented 57 percent of the sample while males represented 43 percent of the sample (See Tables 1 and 2).
Table 1
Sampled Facilities
(Frequency Distribution of Survey Respondents, N=61)

<table>
<thead>
<tr>
<th>Facility</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facility 1</td>
<td>15</td>
<td>25</td>
</tr>
<tr>
<td>Facility 2</td>
<td>16</td>
<td>26</td>
</tr>
<tr>
<td>Facility 3</td>
<td>30</td>
<td>49</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 2
Age & Gender
(Frequency Distribution of Survey Respondents, N=61)

<table>
<thead>
<tr>
<th>Age</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>61-73</td>
<td>22</td>
<td>36</td>
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<tr>
<td>74-85</td>
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<td>86-97</td>
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<td>23</td>
</tr>
<tr>
<td>Total</td>
<td>61</td>
<td>100.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>35</td>
<td>57</td>
</tr>
<tr>
<td>Female</td>
<td>26</td>
<td>43</td>
</tr>
<tr>
<td>Total</td>
<td>61</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Race and ethnicity provided the representation of a dichotomous population comprised of 85 percent Caucasian and 15 percent African-American. While the population of the largest facility serves an African American population of 40 percent, either refusal to participate or decreased cognition prevented participating in this study (See Table 3).
Table 3
Race/Ethnicity
(Frequency Distribution of Survey Respondents, N=61)

<table>
<thead>
<tr>
<th>Race</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>African-American</td>
<td>52</td>
<td>85</td>
</tr>
<tr>
<td>Caucasian</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>61</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Educational attainment of the participants consisted of 32 percent having less than high school, 60 percent completed high school and 8 percent were college graduates (Refer to Table 5). Religious affiliation of the participants was revealed to be 20 percent to be Protestant, 11 percent Baptist, 16 percent Catholic, two percent Methodist, five percent Lutheran, five percent Apostolic, one percent Muslim; and, 41 percent identifying themselves as Non-denominational (Table 4).
### Table 4
**Education & Religion**
*(Frequency Distribution of Survey Respondents, N=61)*

<table>
<thead>
<tr>
<th>Education</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less Than High School</td>
<td>20</td>
<td>33</td>
</tr>
<tr>
<td>High School</td>
<td>36</td>
<td>59</td>
</tr>
<tr>
<td>College Graduate</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>61</td>
<td>100.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Religion</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apostolic</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Baptist</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Catholic</td>
<td>10</td>
<td>16</td>
</tr>
<tr>
<td>Lutheran</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Methodist</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Muslim</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Non-Denominational</td>
<td>25</td>
<td>41</td>
</tr>
<tr>
<td>Protestant</td>
<td>12</td>
<td>20</td>
</tr>
<tr>
<td>Total</td>
<td>61</td>
<td></td>
</tr>
</tbody>
</table>

**Survey data**

The survey instrument utilized to collect data consisted of three distinct sections: Resident Satisfaction Index (RSI); Satisfaction With Life Scale (SWLS); and the Cultural Competence Assessment Instrument (CCAI). The data is presented to reflect these instruments.

**RESIDENT SATISFACTION INDEX (RSI)**

The RSI consists of fifteen questions addressing the areas of health care, physical environment, relationships with staff, social life and activities using a Likert scale 3=always - 0=never. Three percent of the sample chose
“never” as the answer to, “Is the staff making every effort to keep you as healthy as possible?” Ten percent reported rarely or sometimes. Thirty-three responded usually/most of the time and 22 reported “always” for a total 87 percent satisfied in this area. None of the sample revealed the nursing assistants were never nice and courteous while 11 percent responded rarely/sometimes; 57 percent responded usually/most of the time, and 32 percent responded the nursing assistants were always nice and courteous. As reported in the literature review, this group suffers from the most job burnout and is the most intimate with the residents (Ramirez, 1998). These numbers indicate the residents in these facilities maintain good relations with integral members of staff. Seventy-one percent of the sample reported they are comfortable reporting health concerns to the staff (29 percent usually/most of the time; 42 percent always) with 29 percent choosing not to report health concerns or feeling uncomfortable in doing so (seven percent never; 22 percent rarely/sometimes). Overall responses for healthcare were positive.

The RSI contained two questions addressing the physical environment of the facilities. When asked if the facility was a comfortable place to live two percent
responded never, 32 percent responded rarely/sometimes, 45 percent responded usually most of the time and 21 percent felt always. Sixteen percent never felt at home, 32 percent felt at home rarely or sometimes, 34 percent felt at home usually or most of the time and 18 percent always felt at home. While the majority of the residents felt their facility was a comfortable place to live only about half felt “at home.”

Eight questions in the RSI addressed relationships with staff. The literature reveals these relationships are deemed to be very important to the overall happiness of the resident in the long-term care environment (Mattiasson & Andersson, 1997, p. 1123). Ninety percent found the staff was kind and caring while only ten percent did not. Ninety-five percent of the time the staff serving food was found to be both nice and courteous. When questioned about the staff’s attitude and behavior, 81 percent of the sample were unhappy at least some of the time (71 percent rarely/sometimes; seven percent most of the time, and three percent always). Of the 61 participants, 20 percent were never unhappy with the staff’s attitude or behavior. This area warrants further investigation to determine if this is
related to cultural and/or generational differences between staff and residents.

Overall dependability of the staff was found to be positive with 82 percent of residents responding positively (48 percent usually/most of the time; 34 percent always) and 18 percent disagreeing (8 percent never; 10 percent rarely/sometimes). Seventy-one percent were found to believe they have friends among staff (42 percent usually/most of the time; 29 percent always) while 29 percent thought this occurred only rarely/sometimes (26 percent) or never (three percent). Eighty-two percent were satisfied with the personal assistance they were receiving (46 percent usually/most of the time; 35 percent always) while 18 percent were not (two percent never; 16 percent rarely/sometimes).

Seventy-two percent of residents reported sometimes the staff treated residents in a rude way (58 percent rarely/sometimes; 11 percent usually/most of the time; three percent always) while approximately 28 percent of the residents never witnessed this behavior. A majority of the residents (89 percent) responded at least some of the time the staff was slow to respond to their requests (69 percent rarely/sometimes; 18 percent usually/most of the time; two
percent always). Further analysis is needed to determine if this is attributable to understaffing. This was the final question addressing relationship with staff.

The final two questions of the RSI address social life/activities. Meeting residents with whom they share similar interests revealed the following response rate: 15 percent never; 58 percent rarely/sometimes; 19 percent usually/most of the time, and; 8 percent always. This answer would not support a feeling of community because they do not have a shared sense of “likeness.” Food is always a controversial matter in institutional settings and the residents in this survey responded as follows: 24 percent never like the food; 44 percent like the food only sometimes or rarely; 31 percent usually like the food and only one percent always liked the food.

Satisfaction With Life Scale (SWLS)

There are five questions in the SWLS section of the questionnaire. A likert scale is used for the participant to circle their perception with 1=strongly disagree - 7=strongly agree. Fifty-six percent of the sample at least slightly agreed (18 percent slightly agree; 22 percent agree; 16 percent strongly agree) and 42 percent of the sample at least slightly disagreed (eight percent strongly
disagree; 15 percent disagree; 19 percent slightly disagree) their life was close to ideal. Two percent were non-committal (neither agree nor disagree).

Fifty-eight percent of the sample disagreed the conditions of their life were ideal (8 percent strongly disagree; 23 percent disagree; 27 percent disagree) and thirty-five percent agreed (13 percent slightly agree; 17 percent agree; 5 percent strongly agree) while seven percent neither agreed nor disagreed. Seventy-one per cent of the sample indicated they had gotten the important things they wanted in life (14 percent slightly agree; 26 percent agree; 31 percent strongly agree) and 18 percent disagreed (5 percent strongly disagree; 2 percent disagree; 11 percent strongly disagree) while 11 percent neither agreed nor disagreed.

The final question of this portion of the survey was the most moving for most of the residents. The residents all took additional time to reflect on their lives, some emotionally so. Answers were roughly divided equally. Fifty percent of the residents agreed if they could live their lives over they would change almost nothing (six percent slightly agree; 26 percent agree; 18 percent strongly agree) and 48 percent disagreed to some extent (14 percent
strongly disagree; 16 percent disagree; 18 percent slightly disagree) with only two percent neither agreed nor disagreed. Many of the reasons for these responses will be revealed in the qualitative portion of this study.

Cultural Competence Assessment Instrument (CCAI)

The CCAI portion consists of 13 dichotomous (yes, no) questions pertaining to their admission to the facility which will become their new home. Fifty percent were not comfortable when they came to their respective facility and often punctuated they never thought they would end up there. Forty-two percent however did feel comfortable. Most of the participants (86 percent) indicated the facilities made them comfortable when they arrived. Fifteen percent denied this.

Eighty-two percent responded they did not see pictures on the walls reminding them of family and friends, although 18 percent indicated they did. Also 77 percent responded magazines and reading articles were not interesting while 23 percent responded positively. An overwhelming 97 percent were spoken to in their own language. This is attributable
to the geographic locations of the facilities on the fringe of a major metropolitan population.

Of the 61 residents, 87 percent were comfortable with the social worker/DON; 81 percent thought the social worker/DON was interested in family concerns; 68 percent felt the social worker/DON understood their family problems, and 65 percent believed the social worker/DON was interested in their background. Ninety-two percent of the sample indicated the social worker/DON showed respect for them; 75 percent felt the social worker/DON gave good service to them, and 74 percent responded the social worker/DON gives good service to all. Overall, the social workers/DONs were viewed positively by the residents. However, this was a difficult question in one of the sample sets due to turnover in one of the departments. This will be explored further in Chapter Five.

QUALITATIVE DATA

Interviews

The sample was selected based on perceived accuracy and/or enthusiasm exhibited in the survey portion of data collection. Saturation as suggested by Lincoln & Guba
(1985) was achieved at ten interviews. In addition to the questionnaire, the phenomena and underlying concepts explored were guided by asking residents the following questions:

1. How does your life here compare to the world that you once were a part of?
2. What is the best experience that you have had while living here?
3. What is the most disturbing (worst) experience that you have had while living here?
4. Tell me about your friends and those that you interact with.

This portion of the study proved to be the most emotional and yet more telling than the emotionally charged answers of the SWLS. Residents took time to relive certain moments in time relating to the above-mentioned questions/statement. These will be presented in the order listed and body language of the residents will be noted where deviations existed.

The discussions were conducted on a one on one basis in the activity rooms of the facilities. Each facility contributed at least two members of the respective communities. The women outnumbered the men in the sample two to one. This can be explained by the demographics
presented in the previous section. When presenting these results the names will be changed to protect anonymity. It should be noted some of the answers address more than one question. One is able to see the relationship between them. They will be presented as closely as possible to order.

The first question produced unanimous results. Residents stated they “never ever thought they would end up in a place like this.” The postures of these respondents seemed almost rigid, most looking at the floor as though a sense of sadness flowed through them. One 82 year old female resident was tearful when she explained to this researcher:

I never thought this would happen. We had our own home...We were happy there. I never thought we would end up here...

This particular resident and her husband were living together in one of the facilities. Her husband was too cognitively impaired to participate. After 60 plus years of marriage this respondent was confident her answers represented both of them. At this point during the interview, the resident began to cry and the interview was terminated until the resident could continue.

A male respondent answered:

I miss my family, friends, my home and my freedom. I hafta [sic] eat when they say, shower when they say, go to therapy when they say
whether I want to go or not...they don’t give a damn...I worked nights my whole life now I’m here and have to do what they want when they want...reminds me of my army days. Never thought I’d see that again...but I got nowhere else to go.

As the participants answered how this compared to their lives before, answers included loss of friends, seeing less of family, previous social gatherings, food choices and their physical losses leading up to these vacancies in their lives. Many of the residents were placed in the facilities by their families and resentment for placement is discernible. One male resident, 62 years old (included in the young/old) has resigned himself to his situation:

I have a good time with the guys and I have female friends. I get along with everyone. I’m not stayin’ here but my sister seems to like this place. I have lots of brothers and sisters and I gotta go where they tell me. I don’t know where I want to go, I don’t think it matters. I miss my dogs, I had four dogs when I lived in my van. I like it when the dogs come to visit, it makes me smile...

When residents responded to question two regarding their best experience, most smiled and bodies relaxed. However, the responses were limited to mostly one line answers. The responses involved day trips provided by the facilities, activities (specifically Bingo) and
interactions with staff members who exhibited kindness and caring towards them. One resident responded:

The best time I had was when I got here enjoying some of the activities like Bingo, going out to eat, things like that. I don’t go as often, my finances aren’t like they used to be...

Another:

My best time here was with Nurse B, she saved my life.

Descriptions of the responses to the residents describing their worst time involved organizational flaws such as staffing, roommates, others in the facility, lack of satisfaction with ADLs (activities of daily living) feelings of being on display for others, and isolation. Cultural diversity as described by most of the literature is not a significant issue (race/ethnicity). Most residents are able to maintain good and responsible behavior towards other residents and staff members most of the time. For specific examples of this see the next section of this paper. Racial slurs and epithets became much more visible as cognition declined and or to manipulate a situation to their own advantage such as obtaining a private room. This section produced an overwhelming amount of data to be transcribed and bracketed. One male responded to this question with the following:
My worst time was physical therapy when I had pneumonia. They kept pushing me. They laughed at me when I was sweating. They made me ride a bicycle when I was sick. I quit!

A female respondent stated:

I hate the way people stare at me. They are always staring at me...when I walk, when I eat, even when I am just sittin’ in my chair... I don’t know maybe because I am ugly. I don’t talk to many people cause I don’t like too many people.

The last statement was made by a resident who is actually one of the “best liked” by staff and other residents in that particular facility. She did however also complain of favoritism. She also stated when asked about interactions and friends:

M was my best friend for the first year I came here. Now she’s my worst...She is so outspoken and she says everything before she ever thinks about it. I don’t even talk to her now when I go to dinner. She’s got some smart remarks to say and it’s not even sensible these things she’s sayin’. I just don’t talk to many others. Oh and K sends me into orbit! She sends me to outer space.

When responding to the last statement concerning interactions with others, the majority of responses revealed that these residents tend to spend time with one or two people. These relationships are not based on the common definition of friendship but rather, by levels of disability and or ability to be in certain places at
certain times. There were dynamics at play to be explored in the next section of these qualitative results.

Smoking is a significant factor with residents in long term care. Two of the three facilities had liberal smoking schedules. One of the facilities was phasing it out and only permitted residents who had been in the facility prior to the no smoking policy smoke as had been scheduled (in other words they were grandfathered in). Family members were permitted to come to the facility to take the newer resident outside to smoke, but they were not permitted to smoke with the other residents. This caused extreme distress for one female resident:

My worst experience here is the smoking. I been smoking since I was fourteen years old...I used to go out there with the guys...then these people here decide I could not go unless I had a family member with me and since they work that was hard to do and uh I was going anyway until they decided to evict me if I don’t obey the rules. Very disappointing. How can you tell an 81 year old they have to stop smoking? That’s ridiculous. I think I could go by myself without anyone holding my hand while I smoke a cigarette. That’s ridiculous and that hurt me, it hurts very bad. I still have not gotten over that. They still got the ties on me where smokin’s concerned. I don’t know how to get through to them cause I’ve tried everything I know...

Smoking is an issue that will also be addressed in the next section.
The overall results of this portion of the study were both sad and emotional. All of those interviewed balked if the facility was referred to as a community while interviewing. Each insisted that it was not a community; the outside world where they lived was a community. They tended to deny interactions or that true friendships exist. Happiness is limited. Their existence is just that: an existence. The residents’ best times were few. However, their worst were many. Further analysis is conducted in the participant-observer section of this chapter as well as in Chapter Five.

**Participant-Observation**

Because I worked within the facilities, I was privileged to many aspects of long-term caregiving than an outside academic would be. Observations of various attitudes and prejudices were plentiful.

Interactions between residents are an insightful experience. While engaging in conversation with one of the residents one day, another resident was returning to the facility from an appointment with a physician. The resident was being transported by an ambulance cot. The resident whispered, “Oh not another one.” The resident speaking is Caucasian and the returning resident African-American. I
replied, “Grandma, that is Celia from across the hall, remember? She lives here with you.” To which Grandma replied, “Well then, that is okay, as long as they don’t bring a bunch more here.” That was one of the few observations made where racism surfaced. The residents tend to keep their personal prejudices to themselves for the most part with the exception of the marginalized bariatric group. A bariatric patient is one that weighs in excess of 350 pounds.

There was an instance when an African-American was being moved into a room with a Caucasian women and the Caucasian woman hurled racial epithets and slurs at her. The African-American woman was ready to come to physical blows with her. Staff was present to intervene and keep these two stroke victim residents separate. The Caucasian woman utilized this ploy to secure a private room. She won. It is also important to note that in this instance, she would have verbally abused anyone to achieve her goal.

It is plausible the Caucasian resident is not prejudiced. She just did what she felt she had to do. The two never had a relationship thereafter. The African-American resident thought the Caucasian resident racist and she then avoided her at all costs. The incident was up for discussion by staff and other residents in the facility and
the story snowballed. Thus, all of the African-Americans ignored the Caucasian resident. This event was a great matter of concern for the social group of smokers. Events such as this must be diffused and watched closely for some time after the event for there will eventually be three sides: her side; her side; and the true side.

Within these facilities one cannot help but notice that the residents “separate out” based on cognition and physical ability. Small groups surface which resemble community formations within the facilities. Those in the Alzheimer’s Units can be seen in their small groups of diverse residents holding conversations, albeit talking past one another. The group formations are consistent from day to day. Occasionally a new member is permitted to enter after they have settled in to the living situation. These types of groups form throughout all three facilities. They are informal and the residents seem to be happy with the arrangement.

The bariatric group, as mentioned previously is a marginalized group within a facility. They suffer from prejudice and suffer from hurtful comments on a daily basis. Frequently in the dining room, residents have a negative comment as to how much these people eat. This issue is dealt with as far as the staff is concerned, but
educating the general population is extremely difficult and most, if not all, are reluctant to try to understand. This leads to much distress for this group and some do not come out of their rooms until late at night.

The most cohesive group formation is that of the smokers. When it is smoking time, one must move aside. The residents come from all areas with walkers, canes, and scooters. Aside from those, the ambulatory join them. This group smokes together, socializes, gossips, and assesses the facility and staff. They have a tendency to watch out for one another and notice if someone does not make it to the smoke break. The group investigates these absences and explanations are given to those who do not know at the next session. These residents would not get out of their beds without this “activity.” They are funny, serious, and on a mission. This seems to give them some control over their existence without which they would be lost.

Within this close group, instability can occur. A younger member of the population refused to abide by smoking rules of the facility. The other residents were furious for they were told their privileges would be revoked if they did not conform. One resident yelled across the nursing station, “The bigger a jerk you are in this place the more you get away with.” This comment was made
because it seemed as though this resident could smoke whenever he wanted without any sanctions while the others were more heavily scrutinized and some had lost privileges before for not conforming. It was a verbal reaction to inequity.

There was a great deal of data collected as a result of participant observer. The data was bracketed, coded and recoded for utility in this project. Data was informative and very rich. This type of study is ripe for investigators or anyone studying human behavior. A concept map was constructed based on results of quantitative and qualitative data collected and will be further analyzed (see Figure 1).

FIGURE 1: Concept Map
Chapter Five will synthesize and combine findings noting inconsistencies and suggesting improvements. Further analysis of each portion will reveal this is an area ripe for discussion, improvement and study. The final chapter will provide further interpretations and continue to explore relationships between data sources. The following concepts will also be further developed:

- Community,
- Marginalization within an already marginalized community,
- Lack of choices,
- Social construction of Long-term facilities,
- Quality of Life, and
- Diversity.
CHAPTER V

CONCLUSION AND RECOMMENDATIONS

People grow old only by deserting their ideals. Years may wrinkle the skin, but to give up interest wrinkles the soul. You are as young as your faith, as old as your doubt; as young as your self-confidence, as old as your fear; as young as your hope, as old as your despair. In the central place of every heart, there is a recording chamber. So long as it receives messages of beauty, hope, cheer, and courage, so long as you are young. When your heart is covered with the snows of pessimism and the ice of cynicism, then, and then only, are you grown old. And then, indeed as the ballad says, you just fade away.

General of the Army Douglas MacArthur (1880 – 1964)
MacArthur, 1964, p. 436

This exploratory research study focused on determining the perceptions of the quality of life of long-term care residents living in culturally diverse long-term care facilities. To ascertain these perceptions, a mixed methodology (concurrent nested) approach was employed for data collection. There were three components employed for data collection. The survey instrument that was utilized is a combination of Satisfaction with Life Scale (SWLS), Cultural Competence Assessment Instrument (CCAI), and Resident Satisfaction Index (RSI). Questions asked for the interview portion were as follows:
1. Tell me about your life in this facility. How does it compare to the world that you once were a part of?
2. What is the best experience that you have had while living here?
3. What is the most disturbing (worst) experience that you have had while living here?
4. Tell me about your friends and those that you interact with.

Survey and interview data were collected from 61 survey-eligible residents. This purposive convenience sample had some definite ideas as to their quality of life in their residential conditions. The participant observation portion of the study added some depth to the experiences that residents spoke of when answering questions concerning their daily lives in long term care.

The residents surveyed came from Caucasian and African-American racial groups. Caucasians made up 85 percent of the survey while African-American residents were responsible for 15 percent of responses. While Caucasian respondents were over represented in the survey compared to their composition in the general population, African-Americans in the facilities studied were roughly representative of the statistical aggregate

The surveys used to collect data were the Resident Satisfaction Index (RSI), the Satisfaction With Life Scale (SWLS), and the Cultural Competence Assessment Instrument (CCAI). Both the quantitative and qualitative data presented in Chapter IV will be analyzed to give insight on the following long-term care solutions:

- Community,
- Marginalization within an already marginalized community,
- Lack of choices and freedom,
- Social construction of long-term facilities,
- Quality of life, and
- Diversity.

**STUDY LIMITATIONS**

Because this is an exploratory study the limitations are not as stringent as one would expect from stricter empirical studies. The data gathered for this study came from three long-term care facilities in the northeastern Ohio area. Thus, it is geographically restricted. The methodology employed in this study may not be conducive to truthful answers to a researcher
who is not or has not been imbedded in the environments thus
establishing a measure of trust. Residents are not as
forthcoming with “outsiders” who may reveal information the
resident thinks may negatively impact them in some way.

FINDINGS

Community

Tinder (1995) argues in order for a community to be a true
community, the individuals must be tolerant. This means the
individuals must be tolerant of the ideas of others. Community,
to Tinder (1995), is the unity of two or more persons in their
essential being. As is the case with the “accidental community”
(Kane & Kane (1987), Tinder (1995) argues “... forced
relationships cannot possibly be communal” (p.101). Although
residents appreciated and enjoyed activities provided by the
administration and staff, it should be noted they only wanted to
engage in those activities in which they had a desire to
participate. All participants balked at referring to the people
and groups within these facilities as constituting a community.
Residents were very reluctant to engage in forced recreation.

It should be added an integral part of being part of a
community is feeling you are at home. The majority of the
residents surveyed believed their facility was comfortable, but only half felt “at home.” A majority of residents (72 percent) stated staff was sometimes rude. Eighty-nine percent believed staff was late in responding to their requests. Behaviors they would not have tolerated while independent of long-term care are now an integral part of their lives.

Building a sense of community is also hampered by residents believing they have little in common with other residents. The expectation of kinship which may have served as a positive decision-making device where they lived their independent lives is no longer an option for them.

In the interview portion of the data collection, residents unanimously stated they never expected to “end up in a place like this.” With attitudes such as these towards their situation in life and the place in which they reside, building any sense of community will remain a significant challenge for administrators and staff. Interviews did reveal positive aspects of their lives in these facilities. These consisted of day trips and activities like Bingo.

Facilities have a tendency to gather residents for activities that are of no interest to the resident, having been determined to be an area of interest based on an arbitrary set of quantitative findings or because the activities director
thinks that they would enjoy it. Residents should have input into the types of activities in which they would like to engage. Perhaps interviewing the residents about their previous social activities would aid in determining the agenda. For instance, The Red Hat Society was a social entity that some of the female residents identified.

Bingo and activities that involved singing were the most attended by residents. These were activities that they enjoyed when they were in the community. The input for setting the activities agenda should be initiated by the residents themselves. Simply gathering residents in a room where they do not want to be only satisfies the statistical participation needed to justify the existence of the department. Resident input could positively impact satisfaction and more participation from the residents. Fostering a sense of shared enjoyment will produce the essence of community.

The emergent communities or the “separated out” individuals identified during participant-observation, lends itself to disclosure of what the interests of the residents really are. A simple yes or no to the question, “Do you enjoy the activities?” does not give the respondent any latitude in identifying commonalities among residents.
Groups forming were also observed in an Alzheimer’s Unit. Those in the Alzheimer’s Units can be seen in their small groups of diverse residents holding conversations, albeit talking past one another. The group formations are consistent from day to day. Occasionally a new member is permitted to enter after they have settled in the wing. These types of groups form throughout all three facilities. They are informal and the residents seem to be happy with the arrangement.

Smoking was and is an important issue to residents. Of all reasons for developing cohesion among residents, smoking was one the most significant, albeit the shared addiction. Many of the residents have smoked since they were young. A female resident interviewed stated she had been smoking since she was 14. In her opinion and at the age of 81, it would be ridiculous for her to be expected to quit. If there was any one area in which residents felt they were being micromanaged and patronized within the facilities, it was smoking. However, their perceptions of a shared sense of prejudice by staff and residents who ridicule tobacco use have made smokers the most cohesive group within long-term care facilities.

Cliques among residents were also formed around the levels of cognition residents shared and/or their disabilities. The residents “separate out.” Small groups of apparently diverse
residents sit together and talk although their interaction may be limited due to their cognition. These are informal and constructed by the residents, not the administration or staff.

Marginalization

The elderly are already a marginalized population within our society. They are not revered in the United States as they are in other societies. This was reflected in the responses gathered from interviews. Many indicated family members placed them in the facilities and they had no control or voice in the decision-making process. Many realized they were declining and admitted they needed assistance, but also questioned why the family was not “stepping up to the plate” or even discussing options with them. Two of those interviewed simply said they were told they were going for a ride and this is where they have been ever since.

The literature addresses the double jeopardy hypothesis of being a minority and elderly the devaluation of old age found in most modern societies (Dowd & Bengtson, 1978; Mui et al, 1998).

All of those placed in long-term care share the common denominator of being elderly and requiring assistance. Race did not surface as an additional burden. The playing field becomes level. In all three facilities favoritism was denounced by those
interviewed. Hence, the residents felt some were treated differently than others.

Lack of Choices, Freedom

Each long-term care resident enjoyed at least some degree of independence prior to their arrival. Residents commented they had their own homes and apparently thought that this would prevent them from having to endure geriatric care.

Their lack of choices over their daily lives was demonstrated through negative interactions with staff. One male stated he was “pushed” through a grueling regimen of physical therapy while he was ill. Residents also do not have the freedom or ability to develop friendships as they did while independent. Relationships in long-term care facilities are based more on shared disabilities or where they are in the facility at a particular time.

Residents have no options when it comes to room assignment. Perhaps a methodology should be employed to determine residents that may have similar backgrounds and/or interests should play a part in the equation. While not everyone may have the “window seat,” it would be worthwhile to offer an amenity that is a choice of the resident, such as closer to the dining room or
nurses’ station. One of the respondents indicated she does not even speak to her roommate.

Social Construction of Long-term Facilities

Long-term care facilities are for the most part now corporate facilities. Analysts utilize quantitative data to construct facilities and the lifestyles that regulatory agencies require. This methodology produces a clash between rule-bound organizations and individual desire (quality). While the results of this study conflict when the survey responses and interview responses are juxtaposed, perhaps the questions that are being asked are not the correct ones. The simple RSI that is considered valid and reliable is presented with answers that would support the framework of the daily lives of individuals in long term care. However, the interview data suggests otherwise. Can economy, efficiency and accountability still be realized if another approach to providing care for elders be based on the input from the population served?
Quality of Life

Quality of Life is measured in “terms of minutes of life during which one's affect state may be positive, neutral, or negative” (Noelker & Harel, 2001, p.157).

Nearly 60 percent of the sample held the conditions of their lives were not ideal. Yet, a solace to them could be the belief most had gotten the most important things they had wanted out of their lives (71 percent). As mentioned earlier, food is always a controversial matter in facilities and institutional settings. Sixty-eight percent never liked or only sometimes/rarely liked the food served.

The first question was met with unanimity by residents. None believed they would have ever ended up in an institutionalized setting. Many were admitted by their families. Consequentially, resentment on their part is high. What did evoke a positive response from residents were the activities provided by facilities and staff members who were attentive and kind to them. Organizational pathologies such as staffing issues, incompatible roommates, personality conflicts with others in the facility, dissatisfaction with daily activities, feelings of being on display for others, and isolation from the outside world were among the most problematic issues for residents.
The perception of the lack of professionalism on the part of the staff has a negative influence on the happiness of the resident and their contentment within the facility. Generational issues were identified, consistent with the findings of Kikeyoda (2000) and Monaghan (2002). One example is the music played for the residents is more recent and does not reflect the preferences of residents.

Diversity

The qualitative data revealed the opinions regarding the quality of life of residents and how the perceived quality of life was affected by diversity. However, the diversity was not based on race, but the level of the resident’s disability and/or their cognitive abilities. As discussed in Chapter IV, racial slurs were more commonly used by residents who displayed cognitive deterioration. For the most part, residents who still possessed cognitive control were able to maintain respectful behavior towards others in the facility. Quality of life was also not impacted by a person’s gender, their religious background, or former occupation.

It is important to note cognitive deterioration may be exaggerated to obtain those creature comforts the facility can
provide. Using an insult against someone who is a member of an identifiable ethnic background can manipulate the staff into giving them a private room. This may be done to reduce the friction between the insulting residents and others in the facility.

If there is diversity to be assessed in the facility, it is in the form of the resident’s physical and/or mental condition. Groups did form based on the geographic area from which they had previously been an active part of the community. They would discuss former industries, churches and major historical events that affected their lives. Yet, these group formations occurred between members who were ambulatory or able to propel themselves in their wheelchairs. Hence, the macro factors of cultural diversity were less important than the micro factors of cultural diversity.

The findings support the hypotheses for this study. Cultural diversity does impact the quality of life of residents in long term care. Although the definition of cultural diversity morphs into a definition suitable for long term care, it is of great significance. Community is a significant factor for the residents although the majority denied that they were part of a community.
IMPLICATIONS OF FINDINGS

Due to the disparity in the responses between the survey and the interview perhaps the questions that are currently being asked may not be appropriate. The answers to the survey questions simply answered in a dichotomous yes or no answer fail to address the “but” part of the answer. When the residents were permitted to include their personal preferences they felt their opinions were valued and could lead to a better outcome for what they deem would lead to a quality of life acceptable to them.

The results of the survey and interviews indicate the cultural diversity addressed in the literature is focused on demographic data that is not related to the cultural diversity observed in the facilities. Race/ethnicity was not disclosed as indicators to deficits in any of the areas explored in this study. Other factors such as social clubs, and activities the residents participated in while living in their home communities was deemed an important part of their happiness and sense of “belonging.” As such, instruments designed from a sociological premise may serve to promote and/or establish a design that promotes this sense of community. Human beings are social beings
and living as an island at the end of life can be detrimental to the quality of life of the resident.

The survey (combined RSI, SWLS, and CCAI) utilized in this study have been recognized as reliable and valid. However, they may not be appropriate for investigating the true success of a facility fulfilling emotional and social needs of residents living in long-term care environments. The surveys may be incomplete and not able to tease out the information to draw conclusions about community formation in the long term care environment.

Answers may be very different if an interview approach is used rather than surveys, which fail to capture reasons why the communities emerge within these long term care facilities, when assessing resident satisfaction/expectation in long term care facilities. Perhaps the current instruments utilized when evaluating resident satisfaction are not appropriate. The clash of practice with the operationalized questions of standard academic surveys produces invalid results.

FUTURE RESEARCH

Future research should include residents who utilize these facilities. Further investigation of the residents’ former
social life would be helpful in determining activities that would facilitate participation enthusiastically rather than being chaperoned to a room full of people they have nothing in common with and no desire to interact. Bingo served this purpose in all of the facilities in this survey. However, one activity once weekly will not establish a sense of community.

Preserving a sense of identity should be addressed. People are known by what they did for a living, where they lived, and their social organizations. This disappears when they enter a long-term care facility. How can this be preserved? Can a facility form a new social organization that would appeal to this new “accidental community?”

While quality of care such as ADLs (activities of daily living) are monitored by regulatory agencies, the issues of socialization and happiness are not measured in qualitative terms and residents questioned by state examiners are not likely to be forthcoming due to the fear of reprisals.

What measures can long-term care facilities take to promote a sense of community? How and under what circumstances do communities emerge? More qualitative studies need to be conducted to investigate this opportunity to help promote a productive and happy end of life experience. The next step for
researchers to take is to find out what the residents really want, utilizing a qualitative approach with open-ended answers.

SUMMARY

The data harvested from this exploratory study is somewhat contradictory. In response to the objective surveys, responses were limited. Residents’ attitudes towards staff and their environment were complimentary. When residents had a chance to elaborate, their opinions were not so high. Their problems were fairly consistent for those who are institutionalized.

What was found was that diversity based on social and demographic characteristics as found in diversity assessments outside of facilities was not a factor in the enjoyment of their lives. The diversity that did impact them was based on the mental and/or physical limitations of the residents and their sense of not having many friends within the facility that had shared values and interests. Their place within the facility determined happy interactions as opposed to common interest, and is a critical factor for community formation in long term facilities. Some residents are not ambulatory and this is a factor in their ability to participate in the emergent
communities identified in this study. For the participating residents in this study “community” meant a shared sense of belonging and a shared sense of enjoyment.

Perhaps Suh’s (2004) statement should be modified:

The broader, ever-increasing graying population of American Society is composed of a mosaic picture of discrete community groups existing with the context of their own values and identities. Those distinct communities are embedded in the thinking of each resident, affecting his or her perceptions of quality of life in long-term care (p.100).

Existing research has not thoroughly explored if “community” within this environment is important. This exploratory study indicates that is important to residents. We need to redefine what “community” looks like to residents in long term care. What does it mean to them? How must community be modified to reflect the reality of the nursing home environment? The onslaught of baby boomers into long term care is likely to impact the organizational/corporate rules on experience for determining Quality of Life indicators.
References


Armour, M. A Nursing home’s good faith duty “TO” care: Redefining a fragile relationship using the Law of Contract, St. Louis U.L.J. 217, 238.


Bohm, D.A. (2001). Striving for quality care in America's nursing homes: Tracing the history of nursing homes and noting the effect of recent federal government initiatives to ensure quality care in the nursing home setting.


APPENDICES
APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL
NOTICE OF APPROVAL

Date: June 11, 2008

To: donna blackford-busson
15404 Gates St. Ext.
Doylestown, Ohio 44230

From: Sharon McWhorter, IRB Administrator

Re: IRB Number 20080606
"Residents' Perceptions of Quality of Life in Culturally Diverse Long-Term Care Settings"

Thank you for submitting your Exemption Request for the referenced study. Your request was approved on June 11, 2008. The protocol represents minimal risk to subjects and matches the following federal category for exemption:

☐ Exemption 1 - Research conducted in established or commonly accepted educational settings, involving normal educational practices.

☒ Exemption 2 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior.

☐ Exemption 3 - Research involving the use of educational tests, survey procedures, interview procedures, or observation of public behavior not exempt under category 2, but subjects are elected or appointed public officials or candidates for public office.

☐ Exemption 4 - Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens.

☐ Exemption 5 - Research and demonstration projects conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine public programs or benefits.

☐ Exemption 6 - Taste and food quality evaluation and consumer acceptance studies.

Annual continuation applications are not required for exempt projects. If you make changes to the study's design or procedures that increase the risk to subjects or include activities that do not fall within the approved exemption category, please contact me to discuss whether or not a new application must be submitted. Any such changes or modifications must be reviewed and approved by the IRB prior to implementation.

Please retain this letter for your files. If the research is being conducted for a master's thesis or doctoral dissertation, the student must file a copy of this letter with the thesis or dissertation.

☑ Approved consent form/s enclosed

Cc: Raymond Cox III - Advisor
Cc: Rosalie Hall - IRB Chair

Office of Research Services and Sponsored Programs
Akron, OH 44325-2102
330-972-7686 • 330-972-6281 Fax

The University of Akron is an Equal Education and Employment Institution
APPENDIX B

IRB CONSENT FORM
IRB Consent Form

This consent form outlines rights as a participant in the study of Residents' Perception of Quality of Life in a Culturally Diverse Long-Term Environment conducted by Donna Blackford-Busson, Department of Public Administration and Urban Studies, University of Akron, Akron, Ohio 44325.

The questionnaire will explore ideas, impressions and suggestions about the quality of life in a culturally diverse long-term care environment in the United States.

It will take about 45 minutes to fill out the questionnaire. There are no anticipated benefits or risks to you as a participant, aside from helping us have a better understanding of how a culturally diverse environment affects the quality of life of the residents in long-term care.

This research project has been reviewed and approved by The University of Akron Institutional Review Board for the Protection of Human Subjects. Questions about your rights as a research participant can be directed to Ms. Sharon McWhorter, Associate Director, Research Services, at 1-330-972-8311 or 1-888-232-8790

I understand that

1. Taking part in this study is entirely voluntary.
2. It is the right of the participant to decline to answer any questions that are asked.
3. The participant is free to stop answering the questionnaire at any time.
4. The name and identity of the participant will remain confidential in any publications or discussions.
5. Data will only be made available to the nursing home in aggregate form. No one at the home will know what answers any individual has given on the questionnaire.

If you have any questions about the research project, I can be reached at 330-658-5838 or you may call my advisor Dr. Cox at 330-972-7618.

Thank you for your participation!

I HAVE READ THIS CONSENT FORM. I HAVE HAD A CHANCE TO ASK QUESTIONS CONCERNING ANY AREAS THAT I DID NOT UNDERSTAND.

________________________________________
(Signature of Participant)

________________________________________
(Printed name of Participant)

________________________________________
(Date)
APPENDIX C

INSTRUMENT

Satisfaction With Life Scale (SWLS)

Respondents should be "open and honest" as they indicate their agreement with the items on a scale from 1 to 7:

1 = strongly disagree, 2 = disagree, 3 = slightly disagree, 4 = neither agree nor disagree, 5 = slightly agree, 6 = agree, 7 = strongly agree.

1. In most ways my life is close to my ideal.

1  2  3  4  5  6  7

2. The conditions of my life are excellent.

1  2  3  4  5  6  7

3. I am satisfied with my life.

1  2  3  4  5  6  7

5. So far I have gotten the important things I want in life.

1  2  3  4  5  6  7
7. If I could live my life over, I would change almost nothing.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
</table>

Resident Satisfaction Index (RSI)

Please circle the number that best describes your answer to the question.

0 = *never*  1 = *rarely/sometimes*  2 = *usually/most of the time*  3 = *Always*

---

**Health Care**

1. Is the staff making every effort to keep you as healthy as possible?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>

2. Are the nursing assistants nice and courteous?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>

3. Do you feel like talking to the staff if you have any health concerns?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>

**Housekeeping**

4. Is this facility a comfortable place to live?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>

5. Do you feel at "home" here?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
</table>
Relationships With Staff

6. Is the staff kind and caring?

0 1 2 3

Please circle the number that best describes your answer to the question.

0 = never 1 = rarely/sometimes 2 = usually/most of the time 3 = Always

7. Are the people who serve the food nice and courteous?

0 1 2 3

8. Are you unhappy with staff's attitude or behavior?

0 1 2 3

9. Do you think that you have dependable staff taking care of you?

0 1 2 3

10. Do you feel that you have friends among staff members?

0 1 2 3

11. Are you satisfied with personal assistance you are getting here?

0 1 2 3

12. Do you see some staff treating residents in a rude way?

0 1 2 3

13. Is the staff slow to respond to your requests?

0 1 2 3

Social Life/Activities

14. Do you meet residents here with whom you share similar interests?
14. Do you meet residents here with whom you share similar interests?

0   1   2   3

Please circle the number that best describes your answer to the question.

0 = never   1 = rarely/sometimes   2 = usually/most of the time   3 = Always

_____________________________________________________________

15. Do you like the food here?

0   1   2   3
CULTURAL COMPETENCE ASSESSMENT INSTRUMENT

Instructions

Please answer the following by circling yes or no.

1. I felt comfortable when I went to __________________________.
   (name of facility)
   yes  no
   Comments: ____________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________

2. I was welcomed and made to feel comfortable when I arrived.
   yes  no
   Comments: ____________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________
   ______________________________________________________

3. I saw pictures on the walls that reminded me of my family and friends.
   yes  no
   Comments: ____________________________________________
   ______________________________________________________
4. I found the magazines and reading material available contained information that was interesting to me.

yes  no

Comments: ____________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

5. I was spoken to in my own language.

yes  no

Comments: ____________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

6. I felt comfortable with my social worker/DON.

yes  no

Comments: ____________________________________________
7. I believe my social worker/DON worker was interested in my/my family's concerns.

yes  no

Comments: _______________________________________
_____________________________________________________
_____________________________________________________
_____________________________________________________
10. The social worker/DON showed respect for me/my family

yes    no

Comments: ____________________________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

11. I believe my social worker/DON tries to give good service to all of the people with whom he/she works.

yes    no

Comments: ____________________________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

12. I believe the facility tries to give good service to all of the people who go there to reside.

yes    no

Comments: ____________________________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________
13. I saw several staff members at the facility who are of my race/ethnic background

yes  no

Comments:

Additional Comments