LONG-TERM CARE (LTC) RESIDENTS' PERCEPTIONS OF CARE AFTER HUMANISTIC PATIENT NARRATIVE THEORY IN-SERVICE TRAINING TO LTC HEALTHCARE PROFESSIONALS

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ABSTRACT

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D.M.H. Dissertation by

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Residents of LTC facilities deserve to feel safe and secure in the place they call home. Over recent years the reputation of LTC facilities and those working within the field have been under scrutiny. Media coverage regarding the provision of care in LTC facilities that lacks quality, ethical, dignified, and humanistic care has resulted in public scrutiny and governmental oversight. Privacy and autonomy are often affected when residing in LTC facilities. Simple personal rights and freedoms, such as when to wake up or go to bed at night, the ability to take a bath privately, mealtimes, types of food preferred for meals, and the overall control LTC residents have over their own lives is often lost.

LTC facility administrators and healthcare professionals need to learn about the importance of narrative theory for the provision of humanistic care. There is limited research and instruction in the effects of humanistic narrative theory upon the provision of care. This dissertation examines the issue in the context of how to educate healthcare professionals in humanistic narrative theory based upon the principles of ethics, and Edmund D. Pellegrino's theories as they contribute to the provision of humanistic care

for LTC residents' needs. It is healthcare professionals' obligation to ensure that all LTC facility residents receive the provision of ethical and humanistic care.

To my husband, Michael Christopher,

Kyle Michael,

Kaitlin Victoria,

and

Keri Michelle

In memory of my father Walter H. Edgett and my faithful companion, Cane.

CONTENTS

PREFACE

Permission was granted by Long-Term Care (LTC) Facilities Administrators, Nurses, Nursing Assistants, and the LTC Residents. For the privacy of the LTC facilities and all participants, names are not used in conjunction with their responses. I have made every effort to protect the privacy of the participants by not divulging names and have documented results without any identifying characteristics.

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Also, I thank all of the LTC nurses and nursing assistants for recognizing the importance of providing quality care to the LTC residents and for participating in the Humanistic Patient Narrative Theory in-services. I have an extraordinary amount of gratitude for the LTC residents that participated in the completion of multiple surveys. Without the residents' commitment to further my research, this would not have been possible.

It is with deep gratitude that I thank Dr. Phyllis DeJesse for her support and expertise regarding Medical Humanities and especially about Dr. Edmund D. Pellegrino. Her guidance and suggestions promoted greater inquiry and depth. I owe special appreciation to Dr. Liana Piehler for her broad understanding, insight, and supportive guidance. I am thankful that I had the support and inspiration of both of these mentors.

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I am also thankful for the friendship of Frances Figueroa Mal that has strengthened and become so meaningful throughout our time in the Medical Humanities Program.

And I am grateful to my father, who encouraged me to continue my education to become a “doctor.” His memory provided me much determination and strength. I also wish to express my gratitude to my mother, who instilled in me to “always be a leader and not a follower.”

Finally, I am especially thankful for the enduring love, and encouragement of my husband and children. With love and much gratitude to my family, I am thankful for their support and abiding belief in me. The love that I have for my family is the driving force behind my personal and professional success.

INTRODUCTION

The Department of Health and Human Services Administration on Aging research states, "By 2030, there will be about 72.1 million older persons, more than twice their number in 2000. People 65+ represented 12.4% of the population in the year 2000 but are expected to grow to be 19% of the population by 2030."[1] Presently, many people outlive their predecessors due to the technologically advanced diagnostic tests that detect disease at an early onset, treatments that are begun at an earlier stage of disease or illness, increased preventive care measures, access to electronic healthcare information, and healthier lifestyles. The Centers for Disease Control and Prevention research indicates, "Life expectancy at birth rose 0.2 year, from 78.5 years in 2009 to a record high of 78.7 in 2010."[2]

Centers for Medicare and Medicaid Services defines health insurance coverage eligibility: "Medicare is for people age 65 and older and those who have special condition or disability."[3] Increasing longevity past the age of sixty five correlates to a growing need for long-term care (LTC) facilities to provide quality humanistic medical care in the later years of their life. The U.S. Department of Health and Human Services public website emphasizes various payment options for LTC facility care: "And while some

[1] Department of Health and Human Services, "Administration on Aging: Aging Statistics," http://www.aoa.gov/aoaroot/aging_statistics/index.aspx; Internet; accessed 14 March 2010.

[2] Center for Disease Control and Prevention, National Center for Health Statistics, "National Vital Statistics Reports," http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_04.pdf, Internet; accessed 23 Jan. 2014.

[3] Centers for Medicare and Medicaid Services: "Medicare.Gov The Official U.S. Government Site for Medicare: Eligibility and Premium Calculator," http://www.medicare.gov/eligibilitypremiumcalc/?dest=NAV%7cHome%7cGeneralEnrollment&AspxAutoDetectCookieSupport=1#eligibility/results&ebirth_month=11&ebirth_day=12&ebirth_year=1966&fica=yes&disabled=no; Internet; accessed 23 Jan. 2014.

people may qualify for a public program to help pay for these expenses, most people use a variety of options, including LTC insurance, personal income and savings, life insurance, annuities and reverse mortgages to ensure they can pay for the care they require."[4]

Most people cringe at the thought of themselves residing in a LTC facility. Personal interactions with residents residing in LTC facilities often resulted in complaints about nursing homes not being the same as home, with concomitant statements regarding poor quality of care. Residents often compared their previous housing arrangements to their present situation of living in one room within a LTC facility. Is the negativity toward this concept related to a person fearing loss of independence or reliance on others for basic needs? Does the thought of selling all of one's assets to reside in a LTC facility that might provide substandard care compared to what they are used to provoke negativity? Could the main reason for this very common dread that people imagine about LTC facilities be related to negative media publicity or personal experiences with a loved one receiving substandard, dehumanized care?

Many healthcare professionals choose not to work in LTC settings because they find it too depressing. Perhaps they are afraid of their own personal fate. Those professionals that choose to work in a LTC facility often have strong opinions about their loved one residing in these facilities. Based upon my professional experiences and discussions with healthcare professionals employed within this setting, physicians, nurses and nursing assistants often state that they do not want their loved ones to reside in a LTC

[4] U.S. Department of Health and Human Services, Administration on Aging, "Costs and How to Pay," *Long Term Care.Gov Find Your Path Forward*, http://longtermcare.gov/costs-how-to-pay/; Internet; accessed 23 Jan. 2014.

facility. It is “alright to work in the facility,” but they do not want their loved one to reside in a LTC facility.

Healthcare professionals working in this field need to ask themselves if the resident is receiving humanistic care, which includes high quality, dignified, and ethical care. They must also reflect upon their own personal experiences and freedoms associated with living in a private home setting. Privacy and autonomy are often affected when residing in LTC facilities. Simple personal rights and freedoms, such as when to wake up or go to bed at night, the ability to take a bath privately, mealtimes, types of food preferred for meals, and the overall control they have over their own lives, are often lost. The residents, too frequently identified as dehumanized, have the right to respectful, dignified, ethical and quality care provided by healthcare professionals. Residents are human beings that have humanistic needs, which are often forgotten and replaced by the person being seen as a disease process requiring regimented medical care. Having meaningful conversations and the inclusion of humanistic needs into the provision of care is perceived as lower priority in comparison to medical needs that must be met for reimbursement of care. Resident rights, autonomy and self determination are often lost when residing in LTC facilities.

The subject of this dissertation examines this issue in the context of Medical Humanities instruction during LTC facility healthcare professionals’ in-service training and resident survey responses. I will argue that LTC residents benefit from Medical Humanities based Humanistic Patient Narrative Theory in-services provided to LTC healthcare professionals.

Clearly, integrating Humanistic Patient Narrative Theory in-service training into the LTC facilities in-services has worth for residents to receive quality care. The experiential method of instruction is an effective and crucial method to include in healthcare professionals in-services. LTC healthcare professionals primarily receive in-services based upon regulations regarding the provision of care, versus a focus upon nurturing with the inclusion of communication regarding the residents' humanistic needs. Consequently, the lack of humanistic care narrative in-services results in a provision of care focused upon the disease process and mandatory regulations instead of care directed towards treating the whole person.

In Chapter 1, I argue the need for and the relevance of Humanistic Patient Narrative Theory in-service training to LTC facility nurses and nursing assistants. The focus of the dissertation centers on the use of Medical Humanities based Humanistic Patient Narrative Theory in-services affective learning teaching method, and its effect upon LTC residents' perception of healthcare professionals providing humanistic care prior to and after the in-service. Healthcare professional training is necessary in order for the professionals and residents to experience an increased humanistic, ethical and dignified approach to care. Chapter 1 centers on the history of LTC facility development, types of LTC facilities, quality of care regulations, reimbursement criteria, and the need to provide Humanistic Patient Narrative Theory in-service training for LTC professionals to increase the quality of life for residents.

In Chapter 2 I define and discuss the history of Narrative Theory. The effects of narrative theory upon the provision of humanistic care are reviewed. Methods regarding the implementation of Narrative Theory in a clinical setting are explored. I discuss the

development of the Humanistic Patient Narrative Theory in-service. The format and implementation of the in-service conclude the chapter.

In Chapter 3, I describe the LTC residents' role, nurses and nursing assistant roles as they relate to humanistic narrative theory in medicine, ethics based principles, and to Dr. Edmund Pellegrino's opinions regarding professional practice of morals, ethics, and values relating to the provision of quality, ethical, and dignified care. This aspect of research is necessary because the provision of high quality, ethical, and dignified care enhances the residents' experience living in a LTC facility and further confirms the perceived value of Humanistic Patient Narrative Theory in-services.

In Chapter 4, I present the results of the three phase surveys that were answered by groups ranging from ten to fifteen participating residents in four LTC facilities preceding and proceeding the provision of Humanistic Patient Narrative Theory in-services to the nurses and nursing assistants. Residents' survey responses indicate specific areas that continue to lack the provision of humanistic care by the nurses and nursing assistants after in-service training indicating further research and continued training is required. There is limited research about the beneficial effects of narrative theory use in the provision of care in LTC facilities. The continued development and use of Humanistic Patient Narrative Theory in-services in LTC facilities is perceived to be essential in researching best practice methods for the provision of humanistic care.

U.S. medical schools and residency programs, such as St. Barnabas Health Care System, have increasingly recognized the need for continuing education and in-service programs addressing the provision of humanistic care. Many universities, such as Drew University in New Jersey, are incorporating Medical Narrative courses into their

curriculum as a means to provide better humanistic and dignified care. Nursing schools are a bit slower in this process. The nursing schools focus greater attention upon nurse-patient communication techniques and culturally competent care. Nursing assistants' training focuses primarily upon the provision of physical assistive care for basic activities of daily living needs.

Nurses and nursing assistants receive limited training in ethical, dignified, humanistic care prior to becoming licensed or certified. Individualized state practice acts include ethical principles within their expected scope of practice guidelines. Upon graduation from universities, colleges, and technical training schools, the graduate nurses often recite practice oaths that infer their intent to practice ethics-based care. The practice oaths obligate the nurses to abide by the oath and to provide safe, quality, ethical and humanistic care. After graduation, the practicing healthcare professionals receive limited if any continuing education regarding the provision of humanistic care.

The lack of continued education regarding the residents' humanistic needs results in the LTC facility healthcare professionals considering this as a lower priority during a typical day of work. Often medication administration, treatments, bath protocols, bed time routines, or morning regimens to get everybody dressed and out of bed become a greater priority. Residents' activities of daily living are scheduled and controlled with this type of practice. Routines are usually followed with few if any residents asking for changes to meet their personal needs. Often residents have limited knowledge about their Bill of Rights, which decreases autonomy and self-determination while residing in the LTC facility. Nurses and nursing assistants have become very task oriented and have limited time to spend with the residents on a personal humanistic level. Often nurses and

nursing assistants can be overheard complaining amongst themselves about having to complete all of the work tasks before their shift ends. Overtime payment is discouraged by most LTC facility administrators. LTC facility standards and the provision of care are often based upon completion of physical measurable tasks versus the provision of humanistic care which affects the residents' personal experience.

There is a lack of data regarding the benefits of incorporating humanistic patient narrative case scenarios modules into the curriculum and clinical patient care settings. Unfortunately, this lack of educational focus affects the people who are in need of care. LTC facilities need to incorporate in-services including the use of humanistic patient narrative case scenarios modules into nurses and nursing assistants' training. This type of in-service will provide an affective domain learning experience for healthcare professionals and residents alike. Diane Billings, Registered Nurse, Professor of Nursing and Associate Dean, Teaching, Learning, and Information Resources at Indiana University School of Nursing and Judith Halstead, Registered Nurse, Professor and Executive Associate Dean for Academic Affairs at Indiana University School of Nursing, describe this type of experience as, "The affective domain of learning encompasses attitudes, beliefs and values, and feelings and emotions."[5] The incorporation of Humanistic Patient Narrative Theory in-service case scenario modules will enhance this learning domain. Billings and Halstead further clarify the type of affective domain method of teaching delivery:

> Storytelling, with the use of vivid images, has been recommended as a way of enhancing the development of the affective domain. The story could be an experience, a fantasy, or a combination of both. Learning

[5] Diane M. Billings and Judith A. Halstead, *Teaching in Nursing: A Guide for Faculty* (Missouri: Elsevier-Saunders, 2005), 201.

> activities that involve case studies, clinical decision making, group work, practice experiences, and writing also enhance the development of the affective domain.[6]

An experiential learning approach provides an applicable learning experience for all involved. Research in the incorporation of affective domain humanistic care learning experiences within LTC facilities is limited. Further research is needed to prove the benefits of affective learning domain use in LTC.

The provision of humanistic care to LTC residents requires the incorporation of Edmund D. Pellegrino's four components in his description of "The Good of the Patient":

> 1) The physician must use his/her knowledge to return the person to physiological, psychological, emotional and entire wellbeing; 2) The patient should be served by the physician in relation to their values, and wishes on how to live life; 3) The good medical provision of care must be good for the patient and also must be related to the good for humans; 4) The good care provided by the physician must be provided for the good of the patient as a spiritual being.[7]

In this argument, all healthcare professionals must provide care that is for the good of the patient and in the best interest of the patient. Humanistic ethical care is required to fulfill the provision of care for the good of the patient. Humanistic ethics refers to "the need to repair specific damage done to patient's humanity by illness that imposes obligations on physicians."[8] The healthcare professional is obligated to provide care that is going to restore residents' humanity. LTC facility healthcare professionals must become educated about research findings regarding new and effective approaches for the provision of humanistic care.

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[6] Billings and Halstead, 201.

[7] Edmund D. Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, ed. H. Tristram Engelhardt and Fabrice Jotterand (Indiana: University of Notre Dame Press, 2008), 72-74.

[8] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, 93.

State and Federal inspections determine if a LTC facility meets the quality of care standards to remain a provider of care and also receive reimbursement. The public has access to the inspection results on the government websites. An educated consumer is one who makes wise choices regarding LTC facility residency prior to entering one designated as the provider of poor care. Although there are many regulations in place, questions remain as to the type of care residents are actually receiving in LTC facilities. Do the residents actually receive humanistic care in LTC facilities? To be an effective nurse or nursing assistant it is imperative to be knowledgeable about and provide humanistic care in LTC facilities.

Over the course of a sixteen-month period, I provided Humanistic Patient Narrative Theory in-service training to nurses and nursing assistants and conducted a study of resident surveys. LTC residents responded to survey questions regarding the care they received in relation to humanistic care qualities. In-service participants were comprised of day and evening shift Licensed Practical Nurses, Registered Nurses, and nursing assistants that worked time on the LTC facilities units in which the participating residents resided. Research results represent quantitative data. The four participating LTC facilities residents' surveys will be presented as a summarized quantitative comparative results analysis. Comparative analysis will determine common trends in the results amongst the four LTC facilities. Participating research subjects are comprised of a small population of residents and healthcare professionals which will provide limited results and are not indicators for all LTC facilities. Research is performed in a multiphase process.

The first phase includes visiting each of the LTC facilities to discuss the research and obtain consent from the LTC facility administrators. Each LTC facility Director of Nurses or Unit Nurse Manager selected the participating residents based upon the research criteria. The LTC facilities selected their residents due to the high numbers of residents that had co-morbidities including cognitive or physical decline that would inhibit their participation in the research. As the LTC population of residents' life expectancy increases, so do the co-morbidities. Residents' medical conditions frequently worsen with progression of age, resulting in deteriorating eye sight, fine motor skills, and cognitive function. Participating residents were required to be alert and oriented to person, place, and time. After the resident selections were completed, a date was scheduled to meet with the groups of residents at each LTC facility. Participating LTC residents received a detailed explanation about the research, the methodology was distributed, and the consent form was reviewed and discussed with the residents prior to their signing consent. A combined total of 30-45 residents representing each of the four LTC facilities were given the first of three identical surveys to complete. Surveys were written in Times New Roman 16 font type to accommodate for visual changes within this population. Surveys were comprised of multiple choice questions regarding the provision of ethical, quality, dignified, and humanistic care in the LTC facilities. The researcher distributed the first survey, a pen, and a white envelope to the participating residents. Residents were instructed to not write any identifiers on any of the surveys, to place the survey in the white envelope and to seal it. Completed surveys were collected by the researcher from each participant one week later.

The second phase included meeting with each of the facilities nurses and nursing assistants to discuss the research and obtain participation consents. A thirty-minute Part I in-service including a power point handout and class discussion about the history of medicine and evolution of narrative theory was provided to the participating healthcare professionals. Class discussion focused upon each participant's reasons for choosing to become a healthcare professional. Amongst the four LTC facilities, the professionals consistently stated they chose the profession "to help and care for people." In conclusion, an experiential learning exercise was completed by the healthcare professionals.

One week later Part II of the thirty-minute in-service comprised of an audio patient illness narrative spoken in first person and played on a CD player for the participants to listen to. The LTC facility healthcare professionals were asked to reflect upon the illness narrative and to describe their interpretation of the narrative as it relates to a LTC resident. The professionals were able to identify with the narrative experience and humanistic needs of the patient experiencing the illness. Each LTC facility nurse and nursing assistant in-service group had a few professionals that stated, "We have so many job responsibilities that prevent spending quality time with the residents."

During phase three, the second survey was distributed to the LTC facility residents, one week after the nurses and nursing assistants received Humanistic Patient Narrative Theory in-service training. One month after the provision of the Humanistic Patient Narrative Theory in-service training, the third survey was distributed to the LTC facility residents. The focus of the survey completion by the residents one week before the Humanistic Patient Narrative Theory in-service, one week after the in-service, and a month after the completion of in-service training was to determine if the survey results

were different preceding and proceeding the training. Long-term results of the Humanistic Patient Narrative Theory in-service training are based upon the implementation of humanistic care one month after in-service is reflected in the third survey.

The results of my research in this study will be presented as a quantitative comparative analysis of the four LTC facilities survey results, which are reflective of Humanistic Patient Narrative Theory in-service training upon the provision of humanistic care in LTC facilities. Conclusions resulting from this research will provide valuable information and can be an ongoing contribution to Medical Humanities studies and literature for the training of healthcare professionals in the provision of humanistic care.

CHAPTER 1

LONG-TERM CARE FACILITIES IN THE U.S.

During the 1800s, the LTC facilities (commonly known as nursing homes) which we are accustomed to today in the United States were non-existent. Teams of healthcare professionals including physicians, nurses, and nursing assistants were not yet established. There were no governmental oversight or accrediting agencies to monitor the quality or the provision of care to the aged population. Physicians and nurses with limited training or education provided medical care. Men were trained as apprentices with a practicing physician mentor.[9] American medical students frequently trained through an apprenticeship to an older practicing physician, who passed along his own fund of knowledge, good and bad.[10] The Hippocratic Oath that physicians pledge to abide by as practicing physicians states, "I swear by Apollo the physician and by Asclepius and by Health and Panacea and by all the Gods as well as Goddesses, making them judges (witnesses), to bring the following oath . . . to fulfillment, in accordance with my power and my judgment."[11] This statement designated the person to have a powerful important role in society which gave him authority in the professional role. Steven Miles' book *The Hippocratic Oath and the Ethics of Medicine* confirms the "elite" and "generational" societal position of the physician in referencing the Hippocratic Oath passage:

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[9] Jamco Films, "The Civil War Rx The source Guide to Civil War: American Medical Education in the 1860's Medicine," http://civilwarrx.blogspot.com/2013/03/american-medical-education-in-1860s.html; Internet; accessed 8 November 2014.

[10] Jamco Films.

[11] Steven H. Miles, *The Hippocratic Oath and the Ethics of Medicine* (New York: Oxford University Press, 2004), 15.

> To regard him who has taught me this techne' (art and science) as equal to my parents, and to share, in partnership, my livelihood with him and to give him a share when he is in need of necessities, and to judge the offspring (coming) from him equal to (my) male siblings, and to teach them this techne', should they desire to learn (it), without fee and written convenant, and to give a share both of rules and of lectures, and of all the rest of earning to my sons and to the (sons) of him who has taught me and to the pupils who have both made a written contract and sworn by a medical convention but by no other.[12]

During the 1800s, people who presented with illness would stay home and be cared for by family members, home care remedies would be administered until the patient worsened and then they would call for a physician. Physicians saw many people in different locations and there was no transportation for getting to homes other than horse, buggy, or by walking the distance.[13] Depending upon the physician's schedule and location, he could arrive quickly or it could take several days; these delays at times resulted in the patient's death. Physicians were limited with the instruments and medicine they carried in their satchel to each home. Many of the all commonly prescribed twenty-first century antibiotics, pain medications, vaccines, and other medications we are accustomed to today were not developed yet. Physicians based the practice of medicine upon their teachings, and "beliefs" versus the twenty-first century "evidence based medicine" approach:

> In the 1800s, patients and doctors believed the key to good health was balance, both internally and in relation to the environment. Almost anything could throw the body out of balance: stress, the weather, puberty, childbirth, too much food or alcohol, too little exercise and work, too much blood or even too much passion. Any of these imbalances could cause disease. To restore balance, remedies and therapies were generally

[12] Miles, xiii.

[13] Oregon Health and Science University, "Stories of Frontier Settlement Doctors," http://www.ohsu.edu/xd/education/library/about/collections/historical-collections-archives/exhibits/frontier-settlement-doctors.cfm; Internet; accessed 9 November 2014.

> designed to make the sick person bleed, sweat, vomit, or defecate. For example, doctors used *ipecac*, a root medicine, to induce vomiting. *Calomel*, a powerful laxative, was a popular form of mercury that could poison the patient if given in large and frequent doses. But perhaps the remedy that seems strangest to us now is bleeding, or **bloodletting.** To remove blood from a specific area, doctors carried live **leeches** in pewter containers . . . An alternative to leeches was a **scarificator** an instrument used to draw blood. Upon the release of a trigger, 13 blades shot out of the bottom of the instrument into the patient's flesh, creating a series of cuts. The incisions were often followed by **cupping**, placing a heated cup on the wound to form a vacuum and suck out blood. Dry cupping without an incision was also used at times to create blisters, believed to draw disease out of the body.[14]

Physicians were expected to have the knowledge to diagnose and treat any type of illness. The duties of the family physician included caring for all age groups (infancy through old age) and areas of which we refer to as specialty, such as oncology, gastrointestinal, orthopedic, gynecological and obstetrical care, delivery of infants, and end of life care, etc. There were no physician specialists in the 1800s. The physician was expected to be a generalist practitioner, and know enough about everything to care for a person.

Society had a very different response towards women during the nineteenth century. There was a negative societal opinion towards women who chose to become nurses. The women were primarily of the lower socioeconomic class and lacking a formal education. At the time, a nurse's job duties were similar to a maid's. Florence Nightingale, the founder of nursing, professed to receive her first of several calls from

[14] North Carolina Museum of History, "Health and Healing in North Carolina An Interactive Time Line: House Calls and Home Care," http://ncmuseumofhistory.org/exhibits/healthandhealing/topic/5/; Internet; accessed 19 Apr. 2011.

God at age sixteen.[15] Nightingale had a primary concern for sanitation in healthcare settings, disease virulence and the spread of diseases.[16] She emphasized the need for fresh, good ventilation, clean water, light and cleanliness of the environment in which the sick recuperated.[17] Florence saw at first hand the effects of lack of sanitation and basic cleanliness during the Crimean War, when she tended the wounded soldiers.[18] She understood the disease progression and infectious progress, as she cared for the soldiers' infected wounds in less than sanitary battle fields and emerging hospital environments. Her foresight changed how nurses provided care in the 1800s and led to her development of standards of nursing care, hospital reform, and the first nursing training school in London. She was a pioneer for the nursing profession who contributed greatly to the nursing practice.[19]

During the 1800s, there was a lack of evidence based scientific research, non-researched and non-regulated prescribing of medications. An increased exposure to diseases without access to developed vaccines, accompanied by limited diagnostic technology, correlated to the all too often high percentage of women who encountered childbearing complications which resulted in increased maternal and fetal mortality. The following are some reasons for increased transmission of disease:

> Early settlers in America often suffered from malnutrition, which increased their vulnerability to infectious diseases. These maladies,

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[15] Ramona Salotti, introduction to *Notes on Nursing*, by Florence Nightingale (New York: Barnes and Noble Books, 2003), viii.

[16] Salotti, ix-xi.

[17] Salotti, ix-xi.

[18] Salotti, ix.

[19] Salotti, xv-xiv.

> transmitted from one person to another, can be either endemic, that is, always present, or epidemic, appearing from time to time with great intensity. The gravest threats to life and health were malaria and dysentery in summer and respiratory ailments, like influenza and pneumonia, in winter. Sporadic outbreaks of smallpox, yellow fever, and diphtheria created widespread panic, but over the long run they took far fewer lives than the more familiar scourges.[20]

The aforementioned societal lack of access to quality healthcare increased the early age morbidity and mortality of the population during this century. Morbidity refers to the "State of being diseased."[21] Mortality is defined as "The condition of being mortal; The number of deaths in a population."[22] One must keep in mind as Judith Walzer Leavitt and Ronald L. Numbers reference in their book *Sickness and Health in America: Readings in The History of Medicine and Public Health,* statistics documented before 1933 must be used in caution since they were often incomplete or inconsistent with details."[23] Suggested reasons for incomplete or inconsistent details:

> Many of today's clinical distinctions did not exist in the past, and those that did were frequently blurred by practitioners with little diagnostic sophistication. To compound our difficulties, disease patterns varied widely from city to city and state to state, so that what was typical of one region may have been rare in another.[24]

The improved living conditions during the late eighteenth and early nineteenth centuries had a positive effect upon the health of Americans. As portrayed in Figure 1,

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[20] Judith Walzer Leavitt and Ronald L. Numbers, *Sickness and Health in America: Readings in The History of Medicine and Public Health*, 3rd ed. (Madison: University of Wisconsin Press, 1997), 3.

[21] Evelyn Adler et al., eds., *Tabers Cyclopedic Medical Dictionary* (Philadelphia: F.A. Davis Company, 2001), 1386.

[22] Adler et al., 1388.

[23] Leavitt and Numbers, 3.

[24] Leavitt and Numbers, 3.

the increased urbanization and industrialization resulted in the deterioration of the cities which further resulted in the continued high death rates during the late eighteenth and mid-nineteenth centuries.[25] Figure 1 indicates women out live men.[26] Figure 2 portrays the life span as compared to gender and race variances, and historically indicates Caucasians live longer than blacks.[27] Despite improvement in the health of Americans, the quality and provision of health care during this time period was still not adequate in preventing transmission and curing diseases:

> The American health picture began to improve by the late 19th century, as evidenced by the declining urban death rate. The cities of Boston, New York, Philadelphia, and New Orleans, which suffered under a death rate of 30.2 per 1,000 between 1840 and 1864, saw this figure drop to 25.7 between 1865 and 1889 and down to 18.9 between 1890 and 1914. Even more dramatic was the precipitous fall of infant mortality rates; . . . . But despite these improvements, the United States continued to lag behind many other industrialized nations in reducing infant deaths, a symbolic indicator of national health standards.[28]

The victim mortality rate of those who died of the highly transmissible disease known as tuberculosis is portrayed in Figure 3.[29] Figure 4 depicts infant mortality at its highest and also the decline of incidence.[30]

It was not until the late nineteenth century that antibiotics and vaccines became available to treat and prevent transmission of tuberculosis. Unlike tuberculosis, the

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[25] Leavitt and Numbers, 5. See Appendix A, 166.

[26] Leavitt and Numbers, 4. See Appendix A, 167.

[27] Leavitt and Numbers, 4. See Appendix A, 168.

[28] Leavitt and Numbers, 5.

[29] Leavitt and Numbers, 6. See Appendix A, 169.

[30] Leavitt and Numbers, 6. See Appendix A, 170.

antitoxin for Diphtheria was available in 1894; there is a debate as to whether this contributed to the decline in Diphtheria since it had been on the decline for almost two decades prior to the antitoxin use.[31] Although small pox inoculation was available in the 1720s, it plagued Americans until the twentieth century, since most Americans chose not to participate in the medication treatment.[32]

People who did survive to an older age were expected to live and maintain a productive life with their family. Women were expected to assist with household chores, child care, laundry, and cleaning. Men worked outside of the home on the farm or at jobs. Elderly people who were fortunate to have had children would often live with them as they aged. Adult children would assist with the elder's needs (food, shelter, hygiene, and clothing) and health care issues. The aged population who did not have familial support or "needed shelter because of incapacity, impoverishment, or family isolation often ended their days in an almshouse."[33] Poor quality of care and living conditions in the almshouses resulted in inhumane treatment. The Chicago Historical Society description of almshouses states:

> Under state law each county has had responsibility for providing a variety of social services to its most destitute residents, and in the nineteenth century each county in the Chicago region established its own almshouse. The Cook County Almshouse (also known variously as the Cook County Poor Farm, Cook County Poorhouse, Cook County Infirmary, Oak Forest Infirmary, Cook County Old-Age Home, and Oak Forest Tuberculosis Hospital) was the only public institution at any jurisdictional level specifically established to provide long-term refuge for the most extremely destitute people in the Chicago area. These were people with chronic physical illnesses or disabilities, mental illness or retardation,

[31] Leavitt and Numbers, 5.

[32] Leavitt and Numbers, 8.

[33] Carol Haber, "Nursing Homes: History," Net Industries: Education, Knowledge, Information, http://medicine.jrank.org/pages/1243/Nursing-Homes-History.html; Internet; 2011; accessed 27 Mar. 2011.

> elderly people, or single mothers unable to work for a living even during periods when jobs were plentiful. Infamous for its corruption, mismanagement, deplorable living conditions, and maltreatment of inmates, the almshouse was regarded as a refuge of last resort. The number of residents ranged from 75 in 1854 to a peak of about 4,300 in January 1932, but usually the population, of whom approximately 10 percent were children, hovered around 1,000. The insane asylum department housed an additional 500–1,000 persons.[34]

The effects of residing in the almshouses are described in the 1890s by Homer Folks, Chairman, Secretary of the State Charities and Association of New York:

> The history of the poorhouse has been a disgraceful chapter in the annals of every state and country. Under whatever name the institution has been known, -workhouse in England, almshouse in Massachusetts, country home in Pennsylvania, infirmary in Ohio,- its nature has been the same. Everywhere it has been the abomination of desolation. Everywhere men have instinctively spoken of "going to the poorhouse" as the last and bitterest of earthly misfortunes. If the vital statistics of poorhouses could be accurately kept, the percentage of deaths from a broken heart would be surprising.[35]

Folks' writings engage the reader to "experience" his disapproval of the almshouses, and humankinds' allowance of this type of dwelling:

> The poor house became the dumping-ground for wreckage and waste of human society. It was the only open door to all those who were unable to compete successfully in the struggle for a livelihood by reason of mental or physical infirmity, and at the same time had no relatives or friends with sufficient heart and means to give them shelter,-in other words, of all those who from any cause were economically "unfit" and socially isolated.[36]

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[34] Margaret Dorsey Phelps, "Almshouses," The Electronic Encyclopedia of Chicago: Chicago Historical Society, http://www.encyclopedia.chicagohistory.org/pages/1735.html; Internet; 2005; accessed 26 Mar. 2011.

[35] Homer Folks, *The Social Welfare Forum: National Conference on Social Welfare, National Conference of Social Work (U.S.), National Conference of Charities and Correction*, ed. Isabel C. Barrows (Massachusetts: Geo H. Ellis, May 1894), 119; Google e-book; Internet, accessed 26 Mar. 2011.

[36] Folks, 119.

He described the elderly who lived there during the 1890s as, "Those whom old age finds without friends or provision for a rainy day."[37] Folks had early insight into the lack of humanistic care these people received while residing in the substandard housing. The poor houses Folks referred to were erected far from residential neighborhoods during the period of 1824-1856 so they could not be seen by the higher socioeconomic class of people.[38]

Evolving societal outcry and church admonishment of the deplorable living conditions led to a reformative movement. The local charities, church and state organizations led the way towards changing "institutionalized" care towards the provision of a higher quality, ethical and dignified approach to care of the aged. During the 1930s the increased political and governmental involvement accompanied by funding provided the elderly with greater access to "quality regulated" healthcare. PBS NewsHour identified the effect of the governmental Social Security act upon care for the aged:

> The Social Security Act was signed by Franklin Delano Roosevelt on August 14, 1935. The act provided matching grants to each state for Old Age Assistance (OAA) to retired workers. To discourage almshouse living, however, people living in public institutions were not eligible for the payments. That paved the way for the opening of a variety of private old-age homes, so that people could live in a care facility and still collect the Old Age Assistance Payments.[39]

Throughout the years, the government provided funding for various acts to improve the quality of healthcare for the aged. Eventually, almshouses were nonexistent

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[37] Folks, 119-120.

[38] Folks, 121.

[39] *PBS Online NewsHour, "*Today's Nursing Homes: The Evolution of Nursing Home Care in the United States," MacNeil/Lehrer Productions, http://www.pbs.org/newshour/health/nursinghomes/timeline.html; Internet; 1996-2011; accessed 26 Mar. 2011.

due to the continued governmental involvement. The resultant acts and federal laws which provided funding for construction of "state-of- the- art hospitals," provided by the "Hill-Burton Act," contributed towards the provision of humanistic quality care.[40] During the 1950s, changes in the Social Security Act, such as "states must establish some form of licensing for nursing homes," served to increase accountability and regulation over the provision of healthcare to the vulnerable elderly population.[41] Once the government provided funding for the construction of hospital affiliated nursing homes, society as a whole changed their perceptions about nursing homes. In time, nursing homes became recognized as part of the healthcare system.

During the establishment of the hospital associated LTC facilities in the 1960s, areas of weakness were identified by the U.S. government in the provision of care. The administrative operation of the facilities' weaknesses was also identified and eventually became known to the public. As a means of continuing the provision of healthcare services for the aged population: "On July 30, 1965, U.S. President Lyndon B. Johnson passed the Medicare Benefit legislation as an amendment to the Social Security Legislation.Â Medicare is a health insurance program for U.S. citizens at least 65 years old, or those aged younger than 65 years who suffer from certain disabilities."[42] This amendment allowed the expenses incurred for health care services to be paid for by Medicare. The establishment of Medicare provided separate reimbursement categories

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[40] *PBS Online NewsHour*.

[41] *PBS Online NewsHour*.

[42] Michael E. Young, "The Medicare and Medicaid Center Get the Facts on Medicare and Medicaid Programs: The History of Medicare- A Quick Look At How It Got Started," http://medicare-medicaid.com/medicare/the-history-of-medicare-a-quick-look-at-how-it-got-started/; Internet; 2008, accessed 26 Mar. 2011.

which included: "Part A (hospital and nursing home care paid by the individual's tax contribution) and Part B (medical providers, tests, and procedures compensated by additional private payment)."[43]

Currently, the Medicare payment system has other "Parts" which are available for individuals who can afford to pay for added coverage including, "vision, hearing, dental, health/wellness programs and prescribed medications."[44] After the establishment of Medicare, "the Department of Health and Human Services distributed intermediary Letter 371 stamping out much of the coverage for nursing homes the programs had initially allowed."[45]

The intent of Medicare was to maintain standards in the provision of ethical, high quality and dignified care while keeping spending at a minimum. Throughout the years and to the present day, Medicare continues to develop and implement regulations, guidelines, and limitations regarding the amount and type of services which will be reimbursed. Compliance to Medicare established guidelines, regulations and limitations upon the provision of care services continues to be a determining factor for the eligibility of reimbursement to healthcare facilities. An example of imposed limitations includes the length of stay, better known as the amount of days individuals could reside in a LTC facility based upon their diagnosis, ability to care for themselves and other various factors.

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[43] Young.

[44] Department of Health and Human Services: USA, "Medicare.Gov: The Official US Government Site for Medicare: Medicare A (Hospital Insurance)," Centers for Medicare & Medicaid Services http://www.medicare.gov/navigation/medicare-basics/medicare-benefits/part-a.aspx; Internet; 2008; accessed 27 Mar. 2011.

[45] PBS Online NewsHour.

Upon a person's depletion of the allocated Medicare coverage, Medicaid (welfare) could become an alternative payment source for healthcare services. The U.S. Social Security Administration Office of Retirement and Disability Policy describe the Medicaid program:

> Title XIX of the Social Security Act is a federal and state entitlement program that pays for medical assistance for certain individuals and families with low incomes and resources. This program, known as Medicaid, became law in 1965 as a cooperative venture jointly funded by the federal and state governments (including the District of Columbia and the territories) to assist states in furnishing medical assistance to eligible needy persons. Medicaid is the largest source of funding for medical and health-related services for America's poorest people.[46]

Although the government tried to provide healthcare insurance coverage to the elderly in the United States, it fell short in the provision of healthcare to all people. Social Security continues in the present day to identify the existing problem of health care coverage as stated in the following acknowledgement:

> Until 2014, when the Affordable Care Act will expand Medicaid eligibility, Medicaid does not provide medical assistance for all poor persons. Under the broadest provisions of the federal statute, Medicaid does not currently provide health care services even for very poor persons unless they are in one of the groups designated. . . . Low income is only one test for Medicaid eligibility for those within these groups; their financial resources also are tested against threshold levels (as determined by each state within federal guidelines).[47]

Further research regarding the historical timeline of Medicare funding proves to demonstrate many funding and quality of care issues during the 1960s still remain in the present day. PBS Online NewsHour referred to the history of quality care and lack of

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[46] Barbara S. Klees, Christian J. Wolfe, and Catherine A. Curtis, "Medicaid Program Description and Legislative History," *U.S. Social Security Administration Office of Retirement and Disability: Annual Statistical Supplement 2010*, http://www.ssa.gov/policy/docs/statcomps/supplement/2010/medicaid.html; Internet; 2010; accessed 27 Mar. 2011.

[47] Klees, Wolfe, and Curtis.

nursing home funding with reference to "1968 Congress passed legislation known as the 'Moss Amendments' which provided comprehensive legislation to improve nursing homes and raise institutional standards."[48] Due to the number of people who took advantage of the Medicare benefit, it resulted in high costs and was the basis for the Department of Health and Human Services to significantly decrease funding of nursing homes in 1969. Due to the decreased funding, many of the elderly could not afford the healthcare costs. To re-establish federal reimbursement, The Miller Amendment of 1971 established "intermediate-care-facilities." The amendment guidelines required less skilled nurse staffing, and a decreased standard of care. Decreased standards of care ultimately results in a lower quality of provided healthcare. Negative effects of the amendment were identified, and in 1972 Medicaid made an attempt to increase the quality of care by reimbursing nursing homes on a "reasonable cost-related basis" with the passing of Public Law 92-603.[49]

As time progressed the quality of nursing home care continued to deteriorate. Nursing home provider fraud and scandals occurred in some of the nursing homes.[50] Reasonable and adequate provider reimbursement rates were provided by the Boren Amendment which was passed in 1981.[51] A national expert on health care policy, health care financing, and LTC, Dr. Bruce Vladeck described in the *Journal of the American Medical Association* Congress' continued attempts towards the provision of quality

[48] PBS Online NewsHour.

[49] PBS Online NewsHour.

[50] PBS Online NewsHour.

[51] PBS Online NewsHour.

nursing home care at all facilities which led to the enactment of the "Omnibus Reconciliation Act (OBRA) of 1987, which revolutionized the regulatory scheme for nursing homes by significantly raising quality standards and basing those standards on patient outcomes."[52] As Vladeck continues to note, under OBRA-87, nursing homes must "attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident. Residents are protected against involuntary transfer or discharge and have choice in the care they receive."[53]

The Federal Government's identification of the need for better care and enforcement of sanctions in LTC facilities for violations in regards to poor care, led to the need for the 1987 Omnibus Reconciliation Act (OBRA). The OBRA 87 act is commonly still referred to as the "Nursing Home Reform Act." The Omnibus Reconciliation Act of 1987 provided the following federal regulations:

> OBRA 87 changed the previous federal system of regulating nursing homes in three important ways. First, OBRA 87 established new, higher standards that were much more resident focused than previous standards. The law established a number of quality-of-life rights, including freedom from abuse, mistreatment, and neglect and the ability to voice grievances without fear of discrimination or reprisal. Physical restraints, which had been quite common, were allowed under only very narrow circumstances and strict requirements were established limiting the amount of time that residents could be restrained. The law also upgraded staffing requirements . . . [54]

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[52] Bruce C. Vladeck, "The Past, Present, and Future of Nursing Home Quality," *Journal of the American Medical Association* 275, no.6, 14 February 1996 [database on-line] available from http://jama.ama-assn.org/content/275/6/425.full.pdf+html?sid=11f07c92-8c76-47b8-b2f0-0efea7dd1215; Internet; accessed 26 Mar. 2011.

[53] Vladeck, "The Past, Present, and Future of Nursing Home Quality."

[54] David Brown, Marc P. Freiman, RTI International, and Joshua M. Wiener,"Nursing Home Quality: Twenty Years After the Omnibus Reconciliation of 1987," The Henry J. Kaiser Foundation, http://www.kff.org/medicare/upload/7717.pdf; Internet; 2007; accessed 12 Apr. 2011.

During the 1990s federal monetary incentives contributed towards the development of sub-acute care facilities. In 1997, the Balanced Budget Act decreased the amount of reimbursement for LTC facilities which resulted in some bankruptcies within the industry.[55]

Traditional LTC facilities provide a structured environment accompanied by policies and regulations by which the residents and healthcare professionals abide. Based upon my professional experience working in LTC facilities, an institutionalized facility has an appearance of a hospital. LTC facilities often have tiled floors throughout the facility to allow for quick and easy clean ups of spills. The lobby entrance frequently has a hotel or home like appearance. Often times, there are upholstered chairs or couches, ornate lighting fixtures, decorative carpeting, fresh flowers and pretty wallpaper lined walls. Similar to the hospital institutionalized setting, a receptionist whose role is to be a "gate keeper and greeter" is usually stationed at the point of entry. A person's first impression includes this "positive visual environment," which can be misleading about the comparative care residents receive. Beyond the lobby, a different picture may be painted. In many facilities there are few private rooms. Residents often need to share a room and bathroom with their roommate. Upon admission to the LTC facility, the residents cannot choose with whom they want to room. They have lost some privacy once they begin to share the same room with their new "stranger roommate." The experience mirrors an inpatient experience at a hospital.

[55] Department of Health and Human Services Assistant Secretary for Legislation (ASL), "Testimony," http://www.hhs.gov/asl/testify/t000905a.html; Internet; accessed 8 Nov. 2014.

Frequently, residents have to share a room with another resident residing at the facility. Tile linoleum floors add to the "institutionalized" appearance since they are frequently unsightly and cold to bare feet. Linoleum floors are used to decrease the risks of falls for residents that walk or trip easily on rugs due to an unsteady gait. More often than not, each room has two electronic beds situated on wheels with side rails attached as a safety measure. The beds can be positioned in different positions via an electronic positioning control on the bed rail or television remote. To some extent, the beds resemble a crib. Both have a side rail bar on each side of the bed to prevent falls and they are also used to assist with positioning in the bed. Many regulations have been imposed on the dehumanizing use of side rails. The television remote is either attached via a wire to a metal bed side rail, or controls are built into the side rail. In this day of advanced technology, each resident often has a personal television on "their side of the room." An intercom on the wall above each bed provides healthcare providers the ability to verbally respond to a patient's call bell from the nursing station. Patients can "talk to the wall and the wall will talk back."

Invisible lines of division between nursing facility beds separates the room into two living spaces. Each living space is separated by a curtain on small wheels which hangs from a ceiling curtain track that allows the bed to be completely surrounded by the curtain. The curtain creates a visual illusion of privacy. All that is said behind the curtain is open for interpretation on the other side of the curtain. There is no complete privacy in a double occupancy room which uses cloth curtains as barriers for privacy. I consider the invisible division line as the small space between both curtains when pulled around each bed. Each resident has a limited amount of furniture which might include a

nightstand, bedside table on wheels, one vinyl upholstered chair and a clothing storage unit with drawers. Some LTC facilities allow the residents to bring a small piece of furniture, such as a chair from their home. Roommates usually share a bathroom including a toilet and sink with a call bell string attached to the wall for emergencies. A communal shower area is shared amongst all residents who reside on the same floor or nursing home wing. Showers and baths are scheduled on specific days. People share the shower use, so everybody requires an assigned day.

To compensate for the aged residents' decreased body thermoregulation, LTC facilities indoor temperature regulation is usually very warm during winter months and cold during the summer months. Nursing stations are located in the center of medical wings to serve as providers of care and also to supervise residents. Meals are served on plastic lunch room style trays three times per day (breakfast, lunch, and dinner). An evening snack might include an eight ounce container of milk or four ounce container of juice, and four ounces of pudding. Meals and snacks are frequently a standard for all of the residents. Residents may ask for an alternate meal, such as a sandwich, to replace dinner. Alternate meals are frequently limited.

Visitors are permissible according to the administrative selected LTC facility visiting hours. If a friend or family member would like to visit at a different time, they need permission to enter the building. Bedtime is usually controlled subliminally. The Lights begin to dim at bed time in specified areas of the residential living areas. Nursing homes go into sleep mode, and so do the residents. Rise and shine begins by the time breakfast is served which is usually between 7:30 am and 8:00 am. Mornings are frequently loud and a person would not be able to sleep very late with all of the

commotion. Living in a hotel would be much easier for late morning risers, as a person could hang a sign on the door for the maid stating "Do Not Disturb."

If a resident decides to sleep late, breakfast will get cold and the kitchen staff will be preparing the next meal already. Odds are the resident will either have to heat up the food in a microwave on the unit or throw away the meal. Sometimes they will send fruit or a box of cereal to the unit upon the nurse's request. The kitchen usually will not prepare another meal once they are done serving. There are specific rules about leaving the building and grounds. For the most part, residents' basic freedoms are robbed from them once they reside in an institutionalized LTC setting.

Ira Rosofsky, a psychologist who practiced in nursing homes for many years, described the type of nursing home building one most likely approached for the first time as, "A one-story affair surrounded by a parking lot-ranch style on steroids."[56] He describes the nursing home's architecture as follows: "These buildings share their design ethos with banks, schools, and prisons."[57] Rosofsky's blatant negative opinion regarding nursing home environments is exemplified in the following expression:

> You enter a pleasant lobby-often with leather couches and a chandelier. These are easy touches that impress the public and are unrelated to the level of quality of care that lies deeper within. I wonder why they bother at all with pleasant design elements. Aesthetic appeal is not in the guidelines of the Joint Commission on Accreditation of Healthcare Organizations. Strictly speaking, you could set up the lobby with plastic lawn furniture-as long as it was safe lawn furniture- and not be in danger of losing accreditation. There is little need to impress prospective residents. Few make a deliberative choice between Home A and Home B.

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[56] Ira Rosofsky, *Nasty, Brutish & Long: Adventures in Old Age and the World of Eldercare* (New York: Penguin Group 2009), 32.

[57] Rosofsky, 32.

> Few plan on a nursing home in advance. Following an accident or sudden illness, most go to the one that has an available bed.[58]

In comparison, Beth Baker's 1982 personal experience of a loved one dying in a nursing home is not a pleasant description. Her following account is unfortunately still an accurate description of poor quality, and undignified care in some present day nursing home settings. Close your eyes and experience with your own five senses Baker's experience: "To enter, we passed through a glass door and we were met with the malodor of medicine, Mr. Clean, and urine."[59] This is still an all too common occurrence in nursing homes today. Many published guidelines or references for "How to select a nursing home" commonly refer to malodorous smells such as urine or stool as an immediate indicator of poor quality of care. If a nursing home has malodorous smells upon entering the building or has a lingering distinguishable odor upon touring the facility, run as fast as you can! There is no reason other than poor quality of care for such odors. Imagine yourself as the resident living in that facility. This is just the beginning of many reasons why society and healthcare physicians protest living in LTC facilities at any point in their lifetime.

Not all LTC facilities match this description. Today, many are trying to change their institutional image to one of a "home like setting." Due to the many years of governmental funding and oversight of this ongoing "transitioning" of care, they identified that nursing homes in general provided varying levels of quality care. Medicare developed a "Nursing Home Checklist" in response to different provisions of

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[58] Rosofsky, 33.

[59] Beth Baker, *Old Age in a Promise of New Age: The Promise of Transformative Nursing Homes* (Tennessee: Vanderbilt University Press, 2007), xii.

care at each LTC facility.[60] The checklist is accessible to the public for use during a LTC site visit, to determine if the nursing home is a good selection for an individual prior to admission into a facility. Another method of promoting quality care in LTC facilities includes the use of reimbursement for the provision of quality, and safe care in LTC facilities. Medicare regulations for the provision of safe and quality care in the facility must be met to be considered a certified provider or to able to receive reimbursement for services. Medicare and Medicaid programs state,

> To be part of the Medicare and Medicaid programs (that is, be a certified provider), nursing homes have to meet over 150 requirements (regulatory standards) Congress set to protect nursing home residents. These requirements cover a wide range of topics, from protecting residents from physical or mental abuse and inadequate care, to the safe storage and preparation of food.[61]

Government inspections of "certified provider" nursing homes are still required to have intermittent inspections to monitor nursing home compliance with the regulations. The inspector's findings are accessible to the public for their intended use in the selection of nursing homes that provide quality care.

The Department of Health and Human Services suggests, "You can compare the nursing homes you are considering using the Five Star Quality Rating, detailed information on health inspections, nursing home staffing, quality measures, and fire safety inspections. Maps and directions are also available."[62] In the twenty-first century,

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[60] US Dept. of Health and Human Services, "Medicare.Gov: The Official U.S. Government Site for Medicare," Centers for Medicare and Medicaid Services, http://medicare.gov/nursing/checklist.pdf; Internet; accessed 5 Apr. 2011.

[61] Department of Health and Human Services, "Nursing Home: This official governmental booklet explains: How to pay for nursing home care, Your nursing home resident rights, Where to call for help," 9, Centers for Medicare and Medicaid Services, http://www.medicare.gov/publications/pubs/pdf/02174.pdf; Internet; 2008; accessed 5 Apr. 2011.

[62] Department of Health and Human Services, "Medicare.Gov."

the U.S. government is continuing its attempts to increase the quality of care in LTC facilities. It is quite obvious that problems still exist today. The United States government has publicly addressed the issues and has provided open public access to the results of nursing home audits and quality rating results. On May 2, 2007, twenty years after the OBRA '87 Nursing Home Reform Act was enacted, Senator Herb Kohl discussed at the Special Committee on Aging Hearing continuing issues still not resolved by OBRA '87:

> OBRA '87 led to a sharp drop in unnecessary physical and chemical restraints of residents. . . . We will hear today from the GAO that in 2006, nearly one in five nursing homes nationwide was cited for poor care that causes actual harm to residents. Among a group of facilities studied in 1998 and 1999 that provided poor care, the agency found that nearly half have made no progress between that time and now. This is unacceptable, and raises questions about how and why our enforcement system is failing. . . . But it is troubling that fines and sanctions are often not levied –even when inspectors find violations that leave residents suffering.[63]

Residents residing in LTC facilities are entitled to humanistic, ethical, dignified, and quality care. If the government has not been able to resolve the issues plaguing the provision of quality care, a different approach needs to be taken to change the LTC industry. Physicians, nurses, and nursing assistants must be trained in a humanistic approach toward caring for the elderly. Trust, communication, caring, and empathy must be established between the resident and healthcare professionals to prevent the resident and healthcare professionals from perceiving and experiencing an institutionalized LTC setting and approach to humanistic ethical, dignified, and high care quality care.

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[63] Herb Kohl, "Nursing Home Reform Law OBRA '87: May 2, 2007 Oversight Hearing," The National Consumer Voice for Long Term Quality Care, http://www.theconsumervoice.org/advocate/issueindex/archivedissues/obra#May_2__2007_Oversight_Hearing_; Internet; accessed 25 Apr. 2011.

The regulations and reimbursement of healthcare services have not solved the ongoing issues of the many LTC facilities provision of "poor quality, unethical, and non-dignified" care. In an attempt to resolve these issues within the LTC facilities, the United States began to develop and implement new healthcare reform.

> In 2010, Congress passed and the President signed into law comprehensive health care legislation. With the enactment of these laws, collectively referred to in this report as the Affordable Care Act (ACA), the United States has an opportunity to transform its health care system to provide higher-quality, safer, more affordable, and more accessible care.[64]

A component of the twenty-first century aged health reform legislation (ACA) impacting the elderly population known as The Patient Protection and Affordable Care Act (PPACA) has provisions specifically centered upon geriatric care.[65] The PPACA includes sections which focus on many facets of elder care including:

> Insurance reimbursement, Medicare and Medicaid reimbursement, long term care facility owner transparency, grant funding for the purchase, development of Electronic Health Record technology systems, the establishment of an Advisory Board on Elder Abuse, Neglect and Exploitation for the identification, prevention, treatment, intervention and prosecution, continued funding for adult protective services, establishment of grants to fund Ombudsman Programs for training, the creation of an Elder Justice Coordinating Council of government officials from all departments to collaboratively coordinate agencies to address abuse, neglect and exploitation issues, establishment of stationary and mobile forensic centers to research and determine if crimes of abuse, neglect and exploitation occurred and would assist law enforcement agencies investigations, government incentives and grant money which is directed towards incentives (bonuses) for employees who are employed in nursing homes or community based long-term care after they receive education and certification, grant provision for training management practices to

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[64] IOM (Institute of Medicine), *The Future of Nursing: Leading Change, Advancing Health* (Washington, D.C.: The National Academies Press, 2011), S-1, http://www.rwjf.org/content/dam/farm/reports/reports/2011/rwjf67190; Internet; accessed 30 Apr. 2011.

[65] Leading Age, Quality First, "Health Reform and Aging Services: Technology Provisions," Center for Aging Services Technology, Provisions Relevant to Aging Services Technologies Health Care Reform Bill (H.R. 3590): Patient Protection and Affordable Care Act, 25 Mar. 2010, http://www.aahsa.org/healthreformhub.aspx; Internet; accessed 17 Apr. 2011.

> promote retention of those who provide the direct care to the residents, the establishment of a nurses aid national registry, and long term care facilities that receive at least $10,000 in federal funds must report suspicion or crimes against a person receiving care from a long term care facility.[66]

PPACA emphasizes the need for LTC services to be received in the community versus a LTC facility. PPACA states, "Use of Technology in New State Options for Long-Term Services and Supports" provides

> States with new state plan options for providing long-term services and supports, including a community first choice option for home and community-based attendant care services. Under this option, states could utilize technologies to ensure continuity of services and supports. The exact types of technologies permissible will need to be clarified, as the language prohibits reimbursement for assistive technology devices and services but allows beepers and other electronic devices as well as expenditures that substitute for human assistance.[67]

Provision of care in the home setting is the primary focus in this act. Technological advances are vast and changing every day. Types of technological devices are not specified, it does allow for electronic devices that substitute for human assistance. Home healthcare professional visits can be costly. Use of electronic devices that replace human assistance could be a dangerous slippery slope towards the dehumanization of care.

Many areas of the ACA and PPACA are presently under governmental scrutiny. Currently healthcare provider resistance to the PPACA includes provider fears of litigation if they are identified as not following the law. Non-reimbursement for poor services related to transparency of care resulted in minimal support of the legislative act

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[66]Leading Age, Quality First, "Health Care Reform: Elder Justice Act," http://aahsa.org/article.aspx?id=11461; Internet; accessed 17 Apr. 2011.

[67] Leading Age, Quality First, "Health Reform and Aging Services: Technology Provisions," Center for Aging Services Technology, Provisions Relevant to Aging Services Technologies Health Care Reform Bill (H.R. 3590): Patient Protection and Affordable Care Act, http://www.aahsa.orghealthreformhub; Internet; accessed 17 Apr. 2011.

from healthcare providers. The intent of ACA is to provide health insurance coverage to all U.S. citizens with reimbursement of care being dependent upon the provision of quality care criteria being met according to the ACA requirements. Additionally, U.S. citizens have not fully supported purchasing healthcare insurance under the ACA that would purportedly provide the services supported by legislation. Along with changes to the health insurance system that guarantee access to coverage to everyone regardless of pre-existing health conditions, the Affordable Care Act includes a requirement that many people be insured or pay a penalty.[68] The current economy, high unemployment, lack of trust in government, and technological problems involved in government implementation of the insurance plans has deterred citizens from purchasing the healthcare insurance. Another debated additional requirement is that employers of businesses which employ a certain number of employees must offer insurance to employees or they will incur the consequences of a penalty. U.S. citizens are not yet receiving the comprehensive quality care benefits that the ACA and PPACA intended to provide.

The President of the Institute of Medicine (IOM) described the "call for experts to discuss, debate, and examine possible solutions for the multitude of complex health concerns that face the United States and the world."[69] Sponsored by the partnership of Robert Wood Johnson Foundation (RWJF) and IOM, the "Two year RWJF Initiative on the Future of Nursing IOM" states, "Accessible, high-quality care cannot be achieved without exceptional nursing care and leadership."[70] Transformation of health care is

[68] The Henry J. Kaiser Foundation, "Health Care Reform: The Requirement to Buy Coverage Under the Affordable Care Act," 2014; http://kff.org/infographic/the-requirement-to-buy-coverage-under-the-affordable-care-act/; Internet; accessed 20 Feb. 2015.

[69] IOM (Institute of Medicine), ix.

[70] IOM (Institute of Medicine), ix.

affected greatly by the nursing profession. "The nursing profession has more than three million members and represents the largest segment of the health care force."[71] One might ask, "How does the initiative effect care for the aged population in LTC facilities?" This initiative promotes the provision of health care services within the community for the aged population to continue to "reside in their homes" versus moving into "LTC facilities." The RWJF and IOM team envision;

> A future system that makes quality care accessible to the diverse populations of the United States, intentionally promotes wellness and disease prevention, envisioned future, primary care and prevention are central drivers of the health care system. Inter-professional collaboration and coordination are the norm.[72]

To end the duplication of services, the initiative addresses the need to have seamless, coordinated care to end the problems surrounding having many healthcare professionals involved in a person's care and different services for the same ailment (which results in the duplication of health care services and costs).[73] When care is seamless these multiple aspects of care are coordinated to enhance the quality of care and the experience of care. An example of seamless care is the initiative's support and referencing of the non-profit On LOK PACE (Program of All inclusive Care for the Elderly): "The model was founded in the early 1970s by a group of citizens concerned about the plight of elders and the lack of long term options in the community and today

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[71] IOM (Institute of Medicine), S-1.

[72] IOM (Institute of Medicine), S-2.

[73] IOM (Institute of Medicine), 2-12.

offers diverse provisions for all health groups."[74] The model for senior community options is described as seamless care:

> On Lok Lifeways provides care for eligible seniors, who wish to remain living at home in the community, with a complete program of health and health-related services. Our program includes preventative, primary and acute medical services and long-term care. Our primary focus is on preventative measures to maintain the health and well-being of our participants. Our goal is to help these seniors live independently, in their homes for as long as possible. . . . For seniors who are Medicare and Medi-Cal beneficiaries, and recipients of Supplemental Security Income Program (SSI) benefits, there is no premium or co-payment for On Lok Lifeways' comprehensive program of health and health-related services. For other Medicare beneficiaries, there may be a flat monthly fee for our program, with the amount based on factors such as personal income and assets. Our comprehensive package of benefits will be totally covered by this fee, with no additional co-payments of any kind . . . [75]

The current IOM and RWJF movement to keep elders in their homes supports the argument that society as a whole prefers to live in their homes versus LTC facilities. Could other reasons for the IOM and RWJF initiative include, LTC facilities do not all provide dignified, ethical and high quality care? As evidenced by the U.S. Government Health Care Reform Elder Justice Act, there are still issues of abuse, neglect and exploitation occurring in today's nursing homes.[76] Perhaps the U.S. government oversight and reporting to the public of "substandard care" in LTC facilities, such as the Five Star Medicare rating system, is another reason to initiate movement to keep elders in the home care setting.[77] US World and News Report states, "An average yearly U.S.

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[74] On Lok Lifeways, "Our Services," http://www.onlok.org/Sharesite/content.asp?catid=240000335&scatid=; Internet; accessed 17 Apr. 2011.

[75] On Lok Lifeways.

[76] Leading Age, Quality First, "Health Care Reform: Elder Justice Act."

[77] The Department of Health and Human Services, " Medicare.Gov."

nursing home costs $74,000."[78] The costs to the U.S. Government (Medicare and Medicaid), insurance industry, and to the consumers can be enormous.

There are many reasons for returning care of the aged to the home setting. LTC facilities were established and constructed as part of the hospital system to increase the provision of quality, ethical, and dignified care. Almshouses were deplorable and the new LTC facilities were intended to change the industry for the better. Unfortunately, many problems remain regarding substandard, unethical, and undignified care in the present day LTC facilities. Remaining in a home setting is possible as long as needs are met and there is no danger of neglect or potential harm for the person. If there is any risk to the individuals or if they are unable to care for themselves, another option could be to live in a LTC facility. The movement may change the provision of care for a larger percentage of people to a home setting. There will continue to be a need for LTC facilities as many people are unable to live at home and require medical care. Those that require a LTC facility placement have the right and primal need to receive humanistic care and experience quality interpersonal relationships similar to a home like setting.

Sheila Molony, an Assistant Professor, Yale University School of Nursing, analyzed findings from several studies and concluded stating, "A larger interpretive perspective that will lead to ongoing theory and practice development to enable experiences of home during residential transition, thereby informing nursing praxis in creating and shaping therapeutic environments."[79] Molony identified, "Home provides a

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[78] Avery Comarow, "US News and World Report: Health," http://health.usnews.com/health-news/blogs/comarow-on-quality/2009/05/04/do-the-best-nursing-homes-have-to-be-expensive; Internet; 4 May 2009; accessed 17 Apr. 2011.

[79] Sheila L. Molony, "The Meaning of Home," *Research in Geronotological Nursing* 3, no. 4 (2010): 291.

link to self-identity and to personal, societal, and cultural values, beliefs, and norms."[80] She emphasized:

> Shared experiences amongst people, meaningful relationships and belongings contribute to therapeutic environments similar to home. Homeness is experienced as a familiar place of comfort which provides a secure feeling to a person. A home like environment provides pt autonomy, freedom to do as one pleases, a refuge, sense of belonging, identity, self reconciliation (sense of accepting self) a place that one can always return to, a connection with society, bonds of intimacy with family and friends, and a place for family gatherings.[81]

A person who relocates from home to a LTC facility has to re-connect to a new environment. This process of sensing a home like feeling in a LTC facility is not always so easy to accomplish. Molony's research concludes:

> Residential moves may pose a threat to self-concept; self maintenance and/or self "shaping" is part of the transitional experience and may also involve reconsideration of physical/spatial agency and social/spatial boundaries. These concepts seem to be at the critical margin of the residential transitional experience.[82]

The person has to let go of the past and enter into a new unknown territory. If the person does not successfully integrate or experience a home like sense after the transition to the LTC facility, there is a high risk for a condition described by Molony as "Homelessness as powerlessness, lack of choices, loss of identity, disconnectedness, loss of memories, uncertainty, meaningless space, intrusion, and dependent journeying."[83] A successful transition from home to the LTC facility will result in the person being actively engaged in making the LTC facility the new home. The detrimental effects of a resident not

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[80] Molony, 292.

[81] Molony, 291-305.

[82] Molony, 295.

[83] Molony, 304.

successfully integrating into a LTC facility can have negative effects upon one's sense of self and personal growth. It is imperative that LTC facilities begin to recognize the importance of transforming LTC facilities into a warm, welcoming, home like environment.

Based on personal professional experience, the still common institutional type of LTC facility is a no frills type of facility. Bruce C. Vladeck identified the LTC industry problems in his book, *Unloving Care*. The book, which was published in 1980, still chillingly depicts a description similar to many facilities today:

> They have been described as "Houses of Death," "concentration camps," "warehouses for the dying." It is a documented fact that nursing home residents tend to deteriorate physically and psychologically, after being placed in what are presumably therapeutic institutions. The overuse of potent medications in nursing homes is a scandal in itself. Thousands of facilities in every state of the nation fail to meet minimal government standards of sanitation, staffing, or patient care. The best governmental estimate is that roughly half the nation's nursing homes are "substandard."[84]

Although Bruce Vladeck (who is still to this day involved in geriatric reform) wrote the book in the 1980s, many of these issues remain today. Vladeck's essay "Care of the Aged" depicts the all too common depiction of a LTC facility in the essay "Institutional Needs Versus Resident/Patient Needs":

> As time went on, Mary's mental decline continued, and she became frailer as well. At this point, she was forced to spend more time either seated in a wheelchair or in the bed. Because she was no longer reliably able to get to the toilet herself, she began to have the occasional accident. As is most often the case, the institution caring for her did not have the staff that would be required to toilet all of its residents, so Mary was put into a diaper. It took some time for her to become accustomed to soiling herself. She would call for help because she needed to go to the toilet, only to be told she was in diapers and so had no need to use it. Even though her mental abilities were much in decline, Mary would still have been able to

[84] Bruce C. Vladeck, *Unloving Care* (New York: Basic Books, Inc. 1980), 3.

> use a toilet if only she could have been aided in doing so. Her precipitous decline in using the toilet was a function of understaffing, not declining abilities. Being forced to soil herself and then have others to clean her had a deleterious effect on her self-respect, even in her failing mental state; . . . . This is a familiar downward spiral; . . . . Dependency increases, leading to further decline . . . [85]

In comparison, Dr. William H. Thomas has internationally paved the way for a transformative approach to deinstitutionalizing LTC settings towards a more humanistic model. Thomas' Eden Alternative philosophy encompasses "An Elder-centered community commits to creating a Human Habitat where life revolves around close and continuing contact with plants, animals, and children. It is these relationships that provide the young and old alike with a pathway to a life worth living"[86]:

> The Eden Alternative® is an international, nonprofit 501(c) 3 organization that provides education and consultation for organizations across the entire continuum of care. As a person-directed care philosophy, it is dedicated to creating care environments that promote quality of life for Elders and those who support them as care partners. The Eden Alternative's principle-based philosophy empowers all care partners (employees, family members, volunteers, and the Elders themselves) to transform institutional approaches to care into caring communities where life is worth living. Led by our internationally-recognized co-founder, Dr. William Thomas, we apply our 20 years of experience to guiding organizations through the journey of culture change.[87]

The philosophy of the Eden Alternative focuses upon a simple core concept: "We must teach ourselves to see places where Elders live as habitats for human beings rather than facilities for the frail and elderly. We must learn what Mother Nature has to teach us

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[85]Robert Almeder and James M. Humber, eds., *Care of the Aged* (Totowa: Humana Press Inc., 2003), 34-35.

[86] Eden Alternative, "Mission, Vision, Values, Principles," http://www.edenalt.org/about-the-eden-alternative/mission-vision-values/; Internet; accessed 8 Nov. 2014.

[87] Eden Alternative, "Improving the lives of the Elders and their Care partners," http://www.edenalt.org/; Internet; 2009; accessed 21 Mar. 2014.

about vibrant, vigorous living."[88] Nursing home residents must remain involved in human and animal interactions, and surrounding community activities. Medical treatment does not prevail over the residents' human needs such as companionship, belonging, and human interactions. Linda L. Nussbaumer, Ph.D. and Les Rowland describe the characteristics of the human habitats living environments as "Neighborhoods with residential environment; single rooms and bathrooms; contact with children, animals and pets allowed; residential color palette."[89] The human habitat model supports resident autonomy, lifestyle choices, community involvement, and a residential neighborhood atmosphere versus an institutional setting.

There is a swift movement occurring across the country to reform and deinstitutionalize nursing homes. Luxury amenities, residential settings, and residential landscape design are amongst the transformative changes. Landscape architecture Joseph T. Geller describes a nursing home residential landscape as, "Warm outdoor, residential scale lighting, such as wooden post lights and ornamental lighting at building entries . . . flowering shrubs and material that attracts birds . . . stone walls and brick or stone paving . . . comfortable rocking chairs . . . fencing and screening made of wood . . . "[90] Geller discusses many landscape options such as dementia gardens, walking paths, and the need to place LTC facilities near enjoyable landscape views that can be visualized from

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[88] Eden Alternative, "The Eden Alternative Philosophy," http://www.edenalt.org/our-philosophy.html; Internet; 2009; accessed 21 Mar. 2014.

[89] Linda L. Nussbaumer, and Les Rowland, "Transforming Nursing Homes Into … Homes?," *Journal of Family and Consumer Sciences* 99, no. 4 (Nov. 2007): 15-20.

[90] Joseph T. Geller, "Nursing homes: Now healing from the outside in: Strategic site design is giving traditional nursing homes enhanced resident appeal," *Nursing Homes* 55, no. 10 (Oct. 2006): 32-36.

windows for those residents that are unable to go outside.[91] Geller emphasizes that the landscape changes will, "make the facility feel like a home away from home."[92] From Geller's landscape architect designer perspective he emphasizes, "From interior courtyards, rehabilitation gardens, and walking trails, to adding residential character through strategic material selection, nursing homes can raise the level of care for residents while treating them with the dignity and respect they deserve."[93]

Another recent transformational approach called Green House project describes their goal of the provision of senior care as, "The Green House model is a de-institutionalization effort designed to restore individuals to a home in the community by combining small homes with the full range of personal care and clinical services expected in high-quality nursing homes."[94] In 2011 the *New York Times* article, "A Nursing Home Shrinks Until If Feels Like a Home" describes the Green House deinstitutionalized environment:

> Just 10 residents live in each so-called Green House, which looks nothing like a traditional nursing home. The front door opens onto a large living and dining area; on one side is a hearth surrounded by upholstered chairs, and on the other is a long communal dining table where meals are served. An open kitchen faces the table, so caregivers can chat with elderly residents while preparing meals.[95]

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[91] Geller, 34.

[92] Geller, 36.

[93] Geller, 36.

[94] The Green House Project: Caring Homes for Meaningful Lives, "Mission & Vision," http://thegreenhouseproject.org/about-us/mission-vision/; Internet; accessed 22 July 2012.

[95] "A Nursing Home Shrinks Until It Feels Like a Home," *The New York Times*, http://www.nytimes.com/2011/11/01/health/shrinking-the-nursing-home-until-it-feels-like-a-home.html?pagewanted=all; Internet; 1 Nov. 2011; accessed 22 July 2012.

Furthermore the article suggests, fewer residents result in fewer certified nursing assistants and registered nurses and less capital cost for the nursing home. Healthcare professionals appreciate they are not as rushed and able to provide a more flexible schedule of care.

Residents are satisfied with the care and healthcare professional relationships:

> Residents say they feel like they have deeper relationships with the staff, and family members report higher satisfaction with the physical environment, privacy, their own autonomy, health care and meals. Employees, too, report less stress. The turnover rate is significantly lower than in a traditional nursing home. Green House certified nursing assistants are paid on average about 5 percent more than those in institutional settings.[96]

The article emphasizes that The Green House residents experience greater autonomy and socialization with others in this type of environment.

Continuing Care Retirement Communities (CCRCs) are becoming a more popular option for many aging Americans. According to industry sources, the CCRC model has existed for over 100 years, starting with religious and fraternal organizations that provided care for older Americans who turned over their homes and assets to those organizations.[97] US Department of Health and Human Services describes a CCRC as the following:

> A continuing care retirement community (CCRC) is a community living arrangement, typically on a single campus, that provides housing, health care, and social services. CCRCs offer different levels of services ranging from independent housing to care. Joining a CCRC is a way of obtaining more easily. You move into a CCRC as a resident of an independent housing unit where you can usually purchase and receive support services.

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[96] "A Nursing Home Shrinks Until It Feels Like a Home."

[97] GAO, "United States Government Accountability Office Report to the Chairman, Special Committee on Aging, U.S. Senate," June 2010, 3, http://www.gao.gov/new.items/d10611.pdf; Internet; accessed 21 Mar. 2014.

> When you need more care or are unable to live independently, you can move to the on campus. Should you need the next level of care, you can move into the on-site nursing home.[98]

The June 2010 United States Government Accountability Office Report to the Chairman, Special Committee on Aging, U.S. Senate report states,

> CCRCs are one of a number of options older Americans may choose to meet housing and other daily needs and especially to receive long-term care, which Medicare and private health insurance typically do not cover and which can be extremely costly. Older Americans may use a number of options to pay for their short-and long-term care as they age, including relying on savings or investments, purchasing long-term care insurance or annuities, entering into a reverse mortgage, or relying on government-financed programs such as Medicare and Medicaid. For CCRCs specifically, many use the proceeds from the sale of their homes and any retirement assets to pay for the housing and care arrangements.[99]

Initially other than financial requirements, residents are drawn towards the ability to live independently in an apartment or small cottage on the grounds of the CCRC in a home like environment with amenities that such as swimming pools, exercise rooms, community gathering rooms and much more. Residents maintain independence and are able to come and go from their residence as they wish and many drive their own car versus using shuttles for transportation. As health begins to deteriorate or they need some assistance with activities of daily living, residents will transfer to the assisted living facility.

The assisted living facility often still has a warm home like atmosphere that begins to merge into a LTC facility type of environment. Healthcare professionals, including nursing personnel, are assigned to residents for the provision of minimal

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[98] U.S. Department of Human Health Services, "Where You Live Matters," *Long Term Care.gov Find your path forward*, http://longtermcare.gov/where-you-live-matters/living-in-a-facility/continuing-care-retirement-communities/; accessed 9 Nov. 2014.

[99] GAO, 3.

assistance. Medicare and Medicaid will not reimburse for basic needs care and guardianship, which is similar to the type of care provided in assisted living facilities: that is described as the following:

> These facilities provide help with activities of daily living. Some help with care most people can do themselves (like taking medicine, using eye drops, getting to appointments, or preparing meals). Residents often live in their own room or apartment within a building or group of buildings and have some or all of their meals together. Social and recreational activities are usually provided. Some of these facilities have health services on site. Not all assisted living facilities provide the same services. In most cases, assisted living residents pay a regular monthly rent, and then pay additional fees for the services they get.[100]

As the resident transitions into a LTC facility, limited reimbursement by Medicare or Medicaid is provided for skilled nursing care. "Medicare Part A (Hospital Insurance) may cover care given in a certified skilled nursing facility (SNF) if it's medically necessary for you to have skilled nursing care (like changing sterile dressings). However, most nursing home care is custodial care, like help with bathing or dressing. Medicare doesn't cover custodial care if that's the only care you need."[101] Once residents are residing in a LTC facility, they are often exposed to an environment that removes much of their autonomy and self-determination. Residents can move to the different levels based upon their needs and are not required to remain in a LTC facility if they are able to resume living independently or in an assisted living facility setting. In 1997 the U.S. Department of Health and Human Services documented the history and current issues surrounding CCRCs which are still applicable today:

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[100] Medicare.Gov The Official U.S. Government Site for Medicare, "What are my other long-term care choices?," http://www.medicare.gov/what-medicare-covers/part-a/other-long-term-care-choices.html#collapse-4921; Internet; accessed 21 Mar. 2014.

[101] Medicare.Gov The Official U.S. Government Site for Medicare, "Your Medicare Coverage: Is my Test, item, or service covered?," http://www.medicare.gov/coverage/nursing-home-care.html; Internet; accessed 21 Mar. 2014.

> Few studies have been done on exactly what type of people CCRCs attract. There do, however, appear to be some basic trends in resident characteristics when the admission criteria of most CCRCs are considered. Because communities assume risk for providing long-term care, they take certain measures to determine the chances that a resident will use more in long-term care than what he or she pays. Admission criteria, which include assessing such characteristics as income, health, age, gender, and marital status are one way in which CCRCs gain a better understanding of how likely it will be that a resident will need extremely expensive medical care over the amount paid.[102]

Based upon the admission criteria, risks of financial loss for projected excessive need of costly LTC facility services may result in the person not being accepted into the CCRC. CCRCs can be nonprofit or for profit status. There is limited oversight of CCRCs which results in minimal consumer protection and increased risks to the vulnerable aged population:

> CCRCs are primarily regulated by states rather than by the federal government. State CCRC regulation developed over time and in some instances grew out of the need to address financial and consumer protection issues, including solvency, which arose in the CCRC industry in the 1970s and 1980s. States generally license CCRC providers, monitor and oversee their financial condition, and have regulatory provisions designed to inform and protect consumers. The U.S. Department of Health and Human Services (HHS) provides oversight of nursing facilities that are commonly part of CCRCs, but this oversight focuses on the quality of care and safety of residents in those facilities that receive payments under the Medicare and Medicaid programs. While states primarily regulate CCRCs, Congress has considered proposals to introduce greater federal oversight. For example, in 1977 Representatives William Cohen and Gladys Spellman introduced a bill that would provide federal oversight of certain continuing care institutions that received Medicare or Medicaid payments or were constructed with federal assistance. The bill proposed, among other things, requiring that CCRC contracts clearly explain all charges and that CCRCs provide full financial

[102] U.S. Department of Health and Human Services, "A Background and Summary of Current Issues," 24 Feb. 1997, http://aspe.hhs.gov/daltcp/reports/ccrcrpt.htm; Internet; accessed 21 Mar. 2014.

> disclosures, maintain sufficient financial reserves, and undergo an annual audit. While the bill did not pass, one industry sources noted that several states at the time were developing or refining their own CCRC regulation.[103]

The *New York Times* article "C.C.R.C Residents Ask, 'Where's the Money?'" exemplifies the lack of financial regulation and oversight in several CCRCs which led to a class action lawsuit in Federal District Court in Northern California:

> Continuing care retirement communities tend to be costly, but the Vi at Palo Alto is exceptionally expensive: Dr. Cork's one-bedroom cost $674,400 and the Richters' two-bedroom with den, $1.59 million; residents also pay hefty monthly fees. And although 80 percent of such communities are nonprofits, often affiliated with religious groups, the Palo Alto complex and its nine sister developments are part of a corporation that used to be known as Classic Residence by Hyatt; . . . And they agreed to high entrance fees (some such retirement communities use a different model and don't charge them) because by contract, 75 percent to 90 percent of that amount would be refunded after they moved out or died and their apartments were resold . . . ; So the plaintiffs were startled to learn, as a tax appeal led them to scrutinize the balance sheets of 2012, that Vi at Palo Alto had no reserve account earmarked for refunds. They soon also learned that its parent company in Chicago - to which the Palo Alto complex had sent what the plaintiffs say is $190 million - assumed no liability for paying refunds to Palo Alto residents.[104]

Many different LTC nursing home models are surfacing today. Americans are searching for the best LTC, but every model has its flaws. The new models of care commonly advertise that they provide the best deinstitutionalized care. There are varying opinions regarding what actually constitutes a physical home like setting and the provision of quality care. The U.S. government recognizes the challenges for LTC residents to receive quality humanistic care and to protect their rights. There is still no

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[103] GAO, 3-4.

[104] Paula Span, "C.C.R.C Residents Ask,'Where's the Money?,'" *The New York Times*, 20 Mar. 2014.

solution to solve the many issues related to the increasing LTC needs of an aging America. Continual government revisions to healthcare regulations have not been effective in achieving quality humanistic care in LTC facilities. There is an increasing governmental focus upon LTC facilities to provide care according to the requirements for reimbursement. Residents' humanistic needs are often not addressed since the LTC facilities nursing staff has many tasks to achieve during their shift. Healthcare professionals have little time to address basic humanistic needs that will increase the residents' perception of quality care.

LTC settings vary in home like accommodations; quality care should not. Residents of LTC facilities have the right to receive high quality humanistic care. LTC facility nursing healthcare professionals need to recognize the importance of developing interpersonal relationships with the residents that can fulfill the residents' basic humanistic needs and contribute to quality care. Humanistic Patient Narrative Theory in-services can be utilized as an effective means for training LTC healthcare professionals about a humanistic care approach. John D. Engel, et al. clearly suggest the need for narrative theory in the deliverance of healthcare: "Since it is never possible to fully know the lived experience of another, the ability to operate in another's narrative, both in action and in consciousness, requires the ability to imagine that other world. Such imagining in health care must occur in moral landscape, and must be a moral pursuit."[105] Narrative theory becomes the foundation for the development and implementation of Humanistic Patient Narrative Theory in-services for the LTC facility nursing healthcare professionals, as we shall see in Chapter 2.

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[105] John D. Engel et al., *Narrative in Health Care: Healing Patients, Practitioners, Profession, and Community* (New York: Radcliffe Publishing, 2008), 108.

CHAPTER 2

NARRATIVE THEORY AND AGING

Communication between human beings requires at least two people: a sender and a receiver. For example, a person telling a narrative to another is the sender and the person engaged in listening to the narrative is the receiver. Communication between two people also consists of objective data, such as body language and facial expression. Objective data that is congruent with a story teller's verbal statements, known as subjective data, provides validity about the narrative. Kate de Medeiros, Ph.D., Assistant Professor, Department of Sociology & Gerontology at Miami University, describes narrative: "Narrative at its most basic level is a telling of some aspect of self through ordered symbols."[106] Since the beginning of time, communication has been comprised of telling narrative to other human beings. The Proceedings of the National Academy of Sciences of the United States of America 2014 article titled, "A Rock Engraving Made by Neanderthals in Gibraltar," cites evidence about the use of narratives since the beginning of the human evolution:

> The production of purposely made painted or engraved designs on cave walls—a means of recording and transmitting symbolic codes in a durable manner—is recognized as a major cognitive step in human evolution. Considered exclusive to modern humans, this behavior has been used to argue in favor of significant cognitive differences between our direct ancestors and contemporary archaic hominins, including the Neanderthals. Here we present the first known example of an abstract pattern engraved by Neanderthals, from Gorham's Cave in Gibraltar. It consists of a deeply impressed cross-hatching carved into the bedrock of the cave that has remained covered by an undisturbed archaeological level containing Mousterian artifacts made by Neanderthals and is older than 39 cal kyr BP. Geochemical analysis of the epigenetic coating over the engravings and experimental replication show that the engraving was made before accumulation of the archaeological layers, and that most of the lines

[106] Kate De Medeiros, *Narrative Gerontology in Research and Practice* (New York: Springer Publishing Company, 2014), 2.

> composing the design were made by repeatedly and carefully passing a pointed lithic tool into the grooves, excluding the possibility of an unintentional or utilitarian origin (e.g., food or fur processing). This discovery demonstrates the capacity of the Neanderthals for abstract thought and expression through the use of geometric forms.[107]

One can only imagine the interpretation of the Neanderthal engravings on the cave walls. What has become evident over the centuries is that stories have been told by different people of many cultures about life events, family members, enemy combat, illness and death.[108] These narratives have laid the ground work for research across many disciplines ranging from but not limited to archeology, sociology, psychology, architecture, religion, anthropology and medicine.[109] From the beginning of time Clay tablets, Egyptian papyrus scrolls, Chinese bamboo books, European Pergamum and parchment inscriptions have been discovered by historians and they communicate many messages.[110] Adams and Holland describe the evolution of pharmacology, alternative therapy, and variations in cultures through the narrative transcriptions that also demonstrates the necessity of using narrative in medicine research and development throughout the ages:

> One of the oldest forms of healthcare, herbal medicine has been practiced in virtually every culture dating to antiquity. The Babylonians recorded the earliest surviving "prescriptions" on clay tablets in 3000 B.C. At about the same time, the Chinese recorded the Pen Tao (Great Herbal), a 40-volume compendium of plant remedies dating to 2700 B.C. The

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[107] Joaquin Rodríguez-Vidal, et al., "A Rock Engraving Made by Neanderthals in Gibraltar," *Proceedings of the National Academy of Sciences* 111, no. 37 (2014): 13301-13306, http://www.pnas.org/lookup/suppl/doi:10.1073/pnas.1411529111/-/DCSupplemental; Internet; accessed 27 Sept. 2014.

[108] Bamber Gascoigne, "HistoryWorld," (2001 ongoing), http://www.historyworld.net/wrldhis/plaintexthistories.asp?historyid=aa92; Internet; accessed 27 Sept. 2014.

[109] Gascoigne.

[110] Gascoigne.

> Egyptians followed in 1500 B.C. by archiving their remedies on a document known as *Eber's Papyrus*. Little is known about pharmacology during the Dark Ages. Although it is likely that herbal medicine continued to be practiced, few historical events related to this topic were recorded. Pharmacology, and indeed medicine, could not advance until the discipline of science was eventually viewed as legitimate by the religious doctrines of the era.[111]

From the moment we are born into civilization, every human being is immersed into a life of listening to and communicating with other human beings by storytelling. Healthcare professionals (physicians, nurses, respiratory therapists, nursing assistants etc.) gather objective and subjective data from patients as a method of determining how to diagnose and provide the best care to achieve patient wellness. The terms "patient story" and "narrative" are often used interchangeably. Merriam-Webster defines story as, "An account of incidents or events; a statement regarding the facts pertinent to a situation in question."[112] In contrast, the definition of narrative is stated as, "A story that is told or written; having the form of a story."[113] Healthcare professionals obtain information from the patients during their narrative that describes the incident or event that the person is seeking care for. The facts obtained during the process of obtaining the narrative are incorporated into the healthcare professionals' plan of care for the patient.

Katherine Montgomery Hunter, Professor of Medical Humanities and Bioethics, Northwestern University, identifies that healthcare professionals interpret and practice medicine based upon the professionals medical training in biology, narrative descriptions

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[111] Michael Patrick Adams, Leland Norman Holland and Carol Q. Urban, *Pharmacology for Nurses; A Pathophysiological Approach*, 3rd ed. (Upper Saddle River: Pearson, 2011), 3.

[112] Merriam-Webster An Encyclopedia Britannica Company, *Dictionary*, 2014, www.merriam-webster.com/dictionary/story; Internet; accessed 11 Nov. 2014.

[113] Merriam-Webster An Encyclopedia Britannica Company.

on single cases, interpretation of observations (objective data) and diagnostic testing.[114] Montgomery Hunter states, "Medicine is fundamentally narrative-especially the scientific medicine practiced in a tertiary-care teaching hospital-and its daily practice is filled with stories."[115] It is not just the patient's narrative that develops during communication with the healthcare employee; "Oddly enough in this scientific endeavor, the physician's own discourse about illness takes the form of a narrative. The space between the patient's first words to the physician and the physician's closing recommendation to the patient is filled with medicine's narratives."[116]

Healthcare professionals focus on the individual patient's statements of what occurred to bring about illness and the healthcare professionals then orders diagnostic tests to determine a diagnosis. Typically physicians and other healthcare professionals often focus too much upon the diagnostic objective data, such as blood tests, electrocardiograms, x-rays and other medical tests, versus on the patient narrative and the incorporation of the narrative into the plan of care. Increased longevity, higher patient acuity level of illness, decreased staffing with greater patient to healthcare professional ratios results in less time for the healthcare professionals to spend listening to a patient's narrative. Healthcare professionals that do not have the time to listen to a patient's narrative results in less personalized care and a greater number of healthcare professional prescriber orders for diagnostic tests to dictate care. Montgomery Hunter describes the goal of medicine and the innate need of people to have their narrative stories heard in

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[114] Katherine Montgomery Hunter, *Doctors' Stories: The Narrative Structure of Medical Knowledge.* (Princeton: Princeton University Press, 1991), xvii.

[115] Montgomery Hunter, 5.

[116] Montgomery Hunter, 5.

order to receive care based upon the patient experience versus only evidence based scientific medicine care:

> Medicine's goal is to alleviate present suffering. Although it draws on the principles of the biological sciences and owes much of its success to their application, medicine is (as it always has been) a practical body of knowledge brought to bear on the understanding and treatment of particular cases. We seek more from a visit to the doctor than the classification of our malady. We want our condition to be understood and treated. Face to face with a patient, physicians can know disease only indirectly. They depend for its identification on their interpretation of the signs they observe and the story of symptoms the patient tells them.[117]

Montgomery Hunter emphasizes, "Yet medicine's focus on the individual patient, fitting general principles to the particular case, means that the knowledge possessed by clinicians is narratively constructed and transmitted. How else can the patient be known?"[118] Healthcare professionals pre-licensure education includes the how to care for the patient's physical, emotional, spiritual, and mental needs. Most often, healthcare professionals attend to the person's physical needs since the needs are based upon biology, science, evidence based research, and diagnostic studies which lead to a prescribed plan of streamlined care. Physical needs can also be visually seen by the healthcare professionals and it does not require a great amount of time to identify the problem. Emotional, spiritual and mental needs take longer to determine a plan of care that will be effective at alleviating or curing the symptoms since the provider and patient need to engage in narrative conversation about the symptoms. Donald E. Polkinghorne, Emeritus Professor and Chair of Counseling Psychology, at the Rossier School of

[117] Montgomery Hunter, xiii.

[118] Montgomery Hunter, xvii.

Education, at the University of Southern Carolina, describes the concept of self in relation to narrative:

> We humans find the contents of our experience significant and understandable. We do not encounter a buzzing confusion of indistinct and unstructured perceptual elements, but a world that appears as meaningful. Our experience is a construction that results from the interaction of cognitive organizing processes with cues emanating from our external perceptual senses, internal bodily sensations, and cognitive memories. The processes of consciousness interpret and give meaning to cues by identifying them as elements or parts of a structure. For example, an object in the room is experienced as a chair, not as discrete pieces of wood and metal. Similarly, a child can be experienced as a student, a ball player, or someone with a scratched knee, depending on the interpretative frame used to give meaning to the experience. We know what we mean when we speak of sensations and memories. But what are the cognitive organizing processes? One of them, as I argue in this article, is narrative. Narrative is the cognitive process that gives meaning to temporal events by identifying them as parts of a plot.[119]

The healthcare professional needs to be physically and mentally engaged with the patient during the illness journey and self description of events leading to it. Nurses and nursing assistants in LTC settings frequently have many physician orders prescribed such as medications on time specific administration schedules, physical therapy, occupational therapy, wound care, feeding schedules, and recreational activities. Each physician order requires time for the nurse or nursing assistants to complete the tasks required for physical well-being. The more involved the task, the greater the amount of time the healthcare professional must dedicate to complete it. LTC healthcare professionals often have a large patient to nurse and nursing assistant ratio.

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[119] Donald E. Polkinghorne, "Narative and Self-Concept," *Journal of Narrative and Life History*, 1, no. 2&3 (1991): 135-136, http://www.pasadena.edu/library/reserves/tfkeeler/engl1c/polkinghornenarrativeselfconcept.pdf; Internet; accessed 30 Nov. 2014.

A ratio of one nurse assigned to a hallway (wing) of residents' rooms with one or two nursing assistants is not uncommon. An example of a LTC facility nurse's eight-hour shift assignment would be the assignment to one LTC wing comprised of single occupancy resident rooms totaling approximately twenty LTC residents. The number of residents assigned to the nurse and nursing assistant varies greatly upon the staffing levels for each work shift. Administrators reduce the LTC facility operating costs by assigning evening and night shift nurses and nursing assistants a larger patient to nurse and nursing assistant ratio than the day shifts.

Residents are usually active throughout the day going to activities (art, bingo, religious services) or therapies (occupational, recreational or physical therapy) both on and off the nursing unit. Nurses and nursing assistants have limited time to engage in conversation since they are trying to complete the physician orders for each resident and also ensure that each resident is attending required activities. During the evening, resident activities quiet down and the residents get assistance with bathing and bedtime routines. Low staff levels and a large number of task oriented physician orders for each resident ultimately results in less available time for the healthcare professionals to engage in the residents' narrative stories.

If the healthcare professionals and patient do not have a narrative conversation about the physical ailment and the patient's subjective experience with the illness, the patient might not receive complete medical care for all of the needed care. Lack of attention to all of the patient's needs could contribute to worsening of the condition versus healing.

In my past experience, residents often state that they do not want to bother the healthcare professional because they have too much to do on their assigned shift. Also frequently heard by residents is the statement, "The nurses come in long enough to give me a pill and then they leave." This is a chilling statement when one considers that the LTC facility is frequently the residents' last home before they die. I often think how horrible it must be if a LTC resident perceives that a small discussion or request is an added burden for the LTC healthcare professionals. If there is limited narrative shared between the resident and the healthcare professionals, the care is focused upon the prescriber orders versus on the unfolding resident narrative of illness and health.

Rita Charon, MD, general internist in primary care practice at Presbyterian Hospital, Professor of Clinical Medicine and Director of the Program in Narrative Medicine at the Columbia University College of Physicians and Surgeons, author of the article "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," defines Narrative Medicine as:

> The effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others. Medicine practiced with narrative competence, called *narrative medicine*, is proposed as a model for humane and effective medical practice. Adopting methods such as close reading of literature and reflective writing allows narrative medicine to examine and illuminate 4 of medicine's central narrative situations: physician and patient, physician and self, physician and colleagues, and physicians and society. With narrative competence, physicians can reach and join their patients in illness, recognize their own personal journeys through medicine, acknowledge kinship with and duties toward other healthcare professionals, and inaugurate consequential discourse with the public about healthcare. By bridging the divides that separate physicians from patients, themselves, colleagues, and society, narrative medicine offers

> fresh opportunities for respectful, empathic, and nourishing medical care.[120]

Physicians in LTC facilities develop an inter-professional healthcare professional to patient relationship at the time of resident admission. A general admission and history background with a physical assessment begins the process of LTC facility residency. Admission protocols include an inter-professional assessment from departments such as social services to determine relationship and personal needs, activities department for preferred interests and activities, and physical therapy for mobility and safety assessment. Physician orders are then written for the nurses, nursing assistants and inter-professionals to complete. Routine physician visits are frequently completed on a monthly or greater basis in most LTC facilities. Charon's description of reaching and joining the patient in illness by the central narrative situations in relation to the need for the physician and patient also the physician and self can be quite challenging to develop in a LTC facility when there is limited contact with the patient to listen to the ongoing LTC patient narrative.[121]

Interdisciplinary care plan meetings are held with the LTC healthcare professionals who are involved in the residents' care. The physician may or not be present at these meetings. Residents or the family members are invited to attend for the provision of information about the resident care preferences or status changes. Rita Charon's model for a humane narrative medicine approach should be incorporated into practice by all physicians and healthcare professionals. Reality seems to indicate that the

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[120] Rita Charon, "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust," *JAMA* 286, no. 15 (2001): 1897-1902, http://jama.jamanetwork.com/article.aspx?articleid=194300; accessed 27 Sept. 2014.

[121] Charon, 1897-1902.

healthcare system does not support this model. Insurance reimbursement for medical services results in a greater monetary amount for the total number of patients seen for office or hospital visits and diagnostic tests versus the quality of care. The same is true in LTC facilities. All healthcare professionals need to spend time listening to the residents' stories in LTC facilities. Healthcare professionals and resident one to one relationships must continually be built upon in a LTC facility in order for all healthcare professionals to reach and join the patient in illness. Charon's narrative model should be utilized by all of the inter-professionals that care for LTC residents.[122]

Charon emphasizes the healthcare professional competency in order for the healthcare professional to be effective at obtaining information and developing care focused on the individual's needs. Polkinghorne correlates everyday life events that are discussed in narrative storytelling, to being evolved from meaningful experiences that are produced by relating their elements as parts of a conceptual pattern:

> Elements are configured into two primary relations: spatial and temporal. Spatial organization (e.g., of a kitchen or a laboratory) consists of topological relations, such as up, down, left, right, next to, inside, and so forth. Temporal organizations (e.g., a trip to the market) consists of causal and enabling relations . . . I propose that temporality is the primary dimension of human existence and that our actions and life events are made understandable through the cognitive process of narrative.[123]

Each individual in this world has different life events that occur during our existence on earth. Interpretation and reaction to life events is very personal and unique to each human being. Based upon personal experience working in the evolving healthcare system,

[122] Charon, 1897-1902.

[123] Polkinghorne, 139.

culture, spirituality, personal preferences, family influence, societal, and socioeconomic factors often play a large part in a person's decisions and actions towards life events. These factors also must be considered in the care of a LTC resident. The only way to understand and include meaningful self experience of the resident in the delivery of individualized care is to incorporate narrative on a daily basis. Life does not end for a resident because he or she is residing in a LTC facility.

It is also important to be cognizant of and include time as one of the most fundamental and pervasive phenomenal of our lives.[124] Polkinghorne states:

> Human temporal experience consists of drawing out from the continual flow of successive moments episodic patterns by marking off beginning and ending points. Linking events into a unified episode lifts them from their temporal surroundings and yields a whole that is internally articulated into its contributing parts. This configuration creates a temporal part-whole relation through which events are grasped as temporal Gestalten. Temporal configuration not only includes the present and past but extends potentially into the future. The anticipated part of the configuration may not, in fact, occur. If the anticipation is not fulfilled, the actual happening brings about a reconfiguration of the past parts of the event into a differently experienced configuration.[125]

Past life experiences have a direct impact upon the future life experiences. For example, a ninety year old person might have been living a very active life independently in his or her residence prior to falling and fracturing a hip. The hip fracture changed the future course of life by changing the person's active life style to one of requiring hip surgery, immobility and recovery. Once hip surgery is completed, the next future life experience would be rehabilitation. Depending upon the rehabilitation results, it could affect the person's ability to live independently and actively at home or may require continued

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[124] Polkinghorne, 139.

[125] Polkinghorne, 140.

assistance in a LTC facility. Looking at the big picture, the hip fracture incident changed the course of future events for the person but the past events remained the same and would not change in the future.

Residents residing in LTC facilities have a past life that includes many of the events that Polkingthorne refers to as daily experiences. Time spans throughout a person's life result in different life events and daily activities that shape future events and personal outlook on life. For example, young adults are focused upon careers and actively seek education or career path. Within these years families are formed with possible child rearing responsibilities and care for elders as they begin to need care. LTC residents have a rich past of timed life events which unfolded in relation to each other to the point of requiring medical care and residence in a LTC facility. Every event in residents' lives had meaning for individuals and was part of a bigger narrative about their lives.

Polkingthorne identifies how the temporal elements of one's life develop into an individual's personal narrative:

> Emplotment is a procedure that configures temporal elements into a whole by "grasping them together" and directing them toward a conclusion or ending. Emplotment transforms a list or sequence of disconnected events into a unified story with a point or theme. Through the operation of emplotment, particular actions take on meaning as a contribution to the unfolding plot of the story. Without the recognition of significance conferred by being taken up into a plot, each event would appear as discontinuous, and its meaning would be limited to its categorical identification or its spatiotemporal location. Emplotment is the means by which narrators weave together the complex of events into a single story. Through its operation, the historical and social contexts in which events take place exert influence in the understanding of the story. The synthesizing function of the plot provides narrators and storytellers a means to draw together information about physical laws, personal

> dispositions and character, responses to actions, and the processes of deliberation in reaching decisions.[126]

Residents' past life events must be identified in an engaged, empathetic, interactive approach between the healthcare professional and resident. Healthcare professionals need to listen and understand the residents' life events that led to the reason for seeking care in order to understand the plot that will become interactive roles between the healthcare professional and resident. It is essential that the healthcare professional understands the residents' personal meaning and interpretation of the life events as it pertains to their whole life narrative. Within the life narrative, episodes of practical activity are integrated with moral and ethical motives.[127] The narrative that serves to configure a person's life into a self and to provide personal identity is the self-narrative.[128]

A resident's self-awareness is also necessary for a successful healthcare professional to resident relationship. Resident self awareness increases the honesty of the resident during the narration of his or her narrative. David G. Myers refers to previous studies regarding self; "Underlying this research is an assumption that the self, as organizer of our thoughts, feelings, and actions is the center of personality."[129] Myers clearly describes the selves that people may envision themselves as becoming:

> Your possible selves include your visions of the self you dream of becoming-the rich self, the successful self, the loved and admired self. They also include the self you fear becoming- the unemployed self, the lonely self, the academically failed self. Such possible selves motivate us

[126] Polkinghorne, 141.

[127] Polkinghorne, 143.

[128] Polkinghorne, 145.

[129] David G. Myers, *Exploring Psychology* (Michigan: Worth Publishers, 2011), 446.

> by laying out specific goals and calling forth the energy to work toward them.[130]

Healthcare professionals must take into consideration when listening to a LTC resident's narrative that the aging process might not be the most pleasant experience for the resident. The American Psychological Association describes the aging process from a different perspective:

> Unfortunately, the aging process is not always so idyllic. Late-life events such as chronic and debilitating medical disorders, loss of friends and loved ones and the inability to take part in once-cherished activities can take a heavy toll on an aging person's emotional well-being. An older adult may also sense a loss of control over his or her life due to failing eyesight, hearing loss and other physical changes, as well as external pressures such as limited financial resources. These and other issues often give rise to negative emotions such as sadness, anxiety, loneliness and lowered self-esteem, which in turn lead to social withdrawal and apathy.[131]

Negative life experiences may coincide with the residents' narration of their lives, care preferences, and participation in self care at the LTC facility. Healthcare professionals take into account that life experiences of the aged population impact the LTC residents' life narratives, decisions and participation in their care. The American Psychological Association emphasizes that older adults may have fragile self esteem based upon their life experience and states: "An older person with fragile self-esteem may interpret well-intentioned encouragement as further proof of his or her declining condition. Others may resent any attempts at intervention."[132] Based upon experience, healthcare professionals all too often imply their own values and care models on the

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[130] Myers, 446.

[131] American Psychological Association, "Aging and Depression," 2014, www.apa.org/helpcenter/aging-depression.aspx; Internet; accessed 22 Dec. 2014.

[132] American Psychological Association.

elderly residing in LTC facilities and do not take into account the effect of the past resident life experiences. The LTC residents need to be understood for whom they are and the provision of healthcare needs to be collaboratively developed based upon the residents' preferences and previous life experiences. Patient centered realistic and measurable goals should be mutually decided upon between the LTC resident and healthcare professionals, and they need to be based upon the residents' narration.

The healthcare professionals' self knowledge about their personal morals and ethics in the delivery of care is required in order for the healthcare professionals to develop plans of care based upon the residents' needs and not on paternalistic care. Margaret A. Burkhardt and Alvita K. Nathaniel describe the effect of self knowledge upon relationships:

> Ethical relationships with others begin with the self- knowledge and the willingness to express that awareness to others honestly and appropriately. Self knowledge is an ongoing, evolving process that requires us to make a commitment to know the truth about ourselves. This is not an easy commitment to make. Although the truth can be painful at times, paradoxically, it can also set us free.[133]

Each resident has a unique personality, past life experience, and personal values to take into account when listening to a resident's narrative. The healthcare professional needs to be open to the resident's values and to incorporate them into the LTC facility plan of care. Residents' personal preferences of care and their decision making process is partially determined by their own personal values. Healthcare professionals must also identify their own personal values that could interfere with providing resident focused care. Inclusion of healthcare professionals' personal values into a LTC resident's plan of

[133] Margaret A. Burkhardt and Alvita K. Nathaniel, *Ethics & Issues In Contemporary Nursing*, 2nd ed. (New York: Delmar Thomson Learning, 2002), 68-69.

care would be interpreted as a paternalistic physician provider model of care. Healthcare professionals and residents needs to identify their personal values and how they relate to LTC facility residents' plan of care.

Conflict of personal values may be recognized during the physician and LTC resident interaction of storytelling regarding the patient experience and expectations. If the healthcare professional has conflicting values it must not have an effect upon the LTC resident values or provision of care. Burkhardt and Nathaniel emphasize that "No one set of values is appropriate for everyone; we must appreciate that values clarification may lead to different insights for different people."[134] The need for healthcare professionals to understand their personal self values clearly correlates to the facilitation of an effective healthcare professional and LTC resident storytelling experience and outcome:

> To know and appreciate our own value system provides a basis for understanding how and why we react and respond in decision making situations. Knowing our own values enables us to acknowledge similarities and differences in values when interacting with others, which ultimately promotes more effective communication and care. Commitment to developing more awareness of personal values enables us to be more effective in facilitating the process with others. In the professional realm, these others may be staff, patients, families or institutions. When personal values are at odds with those of patients, colleagues, or the institution, internal or interpersonal conflict may result. This can subsequently affect patient care.[135]

Identification of a healthcare professional's personal values that differ from those of LTC residents can affect the provision of humanistic care to the LTC resident. Healthcare professional's prioritization of work related duties such as administration of medications,

[134] Burkhardt and Nathaniel, 69.

[135] Burkhardt and Nathaniel, 70-71.

dressing changes, and documentation versus essential humanistic care needs may affect the resident's experience of receiving quality care.

Narrative Theory Experiential Learning

Affective domain experiential learning activities are an excellent method to utilize as a means for the nurses and nurse assistants to gain insight into a resident's perception of the care received in the LTC facility. For research purposes, a patient narrative was written in first person depicting the sequence of events in an emergency health crisis of a Cerebral Vascular Accident (Stroke) patient. It was developed as an educational experiential learning experience to determine the effects of Humanistic Patient Narrative Theory in-services on LTC facility healthcare professionals training on the provision of care to LTC residents. The first person narrative was based upon my personal reflection of care administered to many patients that had suffered from a stroke and their families over the years. Reflection formed many questions such as: how the affected person might have felt not being able to communicate, what thoughts the person experienced throughout the hospitalization, rehabilitation process, possible losses and grieving process when moving to a LTC facility, change in family relationships and most importantly about whether the person received humanistic care.

The narration depicted the stroke patient as not being able to speak and the effect of being trapped in the body which prevented being able to speak. The patient was depicted as reciting her thoughts in her mind as she actually experienced the health crisis and provision of care in a hospital and LTC facility. The audience consisting of LTC facility healthcare professionals was instructed to envision the patient receiving poor care by listening to the narrative description of events. An example of poor care was

described to the audience during a narration about how the patient during transport by stretcher from her home to the ambulance was nearly dropped during the experience. The narrator effectively depicted the fear that would go through the person's mind as he or she is experiencing almost being dropped.

After developing the first person narration, it was recorded with my voice changed to reflect an elderly person's voice. Altering of the voice allowed for the narrative not to be associated with the researcher during the provision of Humanistic Patient Narrative Theory in-services. Prior to the nurses and nursing assistants listening to the patient narrative, a power point about the history of narrative theory was shown to the healthcare professionals. At the conclusion of the narrative theory power point, each nurse and nursing assistant was asked to write something on a provided index card that they would never want to give up during their life. They were then instructed to tear up the index card. Tearing up the card represented their personal loss of what they would not want to give up in life. The concept of personal loss was correlated and discussed in relation to the losses that LTC residents may experience when they leave their family, belongings, and memories behind to move into a LTC facility. The main discussion emphasized that every LTC resident has a narrative before arriving at the LTC facility and during his or her life at the LTC facility.

Healthcare professionals were instructed about the importance of including the LTC resident's personal requests into the plan of care as a means of preventing paternalism. After the training, discussion regarding how the provision of care could have been implemented differently for the patient described in the patient narrative recording to have received better humanistic, quality, ethical, and dignified care. This

was an extremely effective method of training. Many of the nurses and nursing assistants cried either during the narration or afterwards when they realized the effect of tearing up the index card had upon them personally. Nurses and nursing assistants were reminded that they actually still had what was written on the index card and to compare this experience to the residents who may have left so much behind when entering to reside in a LTC facility. Nurses and nursing assistants stated frequently that they wished they had more time to spend listening to the residents' narrative. The healthcare professionals described feelings guilt regarding when they would need to leave a LTC resident to give medications to other LTC residents. Healthcare professionals explained that they frequently observe LTC residents wanting to continue talking because they are lonely. The nurses and nursing assistants stated that they would like further training with this teaching approach.

Medical Humanities based Narrative Theory and Ethical Principles are important components of effective healthcare professionals' relationships with LTC residents for the provision of humanistic quality care, as we will see in Chapter 3, which examines the principles of medical ethics and how they are intertwined into the provision of Humanistic Narrative Theory based care.

CHAPTER 3

PRINCIPLES OF MEDICAL ETHICS AND HUMANISTIC NARRATIVE THEORY BASED CARE

Physician Patient Relationship

An important component of my research was developing relationships and establishing trust with the LTC residents, nurses and nursing assistants. At the beginning of my research, a majority of the LTC facility residents were hesitant to participate in the research. None of the LTC residents had met me prior to the meeting requesting their participation in completing surveys. The nurses and nursing assistants were also hesitant at first. Their main concern was about the residents' well-being. They had heavy work assignments and their agreement to participate in the research meant that they would need to dedicate time during their shift to participate in the education training. Nurse unit managers interviewed me prior to beginning the research to ensure the protection of the residents' rights.

The LTC residents and healthcare professionals' hesitancy gradually faded away as my face became familiar to them all. Relationships were built with the healthcare professionals during the Humanistic Patient Narrative Theory in-services. As time progressed residents recognized me when I entered the LTC facilities and they were often very eager to confirm their completion of the surveys. The visits to the majority of LTC residents seemed to grow in time with each administration or collection of surveys. During the visits, many of the residents verbalized their narrative about life prior to and during their residing at the LTC facility.

Edmund Pellegrino's concepts for an effective healthcare professional and LTC resident relationship are very relevant and necessary to be incorporated into our current healthcare delivery system. In this chapter, Pellegrino's concepts are interwoven into the Humanistic Narrative Theory care approach. The LTC residents' benefits from the provision of Narrative Theory based care, and ethical principles augments and correlates to the research discussed in Chapter 3.

Based upon the writings of the founder of the field of bioethics Dr. Edmund D. Pellegrino, Professor of Emeritus of Medicine and Medical Ethics at Georgetown University, and David C. Thomasma, a Director of the Medical Humanities Program at Loyola University of Chicago, all healthcare professionals are obligated to practice by ethical principles and concepts to have an effective relationship with patients. Healthcare professionals should respond to and provide care with the intent of assisting the patient in achieving the best outcome possible. Relationships between patients and healthcare professionals must be based upon an open and honest exchange of information. There must be mutual respect and trust between the person seeking care and the healthcare professional that is treating them. Patients must trust and openly confide personal information that is accurate in order for healthcare professionals to understand and determine the best treatment plan for the patient. Greater patient compliance to a healthcare professional's advice or medical treatments occurs when the patient trusts the healthcare professional's good intent and virtues based decisions. Mutual respect for each other's moral values and autonomy is very important. Patients must respect

healthcare professionals as human beings with their own virtues and decision making autonomy.[136]

Pellegrino and Thomasma identify the virtues of a good physician that promotes an effective patient to healthcare professional relationship and well intended outcome: "Honesty, justice, benevolence, humility, and courage are virtues of the good physician, as they are of the good patient, since these virtues dispose both parties to act well in relation to the ends of medicine."[137] The virtues and concepts are necessary for inclusion in every healthcare professional's provision of care to LTC residents. The inclusion of virtues enhances care that is driven by beneficence. Once the LTC resident develops a trusting and honest relationship with the healthcare professional, the LTC resident will begin his or her narrative and healing can begin.

Edmund D. Pellegrino and David Thomasma described that virtuous people or good people do not necessarily make decisions that are moral. They argue that, "A complete moral theory must, at minimum, tie some conceptual knots between duty, principles, and virtue."[138] Pellegrino and Thomasma emphasize that people voluntarily enter into the field of medicine to practice caring for others. Healthcare professionals are guided by principals for the provision of care and virtues that intertwines in the provision of care by directing moral choices to do good and no evil. Moral acts do not necessarily always have to be good. The correlation of the moral action to the provision of care or

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[136] Edmund D. Pellegrino and David C. Thomasma, *The Virtues in Medical Practice* (New York: Oxford University Press 1993), 194.

[137] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 194.

[138] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 21.

person's autonomous chosen preference and purpose on life determines the type of moral action. Healthcare professionals' provision of care is to be virtuous with the intent of respecting other people.[139] The principles of medical ethics as it relates to the provision of care is described by Pellegrino and Thomasma as, "Statements of the right and good that derive from the ends and purposes of medical activity-healing, helping, and caring in a special kind of human relationship."[140]

Healthcare professionals need to have the attributes of honesty and good character. Their actions are to be based upon morals with the intent to perform good versus evil or wrong acts. Every state has a Nurse Practice Act that guides the responsibilities for the provision of care to people. Each Practice Act has an overriding rule and refers to the use of prudence as being necessary for decision making and the provision of care. The healthcare professionals are required to practice prudently, or as others would act in a similar situation, in order to avoid harm to the patient. If healthcare professionals harm a patient by their actions, it could result in litigation. The action that caused the negative outcome to a person's life would be compared to other healthcare professionals' customary prudent actions to determine if the healthcare professional acted outside of his or her scope of practice. Practicing outside the scope of practice or not being prudent in the provision of care could lead to harm of a person and possibly the revocation of a healthcare professional's licensure. Pellegrino's emphasis upon the healthcare professionals providing care to those in need being based upon virtues,

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[139] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 21-22.

[140] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 21.

principles, and duties continues to be a relevant requirement by which all healthcare professionals should practice by.

Dignity and Ethics

Edmund D. Pellegrino provided clarity and gave meaning to how dignity relates to everyday life: "Dignity is the product of intra-and inter-subjectivity."[141] Pellegrino believes that all human beings have "intrinsic dignity" that is the basis for "moral entitlements."[142] Every human being is entitled to be treated by others with respect for "one's person, one's rights, and one's equal treatment under the law in a just political order."[143] "Extrinsic or imputed dignity" is externally measured by others based upon others' perceptions or observations of the person's behavior, appearance, social status, etc.[144] Pellegrino describes how perceptions that people may have about a person can result in "imputed dignity."[145] "Imputed dignity can be gained or lost simply by one's own self-judgment or by the judgment of others."[146]

People go about their lives and do not usually think about their own dignity unless another person within society states negativity about them. Personal life experiences can lead to experiences that may also result in reflection about their own dignity. An

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[141] Edmund D. Pellegrino, "The Lived Experience of Human Dignity," in *Human Dignity and Bioethics*, ed. Edmund D. Pellegrino, Adam Schulman, and Thomas W. Merrill (Indiana: University of Notre Dame Press, 2009), 516.

[142] Pellegrino, "The Lived Experience of Human Dignity," 517.

[143] Pellegrino, "The Lived Experience of Human Dignity," 517.

[144] Pellegrino, "The Lived Experience of Human Dignity," 517.

[145] Pellegrino, "The Lived Experience of Human Dignity," 517.

[146] Pellegrino, "The Lived Experience of Human Dignity," 517.

example of this in a LTC setting is when a healthcare professional is bathing a LTC resident with the door ajar. People walking by in the hallway can see the person being washed and exposed. The LTC resident could be thinking about how others are judging him as they walk by and see him in the room disrobed and in a state of dependence on others for care. Loss of "imputed dignity" could occur due to the LTC residents' personal experience and subjective thoughts about being dependent on the healthcare professionals for care.[147] Intrinsic dignity would be lost if the person begins to doubt their own worth as a human being due to their loss of independence and inability to care for themselves. Loss of the person's autonomy during that experience resulted in a loss of dignity. "Autonomy is a cherished right, as is the right to privacy."[148] Pellegrino insists that autonomy "cannot exist apart from our humanity."[149] In other words, "its moral force is rooted in our inherent dignity as humans."[150]

Pellegrino acknowledges that ethical issues surrounding dignity often occur in healthcare.[151] Narrative theory focuses on the person seeking care. All of the interactions with that patient are centrally focused on the person's narrative: "The central relationship is the one between the patient and physician, though nurses and other health professionals also participate to varying degrees."[152] All people are considered

[147] Pellegrino, "The Lived Experience of Human Dignity," 517.

[148] Pellegrino, "The Lived Experience of Human Dignity," 523.

[149] Pellegrino, "The Lived Experience of Human Dignity," 523.

[150] Pellegrino, "The Lived Experience of Human Dignity," 523.

[151] Pellegrino, "The Lived Experience of Human Dignity," 521-522.

[152] Pellegrino, "The Lived Experience of Human Dignity," 522.

vulnerable when they are ill or seek medical help. Open discussions with the healthcare professional about personal information and illness expose the person that is seeking care to be in "need and vulnerable."[153] During the exchange of information, concerns about how he or she is perceived could threaten the person's dignity. Healthcare professionals have a greater amount of knowledge than the person that is seeking care contributing to "inequality" of knowledge in the relationship.[154] The ill person seeks care from the healthcare professional knowing that he or she possesses greater knowledge than themselves about their health concern. Healthcare professionals have a great amount of medical knowledge that could remove the person's dignity if a paternalistic approach is taken.

Self dignity is at risk when a person experiences illness or is suffering. Pellegrino identifies that feelings of "guilt, shame, and humiliation" might be experienced by the ill person resulting in loss of self dignity.[155] Thoughts of being a burden to family members, experiencing invasion of privacy when receiving care from healthcare professionals, and humiliation over requiring assistance during illness can result in a loss of dignity. Loss of worth and dignity occurs when the person seeking care has no control of healthcare decisions such as when a surrogate decides what plan of care is best for them.[156] Physicians are expected to learn and follow the patient's wishes for care to prevent loss of dignity. Pellegrino does explain that the physician does not have to follow

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[153] Pellegrino, "The Lived Experience of Human Dignity," 522.

[154] Pellegrino, "The Lived Experience of Human Dignity," 523.

[155] Pellegrino, "The Lived Experience of Human Dignity," 523-524.

[156] Pellegrino, "The Lived Experience of Human Dignity," 523-525.

patients' wishes if they conflict with the physician's "personal and professional morals and integrity."[157] Illness creates personal disruption of life which can result in a loss of dignity that may be reparable or irreparable. Severity of the illness and impending death changes the way that the ill person perceives others' actions towards them. The ill persons may increasingly feel as though they are a grotesque sight for people to see or that they are a burden to others. Healthcare professionals need to be mindful that the acutely ill person is very perceptive about others' opinions during this time of crisis and actions need to be taken to preserve their inherent dignity at all times.[158] Pellegrino states, "The preservation of human dignity and the prevention of indignity are built into the ends of medicine."[159] Provision of healthcare to a person seeking care must always be centered on maintaining the person's self worth and inherent dignity: "The ends of medicine are focused on the good of the patient as a human person."[160]

LTC residents are at an increased risk for loss of self worth and dignity. Residents of LTC facilities live in an environment with others from society that they never met until residing in the LTC facility. Residents have multiple healthcare professionals to care for them. The LTC residents are exposed on a daily basis to visitors and strangers walking through the residence. In other words, LTC residents are always subjected to the possibility of judgment from society and continual scrutiny from healthcare professionals and other residents. Healthcare professionals need to identify situations that might increase the risk for the LTC resident to experience a loss of dignity and prevent it to the

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[157] Pellegrino, "The Lived Experience of Human Dignity," 525.

[158] Pellegrino, "The Lived Experience of Human Dignity," 526-528.

[159] Pellegrino, "The Lived Experience of Human Dignity," 530.

[160] Pellegrino, "The Lived Experience of Human Dignity," 530.

best of their ability. Incorporation of Narrative theory into the provision of care provides the LTC resident an opportunity to discuss issues and concerns directly related to self worth during the narrative. Narrative Theory could be an effective means to identify and facilitate the development of a plan of care for resident concerns that indicate potential or actual loss of dignity. It is the responsibility of every human being to treat others in society with dignity.

Beneficence and Trust: Patient's Good

Pellegrino and Thomasma emphasize that autonomy and social utility theories compete with each other in medical ethics. It is expected that physicians respect the autonomy and self-determination of the person seeking care. The expectation in social utility is that the physician is expected to act for the greatest benefit of the patient and medical ends. Social utility can supersede the autonomy of the person seeking care if the autonomy does not provide the greatest benefit.[161]

Since the Industrial Revolution, individual rights and autonomy have been gaining strength. Patients in Modern Day medicine have access to transforming technology that assists them in becoming informed participants in the plan of care. Patients do not have all of the answers since their medical knowledge for the most part is limited as compared to a physician's professional knowledge. Challenges arise when a physician does not agree with the patient's self-determined plans for care. If the physician disagrees with the request of the patient, or prescribes a different plan of care, he or she may be considered

[161] Edmund D. Pellegrino and David C. Thomasma, *For the Patient's Good: The Restoration of Beneficence in Health Care* (New York: Oxford University Press), 7.

to be practicing medical paternalism. Pellegrino and Thomasma state, "Paternalism should be understood to mean a medical decision to benefit a patient without full consent of the latter."[162]

If the physician acted in paternalism, further research would be required to determine the extent of paternalism and whether a competent or incompetent person was treated with this approach. "Strong paternalism" is exemplified when the physician provides paternalistic based care to a person who is competent and able to make self-determined decisions.[163] "Weak paternalism" occurs when the physician decides on the approach to care for a patient who is incompetent or physically unable to make decisions for themselves.[164] An example of weak paternalism is when a person has a life threatening injury from a motor vehicle accident and arrives at the emergency department requiring life saving care without any other family or legal guardian to act on his or her behalf. In this example, the physician might decide to act in the best interest of patient using a medical paternalistic approach to preserve the person's life. The different levels of competency could impose different meaning and violations of moral rules for each situation.[165] Disease process, age, and illness can affect the ability of a person to be autonomous. If a person's illness does not affect their competency it would not affect their autonomy.[166]

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[162] Pellegrino and Thomasma, *For the Patient's Good,* 10.

[163] Pellegrino and Thomasma, *For the Patient's Good,* 14.

[164] Pellegrino and Thomasma, *For the Patient's Good,* 14.

[165] Pellegrino and. Thomasma, *For the Patient's Good,* 14.

[166] Pellegrino and Thomasma, *For the Patient's Good*, 16-18.

Pellegrino and Thomasma argue that physicians act with beneficence if they are practicing medical paternalism in the patients' best interest with good intent for the patient versus as an irresponsible or abuse of power.[167] Society is adverse to medical paternalism based on historical knowledge regarding the medical profession, or media exposure to abuse of power, long waiting room times, and the modern day profit driven healthcare industry. "Nonetheless, autonomy should not be viewed as an absolute model for the doctor-patient relationship itself because it is insufficient to claim, as the move to patient autonomy often does, that medical paternalism is a direct outgrowth of professionalization."[168] Medical paternalism has been considered acceptable in cases that meet the following standards: use is limited for certain medical situations, physicians are not always the experts about the best approach for an individual, and overriding of patients' choices does not allow for total healing of the person.[169]

Physicians enter the field of medicine with the intent to practice beneficence and heal their patients.[170] Healing is seen by Pellegrino and Thomasma as a caring approach to provide restoration of balance, inward, and outward healing that allows the person to live life with meaning. Healing is not only based upon physical needs related to disease processes.[171] Pellegrino and Thomasma explain that physicians are required and obligated to use their medical knowledge as a means to help vulnerable and ill human

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[167] Pellegrino and Thomasma, *For the Patient's Good*, 1.

[168] Pellegrino and Thomasma, *For the Patient's Good*, 14.

[169] Pellegrino and Thomasma, *For the Patient's Good*, 24-25.

[170] Pellegrino and Thomasma, *For the Patient's Good*, 15.

[171] Pellegrino and Thomasma, *For the Patient's Good*, 10.

beings is based upon beneficence and not on harming others.[172] "Harm must be avoided because the physician cannot fulfill the promise of helping if he or she intentionally harms the patient for any reason."[173]

Pellegrino and Thomasma describe that physicians are obligated to act beneficently and all acts must be performed to benefit the patient even in acts of autonomy or paternalism. The beneficence model identifies the necessity of including the patient and healthcare team in decision making, practice as a consensus team, and the physicians treat patients individually based on the surrounding medical or moral aspects of the case.[174] Transformation of the healthcare system to modern day medicine has resulted in changes within the healthcare system such as the continually evolving "contractual model" and "fiduciary models" of care.[175] "In other words, the earlier contractual models were developed to fight against the relative power differential between the physician and patient left over from an overly paternalistic interpretation of the relationship."[176] Contracts between the physician and patient were intended to prevent the physician's societal status and inferred power from empowering the physician to provide care based on paternalism.[177] Fiduciary models represent physicians as being trust worthy and based on "the ethic of virtue rather than the ethic of rules."[178]

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[172] Pellegrino and Thomasma, *For the Patient's Good*, 32.

[173] Pellegrino and Thomasma, *For the Patient's Good*, 32.

[174] Pellegrino and Thomasma, *For the Patient's Good*, 32-34.

[175] Pellegrino and Thomasma, *For the Patient's Good*, 51-52.

[176] Pellegrino and Thomasma, *For the Patient's Good*, 52.

[177] Pellegrino and Thomasma, *For the Patient's Good*, 51-52.

[178] Pellegrino and Thomasma, *For the Patient's Good*, 53.

"Ethic of rules alone cannot provide guarantees that the responsible individual, the person with duties, will carry out those rules."[179] Pellegrino and Thomasma emphasize that fiduciary models are based upon an interactive relationship between the physician and patient that is focused upon treating the whole person. The physician must have the qualities to be a person that can be trusted by the patient. Physician-patient relationships are required to be built on trust. As the physician and patient develop a relationship, trust must be established in order for the person who is seeking care to share his or her narrative. Trust must be mutual in the sense that the patient must be honest in the telling of their narrative. Patients begin their relationship with the physician based on trust that they will receive care that is intended to be in their best interest. Relationships that are based upon trust allow for the physician and patient to openly discuss differences in opinion about care and it facilitates the continual reexamination of each of their own values.[180] The physician-patient relationship is considered to be "moral centered."[181] Pellegrino and Thomasma clearly distinguish this type of relationship to "mean the interaction itself, with all of the human joys and sorrows."[182] Clearly, the interactive relationship is not only based upon a contract or negotiation. The physician's professional knowledge and actions must be intended "patient's good."[183]

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[179] Pellegrino and Thomasma, *For the Patient's Good*, 53.

[180] Pellegrino and Thomasma, *For the Patient's Good*, 52-53.

[181] Pellegrino and Thomasma, *For the Patient's Good*, 54.

[182] Pellegrino and Thomasma, *For the Patient's Good*, 54.

[183] Pellegrino and Thomasma, *For the Patient's Good*, 54.

Pellegrino and Thomasma acknowledge that principles, morals, and rights have in the past governed healthcare practice. They emphasize that "beneficence should be the fundamental principle guiding medical care."[184] Beneficence and autonomy need to be combined to "function as a single principle." Pellegrino and Thomasma describe the meaning as "this sort of beneficence, one that encompasses several other ethical principles, beneficence-in-trust."[185] Physicians should "hold in trust" that they will provide care with the intent that it is in the best interest of the patient.[186] The established relationship based on trust also holds the patient to be trusted as following the mutually decided upon plan of care. Mutually decided plans of care supports the necessity of incorporating Narrative Theory into the provision of care. Trusted relationships between the healthcare professional and patient will foster honest communication during the patient narrative. Not only does the physician have an obligation to the patient, there is an obligation to act in the best interest of the community as well. Perhaps most importantly it is necessary for the physician to understand that respect for the patient's wishes is necessary in beneficence. Pellegrino and Thomasma clearly emphasize that beneficence is not the same as and does not support paternalism.[187]

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[184] Pellegrino and Thomasma, *For the Patient's Good*, 54.

[185] Pellegrino and Thomasma, *For the Patient's Good*, 54.

[186] Pellegrino and Thomasma, *For the Patient's Good*, 54.

[187] Pellegrino and Thomasma, *For the Patient's Good*, 34-35.

Narrative Theory Healthcare Professional and Patient Relationship

Incorporation of Narrative Theory into practice supports the physician's obligation that Pellegrino and Thomasma describe as "four components of the patient's good." The components include the "ultimate good" which refers to what the patient recognizes as being the most important in life.[188] This component clearly recognizes that patients make healthcare decisions that are meaningful or of importance to themselves. Medical interventions that can benefit the patient's well-being must also be recognized by the physician as the "biomedical good."[189] The third component that physicians must take into account is that patients base healthcare decisions upon life circumstances, and current events in a person's life that might have an effect upon the outcome of their decision.[190] Last but not least, the fourth component identifies that physicians must provide care reflective of the "good of the patient as a human person capable of reasoned choices."[191] Pellegrino and Thomasma emphasize that physicians must practice beneficence-in-trust in all physician-patients. Patient values must be incorporated into the plan of care and if for some reason "the values are unknown due to incompetency, wishes guide the practitioner."[192] Beneficence-in-trust must guide all healthcare professionals in the provision of care and must also be incorporated into Narrative Theory as the guiding principle for care.

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[188] Pellegrino and Thomasma, *For the Patient's Good*, 76.

[189] Pellegrino and Thomasma, *For the Patient's Good*, 76.

[190] Pellegrino and Thomasma, *For the Patient's Good*, 76-77.

[191] Pellegrino and Thomasma, *For the Patient's Good*, 77.

[192] Pellegrino and Thomasma, *For the Patient's Good*, 147.

Narrative Theory is built upon the conversation between the healthcare professional and the resident. LTC residents must recognize the reason they are seeking care to honestly tell the narrative about their unique experience. If the resident is not honest, crucial information might not be shared which would negatively affect the outcome and prevent the resident from optimal wellness. The healthcare professional must identify personal biases that could hinder listening and accurate interpretation of the resident's narrative. Both the resident and healthcare professional are expected to be honest and work together. Healthcare professionals have a moral obligation to act in the resident's best interest versus for personal gain. Based upon the resident's narrative and healthcare professionals' exchange of information, they both must collaboratively decide upon goals that enhance patient well-being. The goals must be based upon the healthcare professionals' expertise and the patient's narrative to achieve optimal well-being.

Pellegrino Four-Principles Approach

Pellegrino states, "The four-principles approach should be redefined and grounded in the reality of the doctor-patient relationship."[193] The principles are "Non-maleficence, beneficence, autonomy, and justice."[194] Pellegrino further describes the reason that grounding of the principles is relevant in the doctor-patient relationship: "This grounding can provide a standard against which the fundamental conceptual problem of conflict among prima facie principles can be resolved."[195] The four principles are the

[193] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, 187.

[194] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, 187.

[195] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader,* 188.

basic foundation for the Narrative Theory healthcare professional and LTC resident relationship. Each principle must be utilized by healthcare professionals for the interpretation and provision of medical advice to the LTC residents.

Autonomy

The four-principles are essential to include in the provision of humanistic care and must be included in a Narrative Theory approach to care. Narrative Theory is based upon the healthcare professional listening and responding to the narrative of the person seeking care. Provision of care must be based upon the narrative details and how every aspect of the person's life is affecting the person. An incorrect approach is one that relies on a paternalistic approach. A paternalistic approach to care is one that is controlled by the healthcare professional and does not include the principle of autonomy. The person seeking care has limited or an absence of autonomy in regards to healthcare decisions. Paternalistic driven care does not take into account the narrative of a person's illness and prevents autonomy from being incorporated into the plan of care. From my professional experience, the paternalistic approach to care could result in the healthcare professional ordering many diagnostic tests to diagnose and determine a plan of care.

Pellegrino and Thomasma support the relevance of autonomy for the person seeking care. Autonomy allows the person to be self driven. Persons seeking care can maintain their values, cultures, religious preferences, and their free ability to choose what they prefer for medical treatments and plans of care.[196] Patient Autonomy is the guiding principle of Narrative Theory. The healthcare professional actively engages and listens

[196] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, 189-190.

to the LTC resident's narrative and determines the timeline of events that led to the person seeking care. Instead of the healthcare professional stating medical orders for LTC resident to comply with, the healthcare professional collaboratively constructs a plan of care with the LTC resident. LTC residents' self-determination is necessary to incorporate into their individualized plan of care.

A paternalistic approach will negate the use of Narrative Theory. The paternalistic healthcare professional dictates the type of care necessary for the LTC resident. This often results in non-compliance and a poor healthcare professional and LTC resident relationship. Mistrust could develop between the LTC resident and healthcare professional which will negatively impact the healthcare professional and patient relationship. Edmund Pellegrino's description of power imbalance between an educated and knowledgeable healthcare professional with capability to control the course of treatment and remove a person's autonomy and self-determination is described as:

> There is the *de facto* power mentioned above, which derives from the fact of illness itself. But there is also the power of the doctor's personality or charisma which operates in subtle ways often in apparent to both doctor and patient but, nonetheless, a powerful force in shaping even the independently minded patient's decisions. Finally, there is the force of social sanction of medicine and its monopoly of medical knowledge which operate regardless of the details of a negotiated contract.[197]

Janie B. Butts and Karen L. Rich, nursing faculty at the University of Southern Mississippi and authors of *Nursing Ethics Across the Curriculum and Into Practice*, describe paternalism:"Paternalism occurs when a healthcare professional makes choices for a patient based on the healthcare professionals' beliefs about "the best interest of the

[197] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, 191.

patient" or the "patient's own good."[198] During the practice of early medicine in the 1800s, healthcare professionals utilized a paternalistic approach to medicine. Today, it is still evolving into a shared Narrative Theory approach for the provision of healthcare. Butts and Rich emphasize that elders are at high risk for having their decision making capacity questioned as being competent in order to make autonomous decisions regarding their care. Elders can experience situational confusion or possess minor forgetfulness over small details as a normal aged finding. Society often develops incorrect assumptions about elder's decisional capacities based on physical characteristics and age. Healthcare professionals should assess the entire context and narrative of the person before removing autonomy and replacing it with a paternalistic approach to the provision of care.[199]

Hippocratic Oath and Paternalism

Pellegrino and Thomasma correlate the ancient Hippocratic Oath to present day medicine as an ineffective model to base modern day healthcare upon. The ancient method of practicing medicine as a community of physicians has morphed into a field of many physician specializations resulting in less unity of the oath's ethics. Physicians have now moved away from the practice of medicine as a community to a for profit, corporate, scientist, or blue collar worker role. Physicians' morals, ethics, and traditions have changed during the transformation.[200] Modern day issues continue to effect the

[198] Janie B. Butts and Karen L. Rich, *Nursing Ethics Across the Curriculum and Into Practice*, 3rd ed. (MA: Jones & Bartlett Learning, 2013), 219.

[199] Butts and Rich, 219-220.

[200] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 34.

provision of moral community interest based healthcare. Physicians need to continue to provide care based on their moral obligations in the best interest of the patient.[201] Pellegrino and Thomasma clearly emphasize that medicine should not be regarded as "A commodity, political bauble, an investment opportunity, or bureaucrat's power play."[202]

The Hippocratic Oath model is disputed by Edmund D. Pellegrino and David C. Thomasma as being paternalistic and practiced by an elitist group of affluent physicians that do not provide individualized patient care. Pellegrino and Thomasma are in agreement with the oath stating that physicians are upheld to different societal responsibilities, but due to the inclusiveness and protection of its members they concur that the oath is defective.[203] They describe the model as, "secretive, sexist, paternalistic, and elitist."[204] Pellegrino and Thomasma emphasize, "Three things about medicine as a human activity make it a moral enterprise that imposes collective responsibilities of a great moment on its practitioners: (1) the nature of illness, (2) the nonproprietary nature of medical knowledge, and (3) the nature and circumstances of a professional oath."[205] These things correlate to the concepts of Narrative Theory. Pellegrino's and Thomasma's writings correlate to ill persons seeking care and describing their narrative to the healthcare professional. The person seeking care is vulnerable and a trusting and honest relationship between the healthcare professional and patient must be established prior to

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[201] Pellegrino and Thomasma, *The Virtues in Medical Practice,* 32-33.

[202] Pellegrino and Thomasma, *The Virtues in Medical Practice,* 32.

[203] Pellegrino and Thomasma, *The Virtues in Medical Practice,* 33.

[204] Pellegrino and Thomasma, *The Virtues in Medical Practice,* 33.

[205] Pellegrino and Thomasma, *The Virtues in Medical Practice,* 35.

discussing his or her illness, relationships, and private thoughts. The healthcare professional offers professional knowledge focused upon the entire well-being of the person which is based on the patient narrative.[206]

Development of a relationship and establishing trust with a healthcare professional is of the highest importance for Narrative Theory to be effective at unraveling the LTC residents' narrative. All experiences with illness affects the residents' entire lives. Healthcare professional care is sought by the residents that are in need of telling their narrative to obtain medical assistance for promotion of optimal wellness. Healthcare professionals' medical expertise and the establishment of trusting relationships are necessary components for Narrative Theory to effectively promote the LTC residents' autonomy. Autonomous decisions that are collaboratively decided based upon the narrative provided by the LTC resident are included into the plan of care. Healthcare provider paternalistic decision making regarding the LTC residents' care is not best practice for increasing the LTC residents' autonomy.

Steven H. Miles, Professor of Medicine and Bioethics, University of Minnesota, succinctly describes the unbalanced physician authoritative relationship that is exemplified in the Hippocratic Oath: "And I will use regimens for the benefit of the ill in accordance with my ability and my judgment, but from [what is] to their harm or injustice I will keep [them]."[207] Paternalism was echoed in the oath as physicians decided upon the care provided to the person. To ensure appropriate care for persons with health issues, there are ethical codes which nurses profess to practice upon the completion of

[206] Pellegrino and Thomasma, *The Virtues in Medical Practice,* 35-36.

[207] Miles, xiii.

their training. The Code of Ethics for Nurses is similarly professed by the newest members to the healthcare system as a promise to practice medicine with a commitment towards the patient.

In the modern day, all healthcare professionals are to act in the best interest of the LTC residents and must include the residents' wishes in the plan of care. The incorporation of the residents' preferences based upon the narrative's inclusion into the plan of care demonstrates respect to the patient versus a paternalistic healthcare professional driven approach. Residents in LTC facilities have a voice and need to have their wishes considered in the plan of care to maintain their sense of worth and trust that the healthcare professional's main priority is beneficence. Pellegrino emphasizes, "Respect for the patient's self-determination and, thus, for the integrity of the person, is a moral requirement in all human relationships and especially in those like medicine in which there is a de facto imbalance of power."[208] This moral requirement also applies to Narrative Theory healthcare professional and LTC resident discussions.

Code of Ethics for Nurses

The *"Code of Ethics for Nurses"* emphasizes the protection of the patient's dignity, autonomy, and rights of the patient.[209] In relation to all healthcare professionals and resident care, "To violate or impede a patient's autonomy is a maleficent act. To facilitate, enhance, and restore the capability for self governance is a beneficent act."[210]

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[208] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, 192.

[209] American Nurses Association, *Nursing Scope & Standards of Practice* (Silver Spring: The Publishing Program of the ANA, 2004), 39.

[210] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, 193.

Residents of LTC facilities have the basic right to autonomy in making basic decisions about personal preferences and quality of life while residing in the LTC facilities. Each resident has different personal values which are important to them and need to be incorporated into residential life at the facility. Imagine this scenario: a male LTC resident who has difficulty walking and requires the use of a wheelchair makes a request to learn how to dance so that he can dance at his granddaughter's wedding reception. Instead of the healthcare professionals addressing his request as impossible, one approach might be to ask a physical therapist to assist with a modified dance method that would be safe for the resident. Another person could be on the dance floor and spot guard the resident with the wheelchair nearby should his legs become weak. The main objective of the resident's care should be to listen to his narrative, preserve his integrity, autonomy, and values while incorporating them into the plan of care.

Beneficence

Every healthcare professional's oath indicates that the care provision must be provided with the intent of beneficence and nonmaleficence. Tom L.Beauchamp, Professor of Philosophy and Senior Research Scholar in the Kennedy Institute of Ethics at Georgetown University, and James F. Childress, Professor of Ethics and Professor of Medical Education at the University of Virginia, describe principles of beneficence as healthcare professionals that take the necessary actions and steps towards providing care which is in the best interest of the person seeking care. The healthcare professional must also be active in the provision of care that is beneficial to the person as exemplified in

preventive medicine.[211] Janie B. Butts and Karen L. Rich explain that people often consider nonmaleficence to mean the same as beneficence but they are quite different. Beneficence emphasizes that the healthcare professional should do good. Healthcare professionals are expected to not intentionally do harm to their patients.[212]

Nursing Education and Narrative Theory

Healthcare professionals' goals for the LTC residents' plan of care should be centered on the provision of care that includes the residents' goals and preferences. Inclusion of the residents' narrative in the planning of care demonstrates the first step in the healthcare professional acting in a beneficent approach. Narrative Theory approach is to provide the best care that encompasses the entire person's needs for wellness versus only medical needs. Preventive medicine is determined based upon the LTC residents' narrative. The narrative does not only relate to medical issues that could ultimately affect health outcomes. Frequently, the stories include the personal psychological effects that the illness has upon the LTC resident. Narrative include topics regarding the effects of disease upon the family unit, employment, relationships, self esteem, and finances.

Every nursing student's nursing education and clinical practicum training focuses on the gathering of data to encompass all areas of a patient's life in order to provide beneficent care that embodies the total person's needs. Carolyn Jarvis, Ph.D., APN, CNP a Professor of Nursing at the School of Nursing for Illinois Wesleyan University and

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[211] Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics,* 7th ed. (New York: Oxford University Press, 2013), 202.

[212] Butts and Rich, 40.

Family Nurse Practitioner, describes the student nurse purpose of obtaining information for the complete health history with a great focus upon specific categorical information that includes both subjective and objective data. The subjective data (the person states) is focused upon the history of events that led to the person seeking care from a healthcare professional and directly correlates to a Narrative Theory approach. Many questions are asked by healthcare professionals regarding preventive health lifestyle, health promotion, relationships, religious preferences, and cultural practices. Objective findings (physical findings observed by the healthcare professional) are correlated to the narrative related to the persons' illness to determine a plan of care.

In my professional modern day medicine experience, narrative note connotation is increasingly being replaced at hospitals by check lists and charting by exception designs designated towards asking questions predominately focused on the ailments. Healthcare professionals are often busy with other duties which requires for them to collect data quickly. A narrative theory approach is limitedly being used to collect information about the person seeking care.[213] As directed by the healthcare professional's oaths, provision of care is always intended to benefit the person seeking care. Janie B. Butts and Karen L. Rich describe practice and standards of the provision of care to persons seeking care as being overseen by regulatory and governing agencies. The standards focus upon healthcare professionals providing beneficence and nonmaleficence.[214] Nursing students are taught to learn and practice the provision of care according to the standards to provide

[213] Carolyn Jarvis, *Physical Examination & Health Assessment*, 6th ed., (Canada: Elsevier Saunders, 2012).

[214] Butts and Rich, 40.

the best care to those seeking care. At the entry level into nursing school, a narrative theory approach should be taught as the foundation to data collection.

Patient education is a primary focus of nursing care. The student nurse is taught to observe and listen to the patients' narratives to determine if there is a need for education regarding their illness or wellness care. As a narrative unfolds, nursing students are taught to think critically and to develop connections between the personal narrative compared to the illness. Emphasis is placed upon whether the narrative that is being told is congruent with the observations and subjective narrative of the person seeking care.

The method of teaching nursing students to obtain the aforementioned categories of information during a complete health assessment confirm that narrative theory is a crucial component for developing a plan of care that is centered around the patient's needs. Without the use of narrative theory for the collection of data, the complete narrative of the person would not be obtained and the plan of care could not address all of the personal needs necessary to achieve the best positive health outcomes. If narrative theory is not utilized in obtaining the complete health history, patient autonomy would not be exercised and care could not be provided in the best interest of the patient. There would also be a significantly higher risk of care being driven by a paternalistic approach. Care would not be provided by the guiding principles of autonomy, beneficence and nonmaleficence.

Healthcare Professionals' Qualities, Virtue Ethics, and Ethical Principles

Edmund D. Pellegrino and David C. Thomasma discuss the principle of respect and its effects upon the provision of beneficent care in *Helping and Healing Religious Commitment in Health Care*: "A good argument for treating the vulnerability of individuals might be constructed using the principle of respect for persons. Those who become vulnerable for one reason or another would command special respect."[215] People that live in a LTC facility are vulnerable since they depend on others for care or assistance in activities of daily living. Based upon the principle of respect, LTC residents would therefore command a special respect.

Pellegrino and Thomasma interconnect the principle of respect with the principle of vulnerability: "In human relations generally, if there are inequities of power, knowledge, or material means, the obligation is upon the stronger to respect and protect the vulnerability of the other and not exploit the less advantaged party."[216] Vulnerability of the LTC resident in the healthcare professional relationship must be taken into account when gathering data during the narrative. To provide care that encompasses autonomy, beneficence and nonmaleficence, healthcare professionals must not act to benefit themselves. The providers must be cognizant when collecting data of the LTC residents' vulnerability in order to not impose biases upon the LTC resident's narrative. A virtuous moral healthcare professional is one that has the ability to innately base his or her actions and duties upon the best interest of the LTC residents' needs.

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[215] Edmund D. Pellegrino and David C. Thomasma, *Helping and Healing: Religious Commitment in Health Care* (Washington, D.C.: Georgetown University Press, 2007), 54-55.

[216] Pellegrino and Thomasma, *Helping and Healing: Religious Commitment in Health Care*, 55.

Pellegrino's and Thomasma's writings regarding the principle of vulnerability correlate to healthcare professionals' relationship to the person seeking care in a Narrative Theory approach as both identify that the vulnerable, and sick person is the central focus of the provision of care. Similar correlations exist regarding identification of the ill persons path of life that has gotten off track, dreams that have been put on hold and freedoms that can be lost in the decision making process. The healthcare professional has the knowledge and skill to help the ill person focus upon relief of his or her ailments or a return to health. Trust needs to be established between the healthcare professional and the ill person. Pellegrino and Thomasma explain there is inequality in the relationship since the healthcare professional has more knowledge about the illness than the person seeking care. Vulnerability is present and the healthcare professional must practice by moral obligations based upon this. The healthcare professional has to always act for the good of the patient with no personal gain intended.[217]

LTC residents that need to depend upon others for care and who were once independent autonomous people become vulnerable when residing in a LTC facility. The LTC residents' family members also become vulnerable. Family members entrust their loved ones to healthcare professionals in LTC facilities without personally knowing each individual provider. It is the obligation of all healthcare professionals not to minimize the principle of vulnerability and to recognize the significance of this principle as they provide beneficent and nonmaleficent care. The LTC resident and family members expect healthcare professionals to practice by the ethical principles of autonomy, beneficence, nonmaleficence and justice. To provide care based upon ethical principles,

[217] Pellegrino and Thomasma, *Helping and Healing Religious Commitment in Health Care*, 59-60.

all healthcare professionals must also have ethical qualities. Janie B. Butts and Karen L. Rich describe the nurse who has moral integrity as, "A person with moral integrity usually is described as having honesty, truthfulness, trustworthiness, courage, benevolence, and wisdom."[218]

It is not just nurses that must have the aforementioned ethical qualities. LTC facility healthcare professionals employ people from many disciplines. On a daily basis the LTC residents interact with various healthcare professionals, such as physical therapists, occupational therapists, dieticians, social workers, activities therapists, administrators, physicians, nurses, nursing assistants, and also housekeeping ancillary staff. Healthcare professionals that interact with LTC residents must have moral integrity and ethical qualities so that safe and quality care is continually provided for every aspect of the LTC residents' needs while living in the LTC facility. Janie B. Butts and Karen L. Rich state, "Honesty is more than just telling the truth: it is the substance of human relationships. It involves people having the ability to place emphasis on resolve and action to achieve a just society by exercising a willingness to dig for truth in a rational, methodical, and diligent way."[219]

Honesty is a necessary component of Narrative Theory and storytelling. The healthcare professional and LTC resident must have a continual open and honest dialogue throughout the professional relationship. Healthcare professionals must be genuine regarding their ability and willingness to meet the LTC resident's expectations of care.

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[218] Butts and Rich, 73.

[219] Butts and Rich, 76.

Honesty builds the trust within the relationship and it increases the LTC resident's comfort level for being truthful during the narrative.

According to Butts and Rich ethical nurses must also demonstrate truthfulness: "Truthtelling in the healthcare environment means that nurses are usually ethically obligated to tell the truth and are not intentionally to deceive or mislead patients."[220] Equally important, Butts and Rich emphasize the need for nurses to have moral courage by speaking out and standing up for what is right in a situation even if there is a conflict in the nurse's personal values and beliefs.[221] Edmund D. Pellegrino and David C. Thomasma also identify that trust is a central priority in physician professional ethics and human relationships because ill persons seeking care trust that the healthcare professional has the knowledge and ability to help heal them. The healthcare professional becomes entrusted in providing care based upon their trust.[222]

Throughout the LTC residents' and healthcare professional's relationships, the LTC resident assumes that the healthcare professional's intentions are honest, truthful, trustworthy, and based upon wisdom. Licensed healthcare professionals such as nurses and physicians must successfully pass a national credentialing exam prior to practicing medicine. The registered nurse credentialing exam is primarily based on general nursing knowledge across the person's life span. Pellegrino and Thomasma identify the societal assumption of trust that is present at the beginning of the healthcare professional and LTC resident relationship: "If we take medical relationships as our paradigm case, we

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[220] Butts and Rich, 77.

[221] Butts and Rich, 79-80.

[222] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 67-68.

recognize a certain amount of trust in the system of education, credentialing, and the processes of licensure."[223]

At the beginning of the healthcare professional and LTC resident relationship, trust needs to be established and competence must be demonstrated by the professional. Narrative between the healthcare professional and LTC puts the resident in a vulnerable position. The LTC resident must establish trust and perceive the healthcare professional as being competent and possessing true interest in the resident's well-being. Confidentiality and trust must be maintained throughout the relationship to prevent a breakdown in communication and deliverance of care. Pellegrino and Thomasma describe the expectations of the person seeking care from competent physicians to include trust, objectivity, knowledge, and commitment to the well-being of the vulnerable person seeking care.[224]

There is a growing distrust in the medical system as a whole. In my past experience those seeking care want to be in control over their medical care. Trust in healthcare professionals has decreased in some ways due to the healthcare system insurance regulations dictating what is or is not covered by healthcare insurance. This in turn takes the freedom away from the healthcare professional to prescribe what might be the best option for the treatment of a person. The person seeking care wants to trust the healthcare professional is providing care that is best for his or her needs, yet the plan of preferred care might be blocked due the lack of insurance reimbursement.

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[223] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 68.

[224] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 68.

Healthcare professionals may also be tempted to prescribe medications that provide the healthcare professional with a kick back reimbursement from a pharmaceutical or a durable goods medical company. The medications may not be the best prescription for the person's aliments but healthcare professionals in the past have been enticed successfully to write prescription orders for these medications. As an example, healthcare professionals may distribute sample medications provided by pharmaceutical companies to promote new drugs on the market while also writing prescriptions to increase pharmaceutical sales with a percentage of reimbursement provided to the healthcare professional. Office lunches and trips hosted by pharmaceutical companies are other forms of kick back to prescribers who are involved in this unethical practice.

Increasing numbers of medical errors and growing lack of trust in the modern day medical system has increased threats of law suits or litigation to practicing healthcare professionals. The litigious nature of society currently guides much of the healthcare professionals' practice and how they prescribe a plan of care for those seeking care. An example of this is when a healthcare professional orders a diagnostic test such as a CT scan to rule out cancer. The healthcare professional might order the scan to rule cancer out even though the illness narrative, physical exam, and lab diagnostic tests do not indicate a need for the CT scan. Diagnostic tests will be ordered especially if there is potential for insurance reimbursement, the person seeking care requests to have the test, or the person is in agreement with the recommendation from the physician to have the test to rule out disease. Healthcare professionals use diagnostic tests to rule out diseases, decrease misdiagnosis, and respectively lessen potential litigation.

If the person seeking care is not informed of the ulterior motive in the practice of medicine, they are not receiving honest and trust worthy advice from the healthcare professional. LTC residents that receive care from healthcare professionals are vulnerable persons and need to receive honest, beneficent, truthful, and trustworthy care. The LTC residents ought not to be robbed of this by a healthcare professional's self fulfillment of power. Pellegrino and Thomasma identify that the healthcare professionals' knowledge and skill increase the vulnerability of the person seeking care. Potential litigation and conflicts of interest also increases the ill persons' vulnerability. The healthcare professional is entrusted and expected to act in the best interest of the person seeking care.[225]

Currently, Americans still have a large amount of trust in the healthcare system as compared to other professions. *The Journal of Nursing* article "Gallup Poll: Nursing Ranks As Most Ethical Profession for 13th Consecutive Year" depicts nurses as healthcare professionals as being ranked highest in the poll:

> Americans have been asked to rate the honesty and ethics of various professions annually since 1990, and periodically since 1976. Nurses have topped the list each year since they were first included in 1999, with the exception of 2001 when firefighters were included in response to their work during and after the 9/11 attacks. Since 2005, at least 80% of Americans have said nurses have high ethics and honesty. Two other medical professions-medical doctors and pharmacists- tie this year for second place at 65%, with police officers and clergy approaching 50%.[226]

Gallup poll results, design, and total number of participants is described in the *Journal of Nursing* as, "Results for this Gallup poll are based on telephone interviews conducted

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[225] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 68.

[226] American Society of Registered Nurses, "Gallup Poll: Nursing Ranks As Most Ethical Profession for 13th Consecutive year," *The Journal of Nursing* (1 Jan. 2015), http://www.asrn.org/journal-nursing/1247-gallup-poll-nursing-ranks-as-most-ethical-profession-for-13-consecutive year.html; Internet; accessed 13 Jan. 2015.

Dec. 8-11, 2014, with a random sample of 805 adults, aged 18 and older, living in all 50 U.S. states and the District of Columbia.[227]

The Gallup poll results indicate that nurses are identified as being more honest and ethical than physicians. This demonstrates the need for nurses and nursing assistants to be diligent in maintaining the highest standards for the provision of an ethical and honesty based approach to LTC resident care. Nurses and nursing assistants spend the greatest amount of hours providing care to the LTC residents. It is the responsibility of the nurse and nursing assistants to identify if the LTC resident is becoming distrustful or wary of the prescribed plan of care and to address and rectify it immediately. Pellegrino and Thomasma identify vulnerabilities and potential conflicts of interest of physician provider care. Physicians need to be proactive in providing honest and ethical based care without conflicts of interest interfering with the best plan of care outcome for the LTC resident.

The continuous foresight of Pellegrino and Thomasma in modern medicine demonstrates their explanation of modern day opinion polls results,

> In the last two or three decades, these perennial sources of distrust have been reinforced and expanded by a wide variety of events within and outside medicine-the malpractice crisis; the commercialization of medical care by advertising and entrepreneurialism; the excessive income and free-spending lifestyle of some physicians; the bottom-line, marketplace, 'pay-before-we-treat' policies of hospitals and some doctors; the depersonalization of large group prepayment practices; physicians' growing preferences for 9 to 5 jobs and time off; the retreat from general to specialty practice; the early retirements.[228]

[227] American Society of Registered Nurses.

[228] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 71-72.

The healthcare system has changed the role of healthcare professionals to be one that persons that seek care see as less interested in them versus money, and less interest as being a steward of medical knowledge and caring. Autonomy has strengthened and patients are now able to research their own care and request tests they feel are necessary.[229] This could have negative effect upon the trusting relationship with the healthcare professional.

Nonmaleficence

Providing beneficent, trustworthy and ethical based care supports the provision of care based upon the principle of Nonmaleficence. The principle of Nonmaleficence, or in other words to do no harm, applies to the person seeking treatment and is automatically expected to be practiced by all healthcare professionals. LTC facility residents who are often vulnerable to begin with must receive care that is practiced with the principle of Nonmaleficence. Trust between the healthcare professional and the LTC resident during the initial narrative storytelling is assumed as a principle that is included in all aspects of care.

Thomas L. Beauchamp and James F. Childress define the principle of Nonmaleficence: "The principle of nonmaleficence obligates us to abstain from causing harm to others. In medical ethics this principle has been treated as effectively identical to the celebrated maxim *Primum non nocere*: 'Above all {or first} do no harm.'"[230]

[229] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 71-72.

[230] Beauchamp and Childress, 150.

Edmund Pellegrino's overall viewpoint about the four guiding principles relate to a physician's obligations and Nonmaleficence. Pellegrino argues that, "The primary obligation which unifies the theory of medical ethics is beneficence-beneficence not mistakenly equated with paternalism, but beneficence-in-trust, beneficence which fuses respect for the person of the patient with the obligation not just to prevent or remove harm, but to do good."[231] Healthcare professionals must provide care with the intent to do good for the person's whole well-being. The provision of care based on the principle of beneficence can only be obtained if there is no violation of the principles of autonomy, justice, and Nonmaleficence.[232]

Pellegrino's viewpoint of healthcare professionals providing care based on beneficence and the whole being supports incorporating a Narrative Theory approach to the provision of care in LTC facilities. Narrative storytelling between the healthcare professional and LTC resident follows Pellegrino's guiding principles for the provision of good care without intent to do harm. It is the obligation of the healthcare professionals to provide care to LTC residents based upon beneficence. LTC residents are no different than any other patient in any different healthcare facility setting. Any person that is seeking care from a healthcare professional must receive care based on the principle of beneficence. People that seek care do so with the expectation that the healthcare professional has their personal best interest as the guiding force to the provision of care. All healthcare professionals are obligated to practice by the principles as described by

[231] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, 201.

[232] Pellegrino, *The Philosophy of Medicine Reborn: A Pellegrino Reader*, 201-202.

Pellegrino. Beneficence and Trust is the foundation that care is based upon in both clinical practice and narrative theory.

Justice

The principle of Justice is important to incorporate into the provision of care for the fair distribution of healthcare to all persons. Authors Karen B. Butts and Janie L. Rich affirm, "Justice is a broad concept in the field of ethics and is considered to be both a principle and a virtue."[233] Justice and fairness is of equal importance: "Fairness, treating people equally and without prejudice, and the equitable distribution of benefits and burdens, including assuring fairness in biomedical research represent the basis of justice."[234]

The principle of Justice is also considered to be a virtue. *Stanford Encyclopedia of Ethics* defines justice as a virtue: "When we speak of justice as a virtue, we are usually referring to a trait of individuals, even if we conceive the justice of individuals as having some (grounding) reference to social justice."[235] Pellegrino and Thomasma both state the need for physicians to have a Christian commitment to care and describe the relationship of Christianity and Justice as one of several virtues to practice by. The allocation of healthcare resources and the obligations of physicians and patient are directly impacted

[233] Butts and Rich, 45.

[234] Butts and Rich, 45.

[235] Center for the Study of Language and Information (CSLI), "Stanford Center for the Study of Language and Information: Stanford Encyclopedia of Philosophy," 2013, http://plato.stanford.edu/search/searcher.py?query=justice; Internet; accessed 17 Jan. 2015.

by the justice virtue.[236] Pellegrino and Thomasma state, "Thus, justice is the virtue that disposes humans to respond to the claims of others for equality of treatment-as individuals and as members of a larger whole. As a virtue, it disposes us habitually to respond to needs beyond our own interests and to do so in a fair and equitable way."[237]

All LTC residents that reside in a LTC facility should equally receive quality and ethical based care. The current healthcare system does not allow for this at all times due to health care insurance reimbursement differences. Some healthcare plans will reimburse for care that others will not reimburse for provided care. LTC residents do not receive the same options for treatment if their healthcare insurance does not cover the cost unless they pay out of pocket for the expenses. This places LTC residents who have better insurance reimbursement at a better advantage to receiving different treatment modalities that might benefit them more than others. Unfortunately, this is an issue that cannot be controlled at the present time in modern medicine and it violates the principle of justice. The principle of Justice should however continue to be practiced to the best extent by every LTC healthcare professional. All LTC healthcare professionals must respect the LTC residents' autonomy and not provide paternalistic care that is based on personal gratification of their own autonomy.

Political and Societal Demands on Healthcare and Ethical Principles

There are times where a healthcare professional must make decisions based upon the LTC resident's autonomy which might conflict with the healthcare professional's

[236] Edmund D. Pellegrino and David C. Thomasma, *The Christian Virtues in Medical Practice* (Washington, D.C.: Georgetown University Press, 1996), 125.

[237] Pellegrino and Thomasma, *The Christian Virtues in Medical Practice*, 126.

personal autonomy. Pellegrino and Thomasma identify this growing societal norm of healthcare professionals being required to provide care based upon the autonomy of the individual that is seeking care versus physicians' personal values.[238] In my experience over the past three decades healthcare has evolved from a paternalistic approach to a patient centered approach. Reimbursement from insurance companies focuses primarily upon documentation supporting inclusion of the individual preferences of the person seeking care into the prescribed plan of care. There is continued research regarding the benefits of compliance to medical regimens when the person seeking care is included and has autonomy about his or her plan of care. The current healthcare system has become less of a physician paternalistic Hippocratic Oath approach to medicine and is now much more focused upon patient autonomy. Healthcare practice driven by the principle of patient autonomy supports the incorporation of Narrative Theory and the use of storytelling in the provision of care at LTC facilities.

In my professional experience, patient autonomy can also dictate the healthcare professional's plan of care. Pellegrino and Thomasma physician state, "When the patient or social policy dictates that the physician submerge her own moral values to accommodate the patient's demands, even if what is demanded is accepted practice, then the conflict is between the patient's and the physician's autonomy."[239] Support is stated for the healthcare professional to withdraw services due to the violation of physician autonomy without causing abandonment of the patient and also ensuring that another

[238] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 96.

[239] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 97.

healthcare professional has agreed to care for the person.[240] In other words, if a healthcare professional identifies that the person seeking care requests care that is against the professional's personal principles or virtues, it is incumbent upon the healthcare professional to remove him or herself from the relationship. Healthcare professionals that are practicing against his or her autonomy and decide to remain in the role might provide maleficent care resulting in harm to the person seeking care. Provision of care would not be beneficial or in the best interest of the person seeking care. The healthcare professionals would therefore be violating their oath of practice.

Provision of Quality Care

Each LTC resident has the right to receive quality and ethical based care while residing in the LTC facility. A Narrative Theory approach in the LTC facility includes the incorporation of the LTC resident's narrative to ensure care is centered upon the person's whole being. The healthcare professional's provision of care to LTC residents should be based upon the four principles: beneficence, non-maleficence, autonomy, and justice. Life prolonging technological advances, insurance reimbursement, political, societal and government regulations and transformations continue to effect the provision of principle based, ethical, and quality care in all types of healthcare facilities.

Pellegrino and Thomasma describe the transformative changes in advancing technology that has caused dramatic changes in the provision of geriatric care and to dying patients. Advanced technology does not equate to better care.[241]

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[240] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 97.

[241] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 103.

The effects of the political and societal demands upon the healthcare system have resulted in detrimental effects upon the modern day relationship between the healthcare professional and person seeking care: "In earlier times, the essential moral quality of health care was embedded in the professional codes of the caregivers themselves, largely physicians and nurses."[242] Pellegrino and Thomasma correlate that the changing healthcare system has created a chaotic healthcare professional and patient relationship. Physicians have lost control over values in caring for others. The healthcare system has become profit driven, political, and far removed from the healthcare professional's ability to care for the person in a one-on-one relationship with the healthcare professional.[243]

Narrative Theory Incorporated Into Care

The radical transformation that Pellegrino and Thomasma relate only to a doctor-patient relationship also applies to all healthcare professional-patient relationships in modern day medicine. A trusting relationship that is developed during narrative and the incorporation of a narrative theory approach to the provision of care is necessary to maintain order and the best plan care for the LTC resident that is based upon values and the four ethical principles. Edmund D. Pellegrino's and David C. Thomasma's book *Helping and Healing Religious Commitment in Health Care* states, the physician-patient "healing relationship transcends to the buyer-seller obligation relationship."[244] A buyer-

[242] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 103.

[243] Pellegrino and Thomasma, *The Virtues in Medical Practice*, 103.

[244] Pellegrino and Thomasma, *Helping and Healing: Religious Commitment in Health Care*, 135.

seller relationship has different obligations than a patient and physician relationship. Physicians' relationships with patients rank as a higher order of ethical obligations.[245]

Healthcare professionals are held to a higher standard in society. They are expected to abide by their oaths of practice in a medical setting and also in society. Healthcare professionals are expected by society to be caring, moral, honest, and ethical professionals. A buyer-seller or commodity relationship sets a different tone for the expectations of the healthcare professional. The person seeking care cannot purchase virtues, morals, and ethics. They can purchase a service, such as a healthcare professional completing a physical exam and ordering diagnostic exams. Healthcare professionals that go the extra mile to ensure the person seeking care is receiving quality, ethical and humanistic care cannot be purchased in a buyer-seller relationship. The healthcare professional and LTC resident relationship that is built upon Narrative Theory, storytelling, development of trust, and caring immediately changes the buyer-seller relationship into a healing relationship.

Quality, ethical, and humanistic care is provided by healthcare professionals whose primary goal is to address and care for the whole being of the person seeking care. Identifying needs for the whole being are best identified when Narrative Theory is incorporated into the planning and provision of care. In my experience, modern society has become largely focused upon the buyer-seller relationship, insurance reimbursement diagnostic codes and regulations, versus the healing role of the healthcare professional and person seeking care. A buyer-seller relationship decreases the trust between the healthcare professional and person seeking care. Both parties know that if the person seeking care does not receive what he or she is seeking such as medications or diagnostic

[245] Pellegrino and Thomasma, *Helping and Healing: Religious Commitment in Health Care*, 135.

tests, the relationship can be severed and a new healthcare professional relationship will be obtained to fulfill the needs.

LTC residents that reside in modern day LTC facilities expect the healthcare professionals to provide ethical and quality care. Residents do not expect to be treated as though they are living in an institution for the elderly with a limitation on personal rights, freedoms, and access to ethical care. The modern healthcare system does not refer to LTC facilities as institutions. From my professional experience, most LTC facilities do not practice medicine similar to the archaic methods of practice that were commonly used in the institution type settings. Pellegrino and Thomasma describe the effect of institutionalization upon healthcare professionals in the hospital setting: "The emphasis on technology and institutionalization often makes it possible for individuals to defect from their obligations as moral agents in favor of the rules of the institution."[246] Healthcare professionals may feel as though they are not as responsible for the welfare of the patient.[247] The incorporation of healthcare professional and LTC resident relationships that focus upon narrative prevents institutionalized care that is lacking in the four principles approach to healthcare.

Janie B. Butts and Karen L. Rich describe the effect of quality care provided by healthcare professionals: "The quality of patient care rendered by healthcare professionals and patients' satisfaction with health care often depends on the existence of harmonious relationships between professionals and patients and between the members of

[246] Pellegrino and Thomasma, *Helping and Healing: Religious Commitment in Health Care*, 61.

[247] Pellegrino and Thomasma, *Helping and Healing: Religious Commitment in Health Care*, 61.

professions themselves."[248] Incorporation of narrative health Theory in the healthcare professional and LTC resident relationship develops trust and in most cases builds upon a harmonious relationship. Nurses are also expected to be mindful that patients want to be treated with respect and dignity at all times.[249] Unfortunately, modern day medicine demonstrates that nurses are often so busy with treatments, medication administration, and documentation for insurance reimbursement of services that they often do not have much time available to be mindful of the person seeking care. All healthcare professionals would benefit from incorporating Narrative Theory into their practice. Narrative facilitates learning about the whole person seeking care. A continuum of active listening by nurses and nursing assistants to residents' stories in the LTC setting can facilitate the LTC residents' experience of being treated with the respect that should be afforded to all human beings.

Principlism and Narrative Ethics

An understanding about the relationship of Principlism and Narrative Ethics must be understood for healthcare professionals to effectively include Narrative Theory into practice and the provision of care.[250] Joan McCarthy Ph.D., Department of Nursing Studies, University College Cork, Ireland, emphasizes that ethical decision making related to healthcare decisions is based upon principle based ethics (PBE), and rules.

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[248] Butts and Rich, 48.

[249] Butts and Rich, 49.

[250] Joan McCarthy, "Principlism or narrative ethics: must we choose between them?," *Medical Humanities* 209, no 2 (2003): 66 [database on-line] doi:10.1136/mh.29.2.65, available from http://mh.bmj.com/content/29/2/65; Internet; accessed 6 Feb. 2015.

> The PBE is an ethical decision making process which negotiates between fundamental principles, on the one hand, and the unique nature of specific moral situations on the other. Decisions regarding healthcare decisions are considered "morally justified" if the decision is consistent with relevant principles, rules, background theoretical commitments, and particular judgments.[251]

McCarthy emphasizes that in order for a decision to be morally justified, decisions must have "an overall cohesion" of the principles and rules involved in making the decision.[252]

McCarthy explains that the bioethical principles: autonomy, beneficence, nonmaleficence, and justice support universal rules that guide objective based actions. McCarthy refers to moral rules as the foundation of the principles. Emphasis is placed upon actions following the moral rules in order to be considered an appropriate ethical action. Difficult ethical healthcare decisions that question how to proceed morally must be reflected upon by the healthcare professional. McCarthy states, "The process of reflective equilibrium involves the specification, reciprocal weighing, testing, revising, and balancing of principles, rules, background theories, and particular judgments."[253] Hypotheses are developed and reasoned by the foundation of bioethical principles.

Narrative ethics and principlism are dependent upon each other for healthcare professionals' decisions and provision of care course of action. Every patient has a unique situation with personal meaning. The patient narrative provides the direction of the course of action. Narrative provides honest and credible communication between the healthcare professional and person that is seeking care. McCarthy explains that narrativists focus upon understanding the person's life and its relationship to morals.

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[251] McCarthy, 66.

[252] McCarthy, 66.

[253] McCarthy, 66.

When ethical dilemmas arise narrativists examine the narrative of the person's life in relation to how they perceived and preferred it to be.[254] McCarthy states, "The PBE model, the four principles are prima facie privileged, but may be modified subsequently."[255]

When referring to the narrative, "It is the first person narratives that are prima facie privileged; however like principles, they can be challenged and modified in the process of what I am calling, a 'narrative reflective equilibrium.'"[256] How the people constructs their narrative and what matters most to the person seeking care is of the utmost importance in cases where a patient is incompetent and healthcare decisions must be made. "Narrativists focus less on trying to reduce competing perspectives to a commonly shared view and more on involving as many people as possible in the dialogue."[257] All of the healthcare professionals and significant people that are involved in the care of the person should be included in the plan of care discussions.[258] Narrative ethics approach is not aimed "to reduce discord, disunity, and disagreement."[259] Principlism is based primarily on rules and the distinction of good and bad actions. Principlism looks at societal norms and applies principles that are considered moral norms to ethical healthcare situations. This approach does not take into account the individuality of the patient, his or her life narrative, culture, or creed. Narrative ethics

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[254] McCarthy, 67.

[255] McCarthy, 66.

[256] McCarthy, 68.

[257] McCarthy, 68.

[258] McCarthy, 68-69.

[259] McCarthy, 69.

respects and incorporates the unique narrative of the person seeking care into the provision of medical treatment.[260] The shared understanding of the personal narrative obtained by the incorporation of narrative theory into the provision of care is necessary to achieve a plan of care designed for the whole being.

Modern Day Medicine Effects on Narrative Theory

Historically, primary care healthcare professionals provided care for all of the healthcare needs of the person seeking care. Healthcare professionals were generalists. Modern day medicine has changed from using a primary care healthcare professional that would take care all of the body systems, psychological and emotional needs to healthcare professionals that are specialists, such as a cardiologists or endocrinologists.[261] Primary healthcare professionals have limited care due to the increased volume of specialists and specialty fields of medicine. A person seeking care in the twenty first century frequently has a list of specialists that care for the entire well-being of the person. Modern day technological, pharmaceutical, and biomedical advances have had a direct influence upon referrals from primary healthcare professionals to specialists. Healthcare professionals can often be seen referring a person to a specialist because the ailment is outside their scope of practice.

An increasing number of insurance companies require a referral from the primary healthcare professional for the person seeking care to see a specialist. The specialist consultation authorization is controlled by the insurance company and confirms or denies

[260] McCarthy, 69-70.

[261] Engel et al., 74.

payment for the consultation. Each insurance company provides a different reasonable and customary rate of pay for the specialist's services. Insurance companies are often guilty of not reimbursing healthcare professionals a high enough amount of compensation for healthcare visits. I have witnessed some healthcare professionals having to close their practices due to insufficient funds for operating costs. The current trend for many healthcare professionals is to reduce the amount of time allocated for each consultation visit as a means to increase the number of patients seen in one day. A greater number of people that are seen on a daily basis directly increase the total amount of insurance compensation.

This frequently encountered method of operation has unfortunately changed the method in which many healthcare professionals obtain crucial information from the person seeking care about his or her illness. The majority of healthcare professionals do not have enough time allocated in the work day for an in depth narrative discussion focused upon the reason that a person is seeking care. Medical history gathering and documentation of responses from those seeking care has changed in recent years to a checklist and checkmark documentation format versus a descriptive communicative and written narrative approach.[262] Use of a checkmark format focuses the conversation between the healthcare professional and person seeking care upon the illness only. It does not take into account the person's whole being or all of the factors that might be contributing to the illness. Conversation is usually limited to the pre-selected questions since the primary focus is upon the collection of data for the illness or problem. This

[262]Engel et al., 74-75.

method of data collection obstructs the development of a trusting and self effaced relationship between the healthcare professional and person seeking care.

Modern day medicine has changed the traditional practice of medicine to one that incorporates less use of narrative theory for the provision of quality, ethical, and humanistic care. Based upon this newer depersonalized approach to the provision of care, healthcare professionals are frequently unable to participate in a completely transparent relationship centered care prohibiting the healthcare professional from addressing the needs of the whole being for the person seeking care.[263] Written context from *Narrative in Health Care Healing Patients, Practitioners, Profession, and Community* describe the factors that healthcare professionals have become focused upon the treatment of disease processes with biomedical technology versus talking with the patients to obtain their illness narrative. Clinical care has become depersonalized. Patients are not able to speak about their illness narrative as the history taking process becomes replaced by forms that require ask specific questions that require less narrative. Healthcare professionals cannot reflect with the patient to determine how the disease affects the life and plan of care for the person seeking care.[264]

Paper versions of medical documentation are increasingly becoming replaced by Electronic Health Records (EHR) and Electronic Medical Records (EMR) technology systems. EHR and EMR systems are the newest methods for healthcare professionals to collect and store healthcare documentation data about the person seeking care. Healthcare professionals document physical findings and answers to specific questions in

[263] Engel et al., 74-75.

[264] Engel et al., 74-75.

the EMR and EHR. Limited conversation occurs since the healthcare professional is focused upon entering all of the data into the computer. Data entry results in less eye contact between the healthcare professional and the patient. Healthcare professionals usually sit or stand in front of a computer to document the person's responses. Healthcare professionals have become extremely focused on entering the correct data to ensure the healthcare facility gets reimbursed for services. The electronic documentation frequently takes precedence over narrative conversations with the patient. Less time is spent at the bedside and more time is getting spent in front of computers. Based upon my observations the greatest negative impact of the incorporation of EMR and EHR into the healthcare delivery system is that it removes the healthcare professional from the bedside. Less time is allocated for the healthcare professional to develop a relationship with the person seeking care. Narrative Theory is limitedly getting incorporated into the provision of care.

In recent years, the narrative of illness or self effacement of the healthcare professional and person seeking care has become time constrained. This change of focus has had a negative impact on developing a trusting and open communication relationship between the healthcare professional and person seeking care. The relationship has changed to a buyer business model for services. The days of healthcare professionals sitting at a person's bedside listening to their narrative is quickly evolving into one where the healthcare professionals quietly stare at a computer monitor and type while sitting at desks or standing behind carts with their backs to the person seeking care.

The deliverance of healthcare has become greatly focused upon removing healthcare professionals from caring for the person and having the time to incorporate

Narrative Theory into the provision of care. Healthcare professionals are increasingly discontent that there is a disproportionate amount of greater time focused upon documentation versus human interactive care. Many healthcare professionals are choosing to leave the practice of medicine to seek more lucrative paying positions in the field of IT or within the insurance industry as case managers.

The EMR and EHR systems have brought about great change in the deliverance of healthcare. Healthcare professionals must remain diligent with providing a humanistic approach to care. Empathy and genuineness are best emanated by the healthcare professionals when they practice the provision of care based upon the four principles beneficence, nonmaleficence, autonomy, and justice. All LTC healthcare professionals must incorporate narrative theory into their daily provision of care to LTC residents. LTC healthcare professionals that incorporate this approach will provide better ethical, quality and humanistic care to the LTC residents. Depersonalization of care related to today's societal and healthcare industry transformations can be minimized with the continued provision of care based upon narrative theory and the four ethical principles. Narrative ethics informs principle based ethics in the provision of humanistic care. Chapter 4 examines the LTC residents' perception of the provision of quality, ethical, dignified, and humanistic care in a LTC setting.

CHAPTER 4

RESIDENTS' PERCEPTIONS OF QUALITY CARE IN LTC FACILITIES

During my career as a Registered Nurse practicing in LTC, I have observed many LTC residents complain to nursing administration about not receiving quality care. Complaints were eerily similar at the majority of LTC facilities in which I was employed. The role of practicing nursing, participating in dialogue with dissatisfied residents in regards to the quality of care, and direct observation of nurses and nursing assistants implementation of care permits the researcher to focus on the quality care issues most often complained about by the residents.

Listening to the residents' complaints made me reflect upon the significance of LTC facilities' provision of care. What care was necessary for them to receive quality humanistic care? Do residents perceive they receive quality, dignified, ethical, and humanistic care in their LTC residences? Is the residents' care centered on the ethical principles of autonomy, beneficence, nonmaleficence, and justice? Do the nurses and nursing assistants provide time to speak with the residents about their preferences and is autonomy included in the provision of care? What are the LTC residents' perceptions in relation to having autonomy and choices for their plan of care? Do the LTC residents perceive that they receive fair and equally distributed care? What are the LTC residents' perceptions regarding receiving care safe care? Are the nurses and nursing assistants trusted by the LTC residents? Medical Humanities training has shown value in research.[265] Will training nurses and nursing assistants about Medical Humanities based Humanistic Patient Narrative Theory benefit the residents? Will the residents perceive

[265] Phyllis S. DeJesse, "Internal Medicine Residents' Perceptions of Medical Humanities," (DMH diss., Drew University, 2003), ProQuest Dissertations.

value in the receipt of humanistic care after the nurses and nursing assistants participate in Humanistic Patient Narrative Theory in-services? The four LTC facilities' participating residents' questionnaires focus on (but are not limited) to these issues.

Method

Sample

Three LTC facilities' and one Long Term Assisted Living facility's residents participated in the research. Prior to the research, the LTC facilities' Director of Nursing or Nurse Managers at each LTC facility selected the nurses, nursing assistants, and the LTC residents that participated in the research. LTC residents were required to be alert and oriented to person, place and time without cognitive or sensory deficits that impaired understanding, judgment or reasoning ability. A minimum of two licensed nurses that could be either an LPN or RN, and two nursing assistants during each day and evening shift from three LTC facilities and one Long Term Assisted Living facility participated. Each of the four LTC facilities began with a range of 10-15 residents participating in the completion of identical surveys before the healthcare professionals' training, one week and one month after the training.

Prior to distributing the surveys I spoke to each resident requesting them to participate in the research. Consent from the participants was obtained and none of the participants was offered any inducements to participate. After receiving consent, the residents were each provided a copy of the first survey and a blank envelope for residents to place the survey into after completion. One week after distribution of surveys to

consenting resident participants, the researcher obtained the residents' surveys at each facility.

After residents completed the first survey, consent for participation in the research was obtained from the LTC facility nurses and nursing assistants and part one of the in-service training was provided immediately afterward. Part one included a thirty-minute Humanistic Patient Narrative Theory in-service power point module about the history of narrative theory. Afterwards an experiential exercise was performed that included asking the participants to write on a blank index card something that was very important to them which they would never want to give up. When they wrote the thought down, they were asked to tear the card up and were informed that they could never have what they wrote down in their life again. The participants were instructed to compare their intrinsic feeling from the experience, to how a LTC resident might feel after leaving his family, belongings, pets, and memories behind when moving into a LTC facility. Some healthcare professionals began crying during this experience; it was very effective.

One week later the Part II thirty-minute in-service including the narrated story of a patient illness experience was provided to the LTC facility healthcare professionals. The modules were presented as an affective domain experiential training in-service to educate healthcare professionals about the provision of quality, ethical, humanistic, and dignified care. A thirty-minute in-service was played on a CD player and was comprised of an audio patient illness narrative spoken in first person. The LTC facility healthcare professionals were asked to reflect upon the illness narrative and to describe their interpretation of the narrative as it relates to a LTC resident. Nurses and nursing assistants were able to identify with the narrative experience and humanistic needs of the

patient experiencing the illness. Each LTC facility nurse and nursing assistant group had several healthcare professionals that stated, "We have so many job responsibilities which prevent us from spending quality time with the residents." Other healthcare professionals stated, "I have guilt when the resident wants to talk longer and I have to leave because I have to give medications or treatments to other residents." Several healthcare professionals stated that they try to go back and see the resident before the shift ends but it is not always feasible.

A second survey was provided to the residents one week after the nurses and nursing assistants received Humanistic Patient Narrative Theory in-service training. One week afterwards the surveys were retrieved by the researcher. A month after the provision of the Humanistic Patient Narrative Theory in-service training, the third survey was distributed to the LTC facility residents. One week later the surveys were retrieved by the researcher. The focus of the survey completion by the residents one week before the Humanistic Patient Narrative Theory in-service, one week after the training, and a month after the completion was to determine if the survey results are different preceding and proceeding the training in a comparative analysis of the four LTC facilities' results. Seasonal illness (winter season), hospital admission resulting in absence at the time of survey administration or collection, resident death, residents' leave of absence from the LTC facility to be with family at holidays, or a change in a residents' decision to participate, resulted in inconsistent resident submission of the three surveys. The number of respondents' completion of the three surveys by each LTC facility is defined in Table 1.

Table 1. Number of Residents' Questionnaires Distributed and Returned by Each LTC Facility

	Total Distributed	Survey 1 Return	Survey 2 Return	Survey 3 Return
LTC Facility A…….	15	8	7	10
LTC Facility B…….	12	10	10	10
LTC Facility C…….	10	10	6	8
LTC Facility D…….	10	7	5	4
TOTAL…….	47	35	28	32

There is an unequal number of male and female residents at the beginning of the survey distribution (m=17%, f= 83%) who agreed to participate in the study. Data regarding participants' age and race was not requested.

Two facilities did not meet the minimum research LTC healthcare professional participant amount for Humanistic Patient Narrative Theory in-service training participation (two nurses and two nursing assistants from each day and evening shift) due to lower staffing levels in the facilities and twelve-hour shifts. The total number of healthcare professionals that received in-service training on Humanistic Narrative Theory (nurses and nursing assistants) was greater than the minimum participant target goal. The LTC facilities that had a greater number of nursing assistants trained in the Humanistic Patient Narrative Theory in-service correlated to a greater number of resident survey responses when compared to the initial distribution number. This overall impression is enlightening and should be kept in mind as a significant finding of the study. The number of healthcare professionals that participated in the Humanistic Patient Narrative Theory in-service by each LTC facility is defined in Table 2.

Table 2. Number of Nurses and Nursing Assistants Participating in Humanistic Narrative Theory In-service Training at Each LTC Facility

	Total Nurse Participation	Total Nursing Assistants Participation
LTC Facility A…….	4	8
LTC Facility B…….	2	23
LTC Facility C…….	3	16
LTC Facility D…….	5	4
TOTAL…….	14	51

Limitations

Results from this study apply only to the LTC facilities residents, nurses, and nursing assistants' participation in this research and may not be projectable to other LTC facilities. It was difficult to obtain a large number of LTC residents at each facility due to many of the LTC residents' progressed age that increases co-morbidities and difficulties with reading or writing related physical changes. Residents' morbidity and mortality were unpredictable and limited resident participation in survey responses. Several LTC residents were not always present or were physically incapable to participate in the survey distribution due to illness, hospitalization, or death. LTC residents' receptiveness to complete the survey was dependent on their emotional and psychological well-being. There were some days that certain residents were pre-occupied with personal concerns and refused to participate in the survey collection of data for that day.

The LTC facility healthcare professionals' attendance at the Humanistic Patient Narrative Theory in-services was not always consistent due to the LTC facility staffing fluctuations. There was inconsistency in the healthcare professionals' attendance at the

Humanistic Patient Narrative Theory in-services. Attendance at the in-services was dependent upon each of the LTC facilities number of residents to healthcare professional ratios, resident acuity levels effects upon healthcare professional ratios, and unscheduled healthcare professionals' absences from work. Inconsistencies in attendance at the in-services resulted in back to back in-services for the day and evening shift healthcare professionals and make-up in-services for healthcare professionals' absences from work.

Although the total number of healthcare professionals who received in-service training on Humanistic Patient Narrative Theory was greater than the minimum participant target goal, the in-services were not provided to all LTC facilities health professionals limiting significance of the research results. More specifically, day and evening healthcare professionals were selected by the Directors of Nursing or Nurse Managers to participate in the Humanistic Patient Narrative Theory in-services. The night shift nurses and nursing assistants were not included in the Humanistic Patient Narrative Theory in-services.

Humanistic Patient Narrative Theory Part I and Part II in-services were provided once to each of the participating LTC healthcare professionals. The LTC healthcare professionals had no other Medical Humanities based training in narrative theory. LTC resident surveys showed insignificant quantitative statistical differences overall and the LTC residents' responses to specific questions are included in the Category mean statistics. The mean for the first question in the Quality Category indicated that LTC residents were not receiving the highest quality of care based upon the lack of LTC professionals and resident's discussions. Although the overall mean of quantitative results do not support the thesis, participant responses do.

Discussion

LTC facility residents were asked to respond Strongly Agree (5), Agree (4), Somewhat Agree (3), Disagree (2), No Opinion (1) to the three sets of identical survey questions in the categories of quality, dignity, ethics, and humanistic care. The residents' responses on the first survey prior to the nurses and nursing assistants receiving the Humanistic Patient Narrative in-service is portrayed in the Appendix C Figure 1.1 through Figure 1.9. Residents' responses on the second survey one week after the in-service is seen in Appendix C Figure 2.1 through Figure 2.9. Appendix C Figure 3.1 through Figure 3.9 represents the residents' responses one month after the nurses and nursing assistants received in-service training. Appendix C represents the first, second, and third survey statistics portrayed in Figures as the mean comparison of survey question categories in each LTC facilities, mean comparison of individual LTC facilities survey categories, and combined LTC facilities category mean comparison. Each category question (Q) was calculated as the percent of LTC residents that answered individual score ratings with a calculated mean score for each individual question and a total Q mean of all LTC facilities question responses for each individual question. The Category (C) Mean represents the entire question category for each individual LTC facility. The calculation of the Q Mean, Total Q Mean, and C Mean is based upon resident scores five through two. An answer related to a score of one represents no opinion and is not included in the calculations since it would lower the mean and not represent accurate results regarding quality, dignity, ethical and humanistic care.

LTC A Survey 1 Results

The LTC A survey one was administered prior to the healthcare professionals Humanistic Patient Narrative Theory in-service training. Eight residents participated in the research. Specific results to questions which might be of interest will be discussed in this context. Results indicated a lower category mean in Quality of care (m=3.83) and the highest category mean in Humanistic care (m=4.54). Dignity category (m=4.2) is slightly higher than the Ethics category (m= 4.16). Eight residents participated in the survey. Figure 1.1 represents the LTC A survey one comparative category results.

Disagree responses with question number one regarding the healthcare professionals having a fifteen-minute conversation daily with them accounted for 38 percent of the responses. Residents agreed or somewhat agreed in 50 percent of the responses and 13 percent answered they strongly agreed healthcare professionals spoke to them for fifteen minutes daily. A total of 25 percent strongly agreed or agreed that healthcare professionals teach residents about health prevention to keep healthy, 50 percent somewhat agreed and 25 percent disagreed. Responses to question number ten indicated 38 percent of residents somewhat agreed and 13 percent disagreed that healthcare professionals do not appear rushed when speaking or providing care to them. Residents strongly agreed with a 50 percent response and 38 percent agreed that healthcare professionals take care of their needs in a reasonable amount of time.

The residents' scores for dignity were largely in the strongly agree and agree ratings representing 50 percent or higher of the scores. Residents largely scored the healthcare professionals encouraging them to control their own sleep wake patterns lower than the other categories. Surveys indicated that 50 percent of residents somewhat agreed

and 13 percent disagreed, which indicated residents feel as though they are unable to control their own sleep wake patterns. The residents rated most of the ethics questions as 50 percent or higher as strongly agree or agree. Combined scores of 75 for strongly agreed or agreed represented the residents' answer that the healthcare professionals support individual rights to accept or refuse care. Education regarding the patient bill of rights scored lower than other categories with just 13 percent agreed they are educated regarding the bill of rights, 25 percent disagreed and 13 percent somewhat agreed. A combined 38 percent of the residents indicated they strongly agreed or agreed that healthcare professionals educate them about their care so that they can decide what is right for them; 38 percent of the residents somewhat agree.

Humanistic care ratings were 75 percent or above in all of the question categories. A combined 88 percent of the residents answered strongly agree and agree indicating healthcare professionals maintain their dignity. Residents scored the nurses and nursing assistants as trust worthy in a combined score of 88 percent including strongly agree and agree responses. The residents' response to questions regarding the receipt of Humanistic Care was clearly the highest score for the first survey.

LTC B Survey 1 Results

The mean for the Quality category (m=3.74) at facility B represents the lowest survey one mean. Humanistic Care (m=4.54) has the highest mean. Dignity (m=4.31) is in the second highest with Ethics (m=4.15) having the second lowest mean. Ten residents participated in the survey. Appendix C Figure 1.2 represents the LTC B survey one mean comparison of category results.

The residents' responses to question one regarding healthcare professionals having a fifteen-minute conversation daily received a score of 20 percent strongly agreeing and 10 percent agreeing. Resident responses were 20 percent somewhat agree and 40 percent disagree about healthcare professionals having a fifteen-minute conversation daily with them. The combined 50 percent score of strongly agree and agree responses are indicated for healthcare professionals showing a true interest in the person during conversations, 40 percent somewhat agree and 10 percent disagree indicating a fifty-fifty split in the responses about the healthcare professionals' interest in residents. Positive healthcare professionals' attitudes during the provision of care has similar scores to the latter survey question. Strongly agree and agree scores account for a combined total of 50 percent where as a combined score of 40 percent is represented in somewhat agree and disagree response. It is important to note that 90 percent of the combined strongly agree and agree responses indicate the healthcare professionals provide safe care. A combined 70 percent score of the residents strongly agrees and agree that the healthcare professionals are highly trained and educated. Health prevention education is represented as 50 percent strongly agree or agree and 50 percent somewhat agree and disagree. Spiritual and Emotional needs are also met strongly or agreed upon by a 50 percent resident response while 50 percent somewhat agree. Residents are divided on the last question about the healthcare professionals not appearing rushed when providing care; 50 percent have a combined score of strongly agree and agree accompanied by a 50 percent score of somewhat agree and disagree.

The entire category dignity of care survey questions represents greater than a 50 percent favorable strongly agree and agree response. Combined strongly agree and agree

responses of 90 percent indicate that the healthcare professionals encourages them to be part of the residents' community. Residents also indicate strongly by a 90 percent combined strongly agree and agree responses that healthcare professionals involve family in their care. Residents indicated that the healthcare professionals encourage them to control their own sleep patterns by a 70 percent response. Residents indicated by 60 percent strongly agreeing and 10 percent agreeing about healthcare professionals encouraging them to participate in decisions about their care. The overall mean of this category was the highest on this survey.

LTC B scored over 50 percent in the ethics category questions in a combined score of strongly agree and agree responses. Combined scores of 80 percent include the healthcare professionals' respect about personal needs, healthcare professionals' respect of worth as a human being, right to refuse care, and the healthcare professionals are non-judgmental about residents' personal beliefs.

The Humanistic care category scored as a whole greater than 50 percent in a combined score for strongly agree and agree responses. The residents responded that 40 percent strongly agreed and 40 percent agreed regarding healthcare professionals maintaining dignity. Residents indicated in a score of 80 percent that healthcare professionals advocate for their best interests. Residents strongly agree and agree by 70 percent that healthcare professionals treat them as a whole person and not only as a person with a medical condition.

LTC C Survey 1 Results

The residents' responses indicate that Quality category (m=3.1) has the lowest mean score as compared to the other categories. Dignity (m=3.6) follows as second lowest and Ethics (m=3.65) is the second highest. Humanistic Care (m=3.7) has the highest category mean. Ten residents participated in the survey. Appendix C Figure 1.3 represents the LTC C survey one comparative category results.

Residents disagree with a score of 80 percent about the healthcare professionals having a fifteen-minute conversation daily. Residents responded as a combined 70 percent score of strongly agree and agree responses regarding healthcare professionals having a positive attitude when providing care. A combined score of 80 percent for the residents' responses as strongly agree and agree indicating healthcare professionals provide safe care. Residents' scores decreased as 30 percent somewhat agree and 30 percent disagree about healthcare professionals teaching the residents health prevention to keep healthy. The majority of residents disagreed by 60 percent regarding the healthcare professionals not appearing rushed when speaking or providing care to them.

Dignity of care questions received higher scores overall. A combined strongly agree and agree response equaling 70 percent stated that healthcare professionals treat them with respect. The provision of privacy during physical care was scored as 20 percent stating strongly agree and 50 percent agreeing. Privacy provided during conversations received a total combined strongly agrees and agrees score of 60 percent. Residents scored encouragement by healthcare professionals to be part of the community and inclusion of family in care when residents wished for them to be included, as a combined strongly agree and agree score of over 60 percent. Overall, 60 percent of

residents agree that the healthcare professionals encourage them to control sleep and wake patterns.

Residents' responses to the questions regarding ethics was 40 percent or higher in combined strongly agree and agree responses. Combined scores of 80 percent of the residents strongly agree and agree that the healthcare professionals support individual rights to accept or refuse care. Resident responses of 10 percent strongly agree and 60 percent agree about the healthcare professionals educating them about the bill of rights. Residents' responses indicate by 60 that the healthcare professionals are non-judgmental about personal values and beliefs. Healthcare professionals encouragement for residents' participation in decision making within the residence received scores of 20 percent disagree and 30 percent somewhat agree. The question regarding whether healthcare professionals educate residents about their care so that they can decide what care is right for them received scores of 30 percent somewhat agree and 20 percent disagree.

Mixed responses were identified for the humanistic care category question addressing healthcare professionals respecting residents: 10 percent strongly agree, 30 percent agree, 30 percent somewhat agree, and 25 percent disagree. Residents responded with a 50 percent somewhat agree response regarding healthcare professionals are trust worthy, 30 percent agree, and 10 percent strongly agree. Responses of residents include 10 percent of residents strongly agree and 70 percent agree that healthcare professionals treat them as a whole person not only as a medical condition. Overall, 60 percent of residents agree that the healthcare professionals have good and caring relationships with residents.

LTC D Survey 1 Results

The Quality (m=3.52) category received the lowest mean score out of the four categories. Humanistic Care (m=4.2) remained the highest category. Ethics (m=3.58) had the second lowest mean and Dignity (m=4.04) was the second highest. Seven residents participated in the survey. Appendix C Figure 1.4 represents LTC D survey one comparative category results.

Responses of 29 percent somewhat agree that healthcare professionals have a fifteen-minute conversation daily in contrast to forty three percent disagreeing. There are higher resident responses, indicating 71 percent somewhat agree regarding healthcare professionals teaches them about health prevention to keep healthy. Resident responses indicate 43 percent somewhat agree about healthcare professionals communicating to each other and working as a team during the provision of care. Greater than 50 percent agree about healthcare professionals not appearing rushed when providing care. A combined strongly agree and agree score of 62 percent represents residents' score for healthcare professionals taking care of their needs in a reasonable amount of time.

Residents responded with a combined total of strongly agree and agree responses of 86 percent regarding healthcare professionals treating them with respect. The question regarding healthcare professionals caring for the emotional, spiritual, social, and physical well-being of the residents received mixed responses. A mixed response of 14 percent strongly agreed, 29 percent agreed, 14 somewhat agreed, 14 percent disagreed. Residents agreed by 30 percent that healthcare professionals encouraged them to control their own sleep and wake patterns. The response was matched by 29 percent somewhat agreeing and 14 percent of the respondents disagreeing. The same division of responses is

identified in the question regarding healthcare professionals encouraging residents to participate in decisions about their care; 43 percent of the residents agree and 43 percent of the residents somewhat agree.

The ethics category responses varied with the majority of the responses in the agree and somewhat agree categories. Residents scored healthcare professionals as being respectful and supportive in their unique personal needs as 14 percent strongly agreeing and 57 percent agreeing. A slightly higher than average score of 57 percent of the resident responses agree that the healthcare professionals treat them equally and fairly, while 71 percent of the combined scores represent strongly agree and agree responses in regards to healthcare professionals respecting their worth as a human being. A total of 43 percent of the residents responded that they disagreed about healthcare professionals educating them regarding the bill of rights. Lastly, 57 percent of the resident responses indicated the healthcare professionals somewhat encourages them to participate in decision making.

Humanistic care received the highest mean category score. All of the questions received scores of strongly agree and agree scores above 50 percent. Residents' responses of 75 percent strongly agree and agree responses were indicated for the healthcare professionals' respect of the resident, healthcare professionals maintaining the residents' dignity, residents feeling encouraged to live their lives the way they want to live, being treated as a whole person versus a medical condition, and the healthcare professionals have a good and caring relationship with the residents.

LTC Category Mean Comparisons Survey 1 Results

Appendix C Figure 1.5 indicates that LTC A (m=3.83) ranks with the highest mean for quality of care in comparison to LTC B, LTC C and LTC D. The LTC C (m=3.1) quality mean is the lowest of the four facilities. LTC B (m=4.31) is portrayed in Appendix C Figure 1.6 as the highest mean for the Dignity category and LTC C (m=3.6) as the lowest mean. In Appendix C Figure 1.7 LTC A (m=4.15) has the highest mean in for ethical care and LTC D (m=3.58) represents the lowest mean. All of the LTC facilities scored high for Humanistic care. LTC A (m=4.54) represents the highest Humanistic care mean and LTC C (m=3.71) is the lowest which is portrayed in Appendix C Figure 1.8.

Mean of all LTC Facilities Survey 1 Categories

The mean of all LTC facilities' individual categories combined is represented in Appendix C Figure 1.9. Comparison of all four LTC facilities represents the category of Quality has the lowest mean (m=3.54) and Humanistic Care (m=4.09) represents the highest overall mean score. Ethical Care (m=3.92) represents the second highest mean. The Dignity (m=3.8) category is the second lowest category.

LTC A Survey 2 Results

The second resident survey results that were administered one week after Humanistic Narrative Training indicates that Quality (m=3.76) remains the lowest mean score. Ethics (m=4.16) was second lowest with Humanistic Care (m=4.51) second to highest. Dignity (m= 4.53) ranked as highest. The results are similar to the first survey.

Quality scored slightly lower at a mean of 3.76 versus the 3.83 first survey result. The Dignity mean increased slightly to 4.53. Ethics mean of 4.16 represents the same result as survey 1. Seven residents participated in the survey completion compared to ten respondents for the first survey. Humanistic care was comparable to the first survey. The LTC A survey mean category results are represented in Appendix C Figure 2.1.

Interestingly, the results on the second survey results indicate that 71.42 percent disagree regarding healthcare professionals having a daily fifteen-minute conversation. Somewhat agree responses included 28.57 of the results. The residents strongly agreed at 42.85 percent and agreed by 57.14 percent that the healthcare professionals provide safe care to them. Health prevention teaching remains varied in responses with 14.28 percent strongly agreeing, 28.57 agreeing, 28.57 somewhat agreeing, and 28.57 percent disagreeing. Positive healthcare professional attitudes increased from the first survey. Healthcare professionals' communication scores of 14.28 percent strongly agreeing and 42.85 percent agreeing slightly increased on the second survey as compared to survey one. Healthcare professionals not appearing rushed when speaking or providing care decreased, which is represented by 14.28 percent of residents strongly agrees and 28.57 agree. As compared to the first survey, 37.5 percent strongly agreed that healthcare professionals were not rushed when speaking or providing care and 12.5 percent agreed.

Dignity scored a higher mean on the second survey with 100 percent strongly agreeing that the healthcare professionals treat them with respect versus the first survey mean of 87.5 percent strongly agreeing with this question. Healthcare professionals' provision of privacy when providing care also increased to one hundred percent. Approximately a combined result of 85 percent of the residents strongly agreed and

agreed to the healthcare professionals providing privacy during personal conversations versus a combined result of 75 percent on survey one. Healthcare professionals caring for the emotional, spiritual, social and physical well-being scores also increased on the second survey with 42.85 percent strongly agreeing and 42.85 percent agreeing. Residents indicated higher survey results for the question regarding healthcare professionals encouraging them to be part of the residents' community, which is represented by a score of 14.28 percent strongly agreeing and 71.42 percent agreeing. Inclusion of family in the residents' care survey category also increased to a cumulative strongly agrees and agrees responses of 86 percent versus 75 percent on the first survey. Eighty-four percent of the residents identified that healthcare professionals encourage them to control their own wake patterns, and 85 percent indicate that they are encouraged to participate in their care. These two categories represent higher scores than the first survey.

The Ethics category question related to healthcare professionals treating all residents equally and fairly slightly decreased on the second survey to 57.14 percent strongly agreeing and 14.28 percent agreeing. On the second survey, residents indicated that the healthcare professionals respect their worth as a human being slightly lower with a score of 71.42 strongly agreeing and 14.28 agreeing versus the first survey scores. Resident education regarding the patient bill of rights slightly increased to 28 percent combined strongly agree and agree versus 12.5 percent agreeing on the first survey. There is a significant increase in the resident responses of 14.28 strongly agree and 71.42 agree that healthcare professionals educate them about their care so they can decide what

care is right for them. The first survey results for the same question was 12.5 percent strongly agreed and 25 percent agreed.

The Humanistic Category had higher survey scores on all of the questions except for the question regarding healthcare professionals advocating for the residents' best interests. Survey two indicates 42.85 strongly agree and 42.85 percent agree versus survey one results of 50 percent strongly agreeing and 37.5 percent agreeing. A slightly lower score for the survey two questions regarding healthcare professionals has a good and caring relationship with the residents is represented by scores of 57.14 percent strongly agreeing and 28.57 percent. In comparison, the first survey results indicate a slightly higher score in the categories strongly agree responses representing 37.5 percent and 50 percent agree responses.

LTC B Survey 2 Results

The category results for survey two are closer in range for LTC B. Survey mean results for the Quality category (m=3.61) represent the lowest mean score and Humanistic Care had the highest mean (m=4.21). The Dignity category (m= 4.0) was second highest and Ethics (m= 3.9) represented the second lowest category. The results are different from the first survey which indicated Dignity as the highest score and Humanistic Care as second highest. Both surveys had ten residents participate and complete the surveys. Appendix C Figure 2.2 depicts the LTC B category mean results.

Residents indicated that 10 percent strongly agreed the healthcare professionals have a positive attitude when providing care and 50% agreed as compared to survey one 40 percent strongly agreed and 10 percent agreed. The score for the question regarding

healthcare professionals being highly trained and educated decreased on survey two indicating 10 percent of residents strongly agree and 40 percent agree. The provision of safe care from the healthcare professionals question also had decreased responses with 10 percent of residents strongly agreeing and 50 percent agreeing versus the first survey residents' responses of 60 percent strongly agreeing and 30 percent agreeing. There were slight increases in strongly agree and agree responses for several of the questions as compared to survey one.

Dignity of Care questions for survey two had insignificant slightly lower strongly agree and agree responses. The question regarding healthcare professionals including family in their care when they want them to be involved had lower results with 30 percent of residents stating they strongly agree and 40 percent stating they agree, compared to survey one with 60 percent strongly agreeing and 30 percent agreeing. Results for survey two were higher for the question about whether healthcare professionals encourage the residents to control their own sleep/wake patterns versus survey one. A total of 90 percent combined strongly agree and agree responses for survey two versus survey one combined responses of 70 percent strongly agree and agree indicate improvement on survey two.

The Ethics category of survey questions were all either equal to or had higher mean resident responses for each question with strongly agree or agree responses. The survey two question regarding healthcare professionals are respectful and supportive of their unique personal needs resulted in 90 percent of the respondents answering strongly agree or agree. The residents also indicated a higher mean score on survey two of 30 percent strongly agreeing and 60 percent agreeing that the healthcare professionals

respect their worth as a human being, versus survey one scores of 50 percent strongly agreeing and 30 percent agreeing. The overall mean of the category is slightly lower on the second survey with a result of 3.89 versus 4.01 on survey one.

Humanistic Care category results were higher on the second survey except for the question asking if the healthcare professionals have a good and caring relationship with the residents. Survey two results were 20 percent strongly agree and 50 percent agree compared to survey one results of 60 percent strongly agree and 20 percent agree. Survey two resident responses for healthcare professionals respecting them were higher with median scores of 30 percent strongly agreeing and 50 percent agreeing. Residents responded with higher scores for the topic of healthcare professionals encouraging them to live the way they want to live with scores of 20 percent strongly agreeing and 60 percent agreeing.

LTC C Survey 2 Results

The survey 2 category mean results for LTC C were all lower than the first survey category means. Quality of Care (m=2.83) remains the lowest category and Dignity (m= 3.25) is the second lowest. Humanistic Care (m=3.53) remains the highest category with Ethics (3.28) trailing slightly ahead of Dignity. Appendix C Figure 2.3 depicts the LTC C category mean results. Six people responded on the second survey versus ten respondents on the first survey. Residents rated the healthcare professionals as having a positive attitude when providing care lower with only 16.66 agree and 66.66 somewhat agree responses. The first survey response to the question resulted in a higher combined strongly agree and agree score of 70 percent. The question related to healthcare

professionals being highly trained and educated resulted in lower scores on the second survey with 33.33 percent agreeing, 16.66 percent somewhat agreeing and 50 percent disagreeing. Healthcare professionals teaching residents about health prevention to keep healthy received lower scores of 16.66 agree, 12.66 somewhat agree, and 66.66 percent disagreeing. Residents also strongly disagreed that healthcare professionals provide for the emotional, spiritual, and physical needs with a 66.66 percent disagree rating versus a 30 percent disagree rating on the first survey. 100 percent of the residents scored the question relating to healthcare professionals communicating with each other and working as a team as strongly agree and agree.

Dignity of Care question survey two results are similar to the survey one results except for a couple of question responses. The healthcare professionals encouraging residents to be part of the community received a survey two 66.66 agree rating compared to the survey one, which was 20 percent strongly agree and 60 percent agree. Scores also decreased to 33.33 agree response for the question regarding healthcare professionals encouraging the resident to control his/her sleep wake patterns. A decreased category mean is noted regarding the healthcare professional encouraging residents to participate in decision making. Survey two results indicate 16.66 percent agree versus survey one depicts ten percent strongly agreeing and forty percent agreeing.

Responses vary for the Ethics survey questions. There was an increase of 66.66 percent for the residents' responses indicating that they agree regarding the healthcare professionals treating residents equally and fairly versus survey one combined results of 40 percent strongly agree and agree responses. There is a 10 percent increase for the question relating to healthcare professionals respecting the resident's worth as a human

being. In regards to healthcare professionals supporting individual rights to accept or refuse care, resident responses decreased to 50 percent agree versus the first survey response of 20 percent strongly agree and 60 percent agree. Residents responded with 33.33 percent agreeing in response to the question asking if healthcare professionals encourage them to participate in decision making within the residence.

The Humanistic Care category survey responses indicate 100 percent of the residents agreed that the healthcare professionals maintain their dignity. This represents an increase of 30 percent from survey one. Fifty percent of the residents feel that the healthcare professionals encourage them to live life the way they want to live, versus a 70 percent favorable response on the first survey. A decrease to 50 percent of the residents versus 80 percent of the first survey responses is seen in relation to healthcare professionals treating the resident as a whole person not only as a person with a medical condition.

LTC D Survey 2 Results

LTC D Survey Quality Care results slightly increased (m= 3.71) from survey one Quality Care (m= 3.52). The Dignity category mean decreased from survey one (m=4.04) to (m= 3.69) on survey two. Ethics (m=3.81) and Humanistic Care (m= 4.15) increased slightly in this survey response as represented in Appendix D Figure 2.4. Five residents participated in the survey versus seven responses on the first survey.

The Quality of Care question asking if the healthcare professionals show a true interest in the resident during conversations increased to 80 percent from 57 percent on survey one. Healthcare professionals having a positive attitude also received positive

responses from the residents on the second survey with an increase in the responses to 20 percent strongly agreeing and 80 percent agreeing. Residents responded higher scores for healthcare professionals communicating and working as a team with a response of 60 percent agreeing. Healthcare professionals not appearing rushed when speaking or providing care also received higher scores of 80 percent agreeing with this question.

Residents had an 80 percent combined strongly agree and agree positive response on the second survey in response to the Dignity category question asking if healthcare professionals treat them with respect. There was a decrease in the score for the question about healthcare professionals caring for residents' emotional, spiritual, social, and physical well-being. The score decreased from survey one strongly agreeing and agreeing with a 42 percent response to the second survey response of 20 percent strongly agreeing. Residents decreased the score for healthcare professionals encouraging them to control their own sleep wake patterns to 20 percent agreeing. The healthcare professionals' encouragement of residents to participate in their own care decreased by half the responses from the first survey to 20 percent of the residents agree in the second survey.

The category of Ethics increased slightly in the overall category mean. Residents' responses for being treated by the healthcare professionals respectfully and providing support of their unique personal needs decreased to 40 percent from 71 percent on survey one. There was an increase in 80 percent of the residents agreeing that healthcare professionals respect their worth as a human being. The question regarding healthcare professionals supporting their right to accept or refuse care also had an increased response of 20 percent strongly agreeing and 60 percent agreeing. The healthcare

professionals' encouragement of the resident to participate in decision making within the residence increased to 20 percent strongly agree and 20 percent agree.

Humanistic Care as a whole increased slightly from a survey one category mean of 4.09 to 4.15 on survey two. Residents responded to the first question of healthcare professionals respecting them on survey two with a decreased score of 40 percent strongly agree and 20 percent agree. The question related to healthcare professionals treating the resident as a whole person and not just a person with a medical condition had a resident response increase of 20 percent strongly agree and 80 agree. The same 80 percent strongly agree and 20 percent agree response is seen for the question regarding healthcare professionals having a good and caring relationship with the resident.

LTC Category Mean Comparisons Survey 2 Results

Appendix C Figure 2.5 indicates that LTC A (m=3.76) continues to rank as the highest mean for quality of care in comparison to LTC B, LTC C, and LTC D. The LTC C (m=2.83) quality mean is the lowest of the four facilities. LTC A (m=4.53) has the highest mean for the Dignity category and LTC C (m=3.25) as the lowest mean as represented in Appendix C Figure 2.6. The LTC A (m=4.16) continues to have the highest mean for the Ethics category and LTC C (m=3.28) has the lowest mean which is represented in Appendix C Figure 2.7. Humanistic Care results are identical to the other categories with LTC A (m=4.51) representing the highest mean and LTC C (3.53) with the lowest mean in Appendix C Figure 2.8.

Mean of all LTC Facilities Survey 2 Categories

The mean of all LTC facilities individual categories combined is represented in Appendix C Figure 2.9. Comparison of all four LTC facilities represents a similar pattern of the lowest and highest means on the survey one LTC facility comparison. The category of Quality has the lowest mean and Humanistic Care represents the highest overall mean score. Ethical Care represents the second lowest mean. The Dignity category is the second highest category. The Quality (m=3.53) category mean decreased along with the Humanistic Care (m=4.05) category mean decreased. These are insignificant mean differences from the first survey. The Dignity (m=3.96) category mean increased from (m=3.8) compared to survey one. Similarly, the Ethics (m=3.86) category increased from (m=3.6) on survey one.

LTC A Survey 3 Results

The last of the three surveys for LTC A indicates the Quality (m=3.52) category remains the lowest mean out of the four categories. Ethics (m=3.61) is the second lowest category, Dignity (m=3.69) is the second highest. Humanistic Care (3.72) has the highest mean. Quality of care mean has been consistent as being the lowest mean for LTC A throughout the three surveys. Ten residents participated in this survey. Appendix C Figure 3.1 represents the LTC A survey three comparative category results.

Quality of care in relation to the question about healthcare professionals having a positive attitude when providing care to the residents had an increased response of 90 percent agree. A continued decrease in residents' responses that healthcare professionals have a fifteen-minute conversation daily is represented as 10 percent agree and 80

percent disagree. The third survey shows a continued decline in the score for healthcare professionals teaching about health prevention to keep residents healthy with a score of 20 percent, 40 percent somewhat agree and 30 percent disagree. Healthcare professionals' communication and working as a team increased to 90 percent agree. Healthcare professionals not appearing rushed when speaking or providing care increased to a score of 70 percent agree.

The Dignity category question regarding healthcare professionals treating residents with respect indicated 100 percent agree. The healthcare professionals treating all residents equally and fairly are identified as improved in the Ethics category with 90 percent of agrees responses. The question asking if healthcare professionals educate the residents about the bill of rights continues to decline with the survey response of 20 percent agrees and 80 percent disagree. The question regarding healthcare professionals keeps care confidential increased to 100 percent of the responses agree. The same holds true for a 100 percent agree response to healthcare professionals are non-judgmental about personal values and beliefs. Resident responses regarding healthcare professionals education about care so they could decide what is right for them decreased from a combined strongly agree and agree response of 85 percent on survey two to 50 percent agree and 20 percent somewhat agree on survey three.

The Humanistic care category scores are excellent with combined strongly agree and agree scores of 90 percent for all except for the question regarding healthcare professionals advocating for the resident's best interests. The response to this question decreased to slightly less than the first survey response by a score of 70 percent agree and 10 percent somewhat agree.

LTC B Survey 3 Results

Quality (m=3.58) remains the lowest category and Ethics (m=3.67) is the second lowest for all three survey responses. Dignity (m=3.77) and Humanistic Care (m=3.95) fluctuated on the survey means with the end result of Humanistic Care having the highest third survey mean. Ten residents participated in the survey. The survey results are depicted in Appendix C Figure 3.2 LTC B Survey 3 Mean Comparison all categories.

Overall the Quality of Care category increased in positive agrees responses with slightly higher results in several of the categories compared to the first and second surveys. Residents responded to the question about the healthcare professionals having a fifteen-minute conversation with them daily as 12.5 somewhat agrees and 87.5 percent disagree. Responses to healthcare professionals showing interest during conversations increased to 62.5 percent agree, 12.51 somewhat agree and 25 percent disagree.

Residents responded as 62.5 percent agree and 25 percent somewhat agree in regards to healthcare professionals have a positive attitude when providing care. A response stating 100 percent agree is noted for the question about healthcare professionals providing safe care. A decrease in scores is identified for the question about healthcare professionals teaching health prevention to keep residents healthy with scores of 12.5 percent strongly agree, 12.5 percent agree, 25 percent somewhat agree, 50 percent disagree. The question regarding healthcare professionals communication and teamwork during the provision of care increased to 12.5 percent strongly agree, 62.5 percent agree and 25 percent somewhat agree.

The Dignity of Care question corresponding to healthcare professionals treating the resident with respect results are 12.5 percent strongly agree and 87.5 percent agree.

Healthcare professionals caring for the emotional, spiritual, social, and physical well-being resulted in 37.5 percent agree, 25 percent somewhat agree, and 25 percent disagree. The other questions related to Dignity had insignificant differences in results for all three surveys. Overall the Dignity category resulted in favorable responses for all surveys.

Healthcare professionals that are respectful and supportive of the resident's needs received 75 percent agree, 12.5 percent somewhat agree, and 12.5 percent disagree. This Ethics question has indicated a gradual increase in all three surveys after the in-service training. The question regarding healthcare professionals respect of worth as a human being increased gradually over the past three surveys to 12.5 percent strongly agree and 62.5 percent agree, and 12.5 percent somewhat agree. Healthcare professionals' support of the individual resident's rights to accept or refuse care resulted in 62.5 percent agree and 25 percent somewhat agree responses. Education about the patient bill of rights is decreased with scores of 37.5 percent agree and 62.5 percent disagree. Residents responded as 87.5 percent agree and 12.5 disagree about the question regarding healthcare professionals keeping care confidential. The question in relation to healthcare professionals encouraging the resident to participate in decision making within the residence increased slightly to 37.5 percent agree, 12.5 percent somewhat agree, and 37.5 percent disagree.

The Humanistic Care category results positively increased in the majority of answers within the strongly agree and agree categories. Residents identified that healthcare professionals respect them with 100 percent agree responses. The question regarding healthcare professionals maintaining their dignity resulted in 87.5 percent agree and 12.5 disagree responses. Residents agree by 75 percent that healthcare professionals

encourage them to live their life the way they want it to be lived and 25 percent disagree. Scores indicated improvement in the residents' responses that healthcare professionals advocate for their best interests by 62.5 percent agree, 25 percent somewhat agree and 12.5 percent disagree responses. Residents responded as 75 percent agree about healthcare professionals treating them as a whole person and also that the healthcare professionals has a good and caring relationship with the residents.

LTC C Survey 3 Results

Quality Care (3.3) continues to be the lowest mean and Humanistic Care (m=3.8) represents the highest mean. Dignity (m=3.66) represents a higher category mean than Ethics (m=3.35). Ten residents responded to the third survey. The survey results are depicted in Appendix C Figure 3.3 LTC C Survey 3 Mean Comparison all categories.

Residents' response to the question about healthcare professionals having a fifteen-minute conversation daily continues to demonstrate the similar survey results of 80 percent disagree, 10 percent agree and 10 percent somewhat agree. Healthcare professionals showing true interest in the residents during conversations had scores of 30 percent agree, 50 percent somewhat agree, 20 percent disagree. Positive attitudes from healthcare professionals during the provision of care are scored as 10 percent strongly agree and 60 percent agree. Residents had a positive response indicated by 10 percent strongly agree and 30 percent agree about healthcare professionals being highly trained and educated. There is a slight increase in the resident response to the question about healthcare professionals teaching about health prevention to keep residents healthy. The results indicate that 10 percent of the participants strongly agree, 30 percent agree, and 30

percent somewhat agree. Healthcare professionals provision of care for the resident's emotional, spiritual, and physical needs increased to 30 percent agree and 40 percent somewhat agree. The healthcare professionals' communication and working as a team received decreased responses of 30 percent agree, 30 percent somewhat agree, 30 percent disagree. There is a consistent decline in the scores for healthcare professionals taking care of needs in a reasonable amount of time and is represented as 30 percent agree, 50 percent somewhat agree, 20 percent disagree. Less than half the responses indicate that the healthcare professionals do not appear rushed when speaking or providing care to the resident with scores of 40 percent agrees and 60 percent disagree.

Dignity of care responses for the healthcare professionals treating residents with respect has decreased to 10 percent strongly agree, 60 percent agree, 30 percent somewhat agree. The results for healthcare professionals caring for the emotional, spiritual, social, and physical well-being remain low and have not fluctuated much on the three surveys with survey three results of 10 percent strongly agree, 10 percent agree, 50 percent somewhat agree, and 30 percent disagree. Residents responded to the question regarding healthcare professionals encouraging them to control their own sleep wake patterns as 60 percent agree. Results remain similar to survey one about healthcare professionals encouraging residents to participate in decisions about their care evidenced by results of 10 percent strongly agree, 40 percent agree, 20 percent somewhat agree, and 30 percent disagree.

The Ethics category question of healthcare professionals treat all residents equally and fairly resulted in 10 percent strongly agree, 30 percent agree, 30 percent somewhat agree, and 20 percent disagree. The healthcare professionals respect for the residents'

worth as a human being had decreased responses of 20% strongly agree, 20% agree, and 10% disagree. An increase of 20 percent and 60 percent of residents' responses for the question corresponding to healthcare professional's support of individual rights to accept or refuse care.

LTC D Survey 3 Results

The Ethics (m=3.76) ranks the lowest the four category means with Humanistic Care (4.2) representing the highest mean. Quality Care (3.8) is the second lowest with Dignity (4.0) representing the second highest category. Four residents participated in this survey. Appendix C Figure 3.4 represents the LTC D survey three comparative category results.

The Quality Care category survey three results have similar responses on all three surveys. A significant increase in responses is identified for the question related to healthcare professionals providing care for the emotional, spiritual, and physical needs of the residents with responses of 75 percent agree and 25 percent disagree. Healthcare professionals' communication and teamwork during the provision of care also received higher scores with 75 percent agree and 25 percent somewhat agree responses. Residents responded positively with 25 percent strongly agree and 75 percent agree about healthcare professionals taking care of the needs in a reasonable amount of time.

The Dignity of Care category overall has positive survey responses for all three surveys. Survey three indicates improvement in several of these areas. Residents responded as 25 percent strongly agree and 75 percent agree about healthcare professionals treating them with respect. The healthcare professionals' provision of

privacy when providing physical care resulted in 25 percent of strongly agree and 75 percent agree responses. An improvement in the score for the question about healthcare professionals encouraging the resident to be part of the community is indicated in the 75 percent agrees response. Family inclusion in the resident's care when the resident desired it had a 100 percent agree response. A 100 percent agree response indicates improvement in responses for healthcare professionals encouraging the resident to control their own sleep and wake patterns. Healthcare professionals encouragement for the residents to participate in their care increased to 75 agree and 25 percent somewhat agree responses.

Residents identified that healthcare professionals are respectful and supportive of unique personal needs in the response of 100 percent agree. The question regarding healthcare professionals treating all residents equally and fairly resulted in 50 percent agree, 25 percent somewhat agree responses, which indicates similar responses for all three surveys. Healthcare professionals respecting the resident's worth as a human being scores decreased to 50 percent agree. Support of the resident's rights to accept or refuse care received 100 percent agree responses. Healthcare professionals' education about the bill of rights had a 50 percent agree response. The healthcare professionals' encouragement for residents to participate in decision making remains at 50 percent agree. Education by the healthcare professionals about the residents' care so they can decide what is right for them had a 50 percent agree response.

The Humanistic Care category responses are similar for all three surveys. All three surveys have mostly strongly agreed and agree responses. The question about healthcare professionals encouraging the residents to live their life the way that they want

it to be lived increased to 75 percent agree. Healthcare professionals advocating for the best interests of the residents increased to 75 percent agree.

LTC Category Mean Comparisons Survey 3 Results

Appendix C Figure 3.5 represents the mean comparison of individual LTC Facilities Quality Category as LTC D (m=3.8) indicates the highest Quality mean of the four LTC facilities for survey 3 and LTC C (m=3. 3) ranks the lowest. LTC B (m=3.58) ranks second highest and LTC A (m= 3.52) is the third highest. The highest Dignity Category mean is represented in Appendix C Figure 3.6 as LTC D (m=4.02) having the greatest mean and LTC C (m=3.66) as the lowest mean. The mean comparison of Ethics in Appendix C Figure 3.7 indicates LTC D (m=3.75) as the highest mean and LTC B (m=3.67) results indicate the second highest mean. LTC A (m=3.61) is in the middle range and LTC C (m=3.35) represents the lowest mean. Appendix C Figure 3.8 represents the comparison of means for the category Humanistic Care. LTC D (m=4.2) continues to have the highest mean for all four categories and LTC A (m=3.72) represents the lowest mean for the Humanistic Care category. LTC B (m=3.96) has the second highest mean and LTC C (m=3.8) has the third highest.

Mean of all LTC Facilities Survey 3 Categories

The Dignity category (m=3.31) in Appendix C Figure 3.9 represents the lowest category mean and Humanistic Care (m=3.99) represents the highest category mean. Ethics (m=3.63) is the second highest category mean and Quality (m=3.56) is the second lowest mean.

The survey results indicate that 83 percent of individual LTC facilities Quality Category results for survey one through survey three represented the lowest mean of the four categories. Survey one through survey three results indicate that 75 percent of individual LTC facilities Ethics Category results represent the second lowest mean of the four categories. The combined Quality Category question one mean of all LTC facilities on the three surveys was the lowest question mean of all survey questions (m= 2.6) in each category. Question one asked if the healthcare professionals had a fifteen-minute conversation with the resident every day. Although the overall Quality Category mean findings are insignificant the research indicates that Question one in the Quality Category consistently resulted in lower scores by the LTC residents and indirectly lowered the overall category mean. Appendix C Figures 1.1 through 1.4, Figures 2.1 through 2.4, Figures 3.1 through 3.4, and Figures 4.1 through 4.4 portray the Quality Category means of the LTC facilities.

When retrieving the completed surveys many LTC residents requested that the researcher sit down and stay for a while to have a discussion with them. This further supports the LTC residents' needs to have meaningful conversation with others. During the discussion several LTC residents stated that the nurse does not have time to talk to them. Some residents stated that nurses came in to see them long enough to give a pill and then they left. Several LTC residents developed trust in the researcher and began to disclose concerns about the provision of care in the LTC facility that they resided in. LTC residents were asked if the concerns should be brought forward to the healthcare professionals. All of the residents involved did not feel comfortable with this and requested that the discussions not be disclosed. My personal observations during the

research indicated that the healthcare professionals are often busy providing direct care to many LTC residents without much spare time to have meaningful discussions with LTC residents. The healthcare professionals identified during the Humanistic Patient Narrative Theory in-services that they do not have the time during their scheduled work hours to speak at length with residents. The LTC residents' survey responses to question one support the limited number of conversations between LTC healthcare professionals and LTC residents.

The Humanistic Patient Narrative Theory in-services reinforce to healthcare professionals the basic needs for narrative as human beings to perceive and experience the provision of quality care. Meaningful and trust worthy conversations between LTC residents and healthcare professionals are a necessary component in the provision of quality care. Narrative guides the healthcare professionals in providing the LTC resident's individualized ethics based care. Nurses and nursing assistants learn the principles about the provision of quality, ethical, patient centered, and individualized care in their pre-licensure educational programs. The in-services serve as a reminder that the LTC resident is a human being who has past, present, and future life experiences. The resident's life experiences and preferences need to be incorporated into the care of the patient at all times by the use of Humanistic Patient Narrative Theory.

The LTC residents' responses to the surveys emphasize that they still have feelings and can identify whether their personal needs are being met. Compassion, inclusion of the residents in their care and basic need for human interaction must be met in order for the residents to receive a humanistic approach to quality care. It is important

to know that without the individual residents' preferences of inclusions in his or her care on a consistent daily basis, the residents will not receive humanistic care.

CHAPTER 5

CONCLUSION

All too frequently, in Western Medicine, LTC facility residents are dehumanized. The vulnerable elderly population lived the greater part of their lives the way that they preferred to live prior to residing in a LTC facility. Some LTC residents may have chosen to reside in a LTC facility while others may not have had a choice. Those that did not have a choice are more than likely living in the LTC facility due to the inability to care for themselves, lack of familial resources, or for safety reasons. What is supposed to be a positive living experience may indeed be perceived as an unethical, dehumanizing, undignified, and poor quality of life.

Factors that may contribute to a LTC resident's sense of feeling uncared for and alone during this experience are spousal death, distance from grown children who have families and responsibilities of their own, and the death of close relatives and friends close to their age. Clearly, the thoughts of living at their final place of residence without the people who were part of their entire life narrative may foster a sense of loneliness, apathy, and little interest in life's events.

Society views LTC facilities as the place to live when there are no other options available. Dehumanized, abusive, unethical, and poor quality care has been experienced by some LTC residents. The government and media openly expose the LTC facilities that have violated regulations or provided substandard care to LTC residents. LTC residents are always considered vulnerable for receiving substandard care at LTC facilities. LTC healthcare professionals take an oath to provide care based on

beneficence and nonmaleficence. The reciting of the oath does not guarantee the provision of ethical and humanistic care.

Society recognizes that the elderly are the fastest growing population in America. The American society and healthcare industry are facing many crises that affect the provision of humanistic and quality care. Some of the crises include high unemployment, less people having medical insurance, healthcare industry financial instability, increased longevity of the American people, ethical issues about end of life decisions, and poor quality of health care. Incorporation of Narrative Theory and a humanistic approach to the provision of care for LTC residents inform the healthcare professional as to what the LTC residents' value and want. It is inherent for the LTC residents to want kind, humane, honest, and trustworthy relationships with the healthcare professionals that care for them. Over time the LTC facilities healthcare professionals become family to the LTC resident. LTC residents' biological family members assume that only ethical, humanistic, empathetic, and compassionate care will be provided.

How can this be achieved? What is the solution? How can confidence and trust in the patient/healthcare professional relationships be nurtured? What methods can be employed to support and help the healthcare professionals develop humanistic skills? Advancing technology that is meant to increase proficiency and the provision of quality care actually places greater time constraints on the healthcare professionals' ability to provide quality and humanistic care. LTC residents want their life narratives to be heard. They want their individual needs to be met. Is it possible to meet the LTC residents' individual humanistic needs in a continually transforming and technologically advanced healthcare system?

I have shown how to develop a balance between science, technology, and art of medicine. The research conducted at four LTC facilities indicated by the LTC healthcare professionals' statements after receiving Humanistic Patient Narrative Theory in-services, that they valued and agreed about the necessity to center care based upon the LTC residents' narratives. The LTC healthcare professionals stated that the use of Humanistic Patient Narrative in-services was thought provoking and a reminder of the necessity to include the LTC residents in the decision making process for their plan of care. The training sessions increased the LTC healthcare professionals awareness about time constraints related to other task oriented duties that inhibit quality narrative based discussions with the LTC residents. Healthcare professionals stated, "We have so many job responsibilities which prevents us from spending quality time with the residents."

Furthermore, the in-service training opened the healthcare professionals' minds to think about how the course of illness disrupted and changed each LTC resident's planned path of life. Some of the nurses stated that they had not looked at the resident's perspective in the past as it had been learned. The nurses and nursing assistants identified their personal values in life and developed a greater understanding for the losses LTC residents may experience living in a LTC facility. Humanistic Patient Narrative Theory in-services also reminded the healthcare professionals that their oaths to practice are based upon the four ethical principles: beneficence, nonmaleficence, autonomy, and justice. It was clearly agreed upon by the LTC nurses and nursing assistants that their relationships with the LTC residents must be built upon trust and honesty. Many of the healthcare professionals requested continuing education based upon the Humanistic Patient Narrative Theory in-service training modules.

I have demonstrated that the LTC residents identified the provision of humanistic care as a priority by their willingness to participate in the research and survey completion regarding whether the care they received was humanistic, quality, ethical, and dignified. The total number of LTC resident responses varied throughout the research. This was greatly due to the progressed age and morbidity of the LTC residents participating in the research. Some of the LTC residents became ill which frequently resulted in prolonged hospitalizations. A few of the LTC residents died during the survey administration time frame. Some of the residents that had been hospitalized returned to their LTC facility and continued participating in the research by completing the remaining surveys. The LTC residents' preferences to have a voice in their care is demonstrated by the development of trusting relationships with the LTC residents and their compliance with the completion of surveys.

Distribution and retrieval of surveys from the LTC residents often took much longer than the researcher expected. For you see, the LTC residents frequently began to discuss their life stories because the researcher had time to listen and participate in conversation. It supports the residents' desire to have narrative theory incorporated into the provision of their care. Although the overall survey results are of little significance, fifty-one percent of LTC residents identified that healthcare professionals do not speak with them for fifteen minutes daily in the first Quality Category survey question. The mean for the first question in the Quality Category indicated that LTC residents were not receiving the highest quality of care based upon the lack of LTC professionals' and residents' discussions. Quantitative results do not support the thesis,

but participant responses do. Residents frequently requested that the researcher stay and speak with them.

Category Quality question number one survey responses indicated the need for nurses and nursing assistants to take greater time to speak with them. Comments by the LTC residents about healthcare professionals not having time to talk with them supports the need for further discussion and research. Several LTC residents made comments such as, "The nurses come in just long enough to administer a pill and then they leave." The majority of LTC residents were thankful for the care provided by the healthcare professionals but indicated that the nurses and nursing assistants were too busy to talk with them for fifteen minutes each day. Residents' survey comments support the benefit and need to incorporate narrative theory and Humanistic Training into the provision of care.

The comparison of survey categories amongst the four LTC facilities indicated that the provision of Humanistic Care received the highest score. The LTC residents' survey responses show the second highest category response of care received by the residents is Dignified care. Ethical care places third and Quality care ranks last. Interestingly, the survey responses for each of the four LTC facilities demonstrate similar results of Quality of care ranking frequently slightly lower than Ethical care.

LTC residents at each facility similarly responded that they are not always taught about their illness and health prevention. Use of narrative theory would be an effective method for gaining information about the LTC residents' level of knowledge regarding preventative care and their illness. Education could easily be incorporated into the discussion into the LTC healthcare professional and LTC resident's discussion.

It is not surprising that the comparison of the survey results in relation to the provision of Humanistic Patient Narrative Theory in-services indicates insignificant results. The size of the research sample is limited and the results are of little significance. LTC residents' and healthcare professionals' participation in the research was limited in number and inconsistent. Furthermore, it is important to take into account that the healthcare professionals only participated in two Humanistic Patient Narrative Theory in-services and that they had never received any previous Medical Humanities training. Research has shown value in structured Medical Humanities training as it can change outcome and assist healthcare professionals to identify their personal values including reaffirmation of the necessity to include a humanistic approach in the provision of care.[266] Further research is warranted to determine the benefit of providing continued Medical Humanities based Humanistic Patient Narrative Theory in-services to healthcare professionals. Narrative ethics informs principle ethics in the provision of care. The LTC residents' narratives inform healthcare professionals about residents' desired preferences of care and it drives the principles of ethics during the care.

Results of this research may be used by existing programs and LTC facilities to continue further research. Perhaps the best outcome will be if the research inspires LTC healthcare professionals to include a narrative theory approach in the provision of humanistic care. Integrating ethical principles and narrative theory into the provision of care affords the opportunity for LTC healthcare professionals to develop trusting and therapeutic relationships that can benefit the LTC residents' complete well-being. LTC healthcare professionals that incorporate the provision of narrative theory and humanistic

[266] DeJesse.

care into their practice address the needs of a whole person, and are a positive role model for future healthcare professionals and the LTC residents that receive their care.

APPENDIX

A

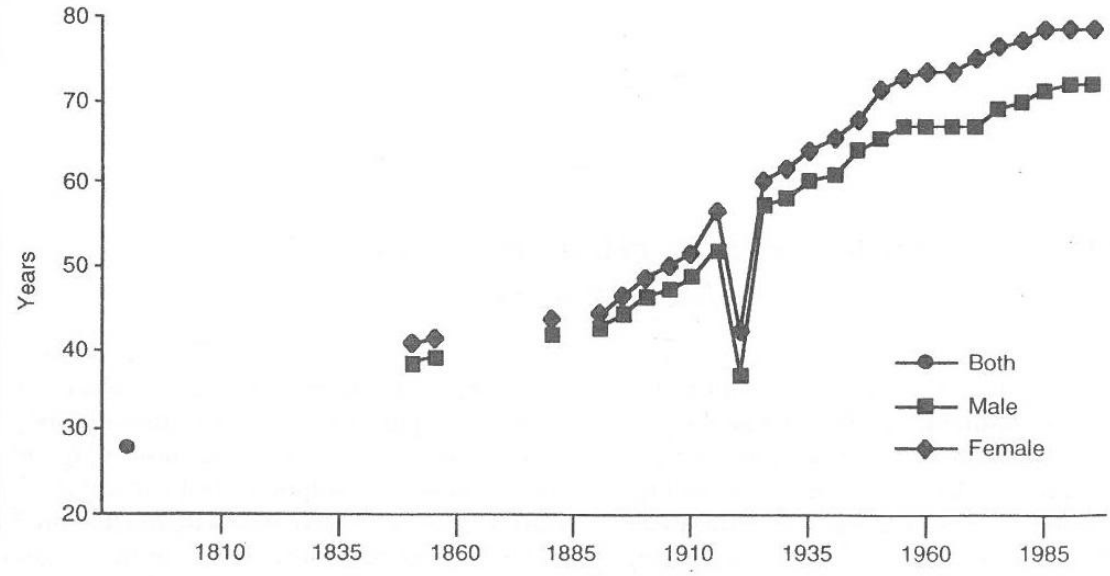

Fig. 1: Life expectancy at birth, 1789–1993, United States. Sources: Frederick L. Hoffman, "American mortality progress during the past half century," in *A Half Century of Public Health*, ed. Mazÿck P. Ravenel (New York: American Public Health Association, 1921), p. 98; U.S. Bureau of the Census, *Historical Statistics of the United States: Colonial Times to 1970* (Washington, D.C.: Government Printing Office, 1975), Part 1, pp. 55–56; U.S. Bureau of the Census, *Statistical Abstract of the United States, 1995* (Washington, D.C.: Government Printing Office, 1995), p. 86. Note: The figure for 1789 is for Massachusetts and New Hampshire only, and the data between 1850 and 1900 are for Massachusetts only. The decrease in life expectancy in 1918–1919 is largely attributable to a severe influenza epidemic.

Figure 1: Life expectancy at birth, 1789-1993

Source: Judith Walzer Leavitt and Ronald L. Numbers, *Sickness and Health in America: Readings in The History of Medicine and Public Health*, 3rd ed. (Madison: University of Wisconsin Press, 1997), 4.

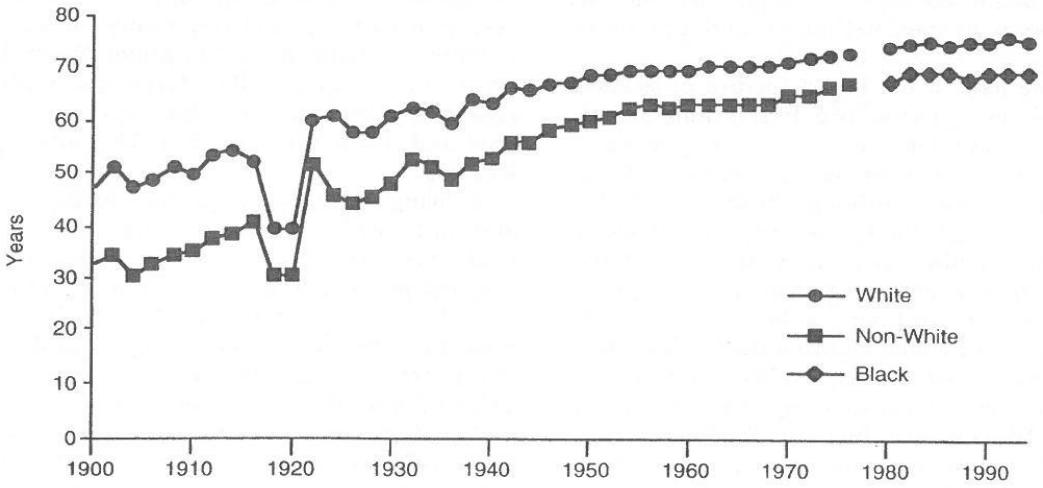

Fig. 2: Life expectancy by race, 1900–1993, United States. The category "Non-white" includes Hispanics, Asians, Indians, and Blacks. From 1975 on, government agencies distinguished between Blacks and other Non-whites; data for the latter are not included here. Sources: U.S. Bureau of the Census, *Historical Statistics of the United States: Colonial Times to 1970* (Washington, D.C.: Government Printing Office, 1975), Part 1, p. 55; U.S. Bureau of the Census, *Statistical Abstract of the United States, 1976* (Washington, D.C.: Government Printing Office, 1976), p. 60; U.S. Bureau of the Census, *Statistical Abstract of the United States, 1995* (Washington, D.C.: Government Printing Office, 1995), p. 86.

Figure 2: Life expectancy by race

Source: Walzer Leavitt and Numbers, 4.

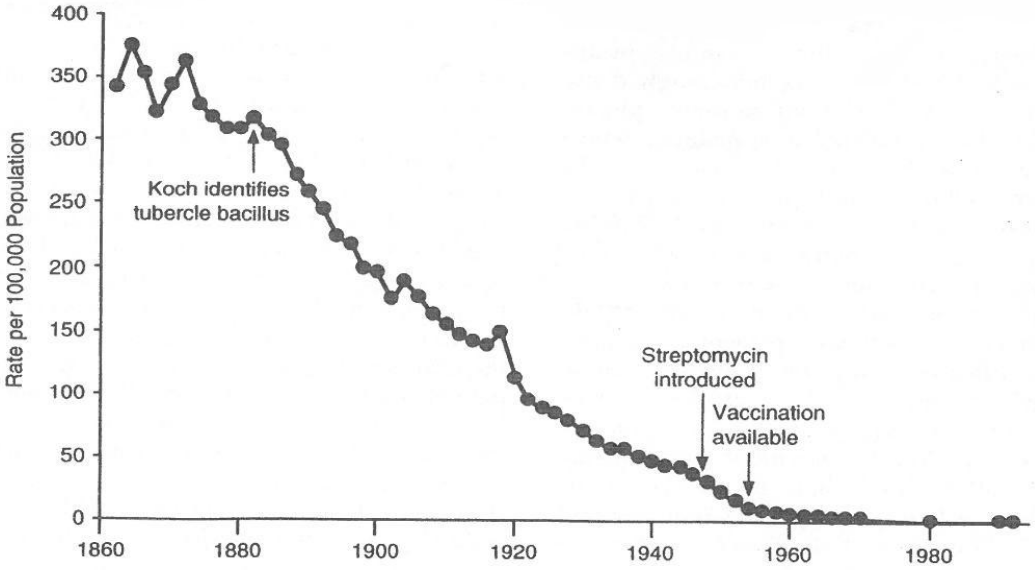

Fig. 3: Death rate for tuberculosis, 1860–1993, United States. Source: U.S. Bureau of the Census, *Historical Statistics of the United States: Colonial Times to 1970* (Washington, D.C.: Government Printing Office, 1975), Part 1, pp. 58, 63; U.S. Bureau of the Census, *Statistical Abstract of the United States, 1995* (Washington, D.C.: Government Printing Office, 1995), p. 92. Note: Data between 1860 and 1900 are for Massachusetts only.

Figure 3: TB death rate, mid-eighteenth through mid-nineteenth centuries

Source: Source: Walzer Leavitt and Numbers, 6.

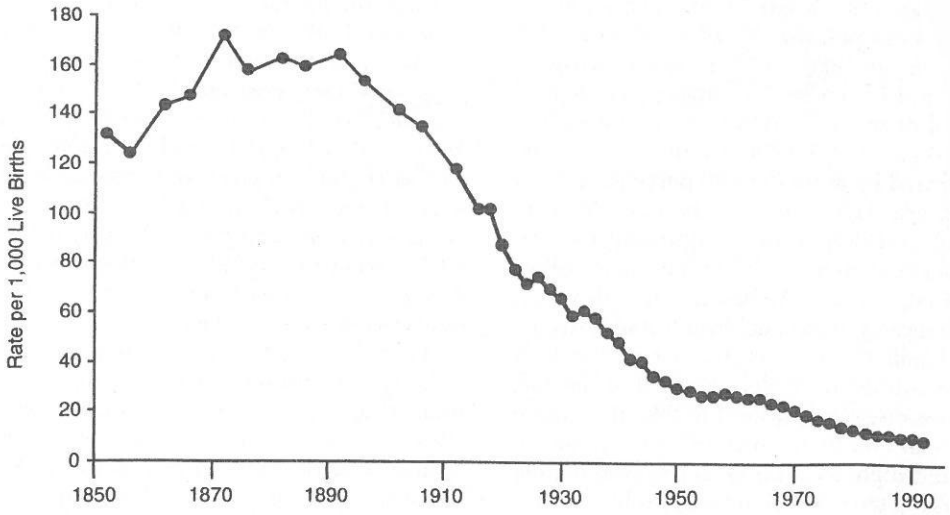

Fig. 4: Infant mortality rate per 1,000 live births, 1851–1993, United States. Sources: U.S. Bureau of the Census, *Historical Statistics of the United States: Colonial Times to 1970* (Washington, D.C.: Government Printing Office, 1975), Part 1, p. 57; U.S. Bureau of the Census, *Statistical Abstract of the United States, 1995* (Washington, D.C.: Government Printing Office, 1995), p. 73. Note: Data between 1851 and 1913 are for Massachusetts only.

Figure 4: Infant mortality rates during 1851-1993

Source: Source: Walzer Leavitt and Numbers, 6.

APPENDIX B

Narrative Theory
in Everyday Clinical Practice Part I

I. Narrative Theory in Everyday Clinical Practice.

A. Beginning of Narration

1. 1700s-1900s Medical training

2. Apprenticeship

II. Almhouses and hospitals.

A. History and early training of physicians

1. Observation, written recording and patient story

2. Case based clinical training in classroom and infirmaries

3. Care for all of humankind

III. Statistical Techniques & Clinical Research.

A. Effects upon care

1. Laennec invented stethoscope in 1866

2. Morbid autopsy anatomy versus clinical investigations

3. Clinical decisions: Examination and autopsy versus

4. French, Germans, and American Physicians' approaches to care

IV. Healthcare system transformation.

A. Experimentation and Emergence of universities

1. Scientific Inquiry

2. Biomedical Model

3. Objective data focus versus subjective

4. Effects upon patient care

V. Physician training transformation.

A. Historical

1. Mid 1800s-1900s Evidence Based Data

2. Academics and acceptance into programs rigorous

VI. What Shapes a Patient's Story?

A. Narrative Theory

1. Author of illness story

2. Healthcare Professionals (HCP) and inter-professionals

3. Gathering of data

4. Illness effect upon patient life

5. Plan of care development based on story

VII. Healthcare Professional Data Gathering

A. Chronological order and comparison

1. Subjective data related to illness events

2. Comparison to objective data

3. Decision regarding treatment plan.

4. Interpretation and deconstruction of story and diagnosis: Katherine Montgomery

VIII. What is the Goal of Medical Narrative Theory?

IX. Ethical principles based care

X .Identify, experience, visualize patient experience

A. Self Determination.

1. Pt determines course of care.

2. Realistic in today's society?

3. Legal implications?

4. What do patients want?

XI. Narrative Medicine

A. Necessary Components.

1. Patient driven autobiography of events

2. HCP re-writes story based on patient autobiography

3. Chronological order or sense out of patient story.

XIII. Ethical Issues.

A. Types of reporting

1. Clinical Rounds

2. Shift report

3. Documentation: Charting

4. Patient Centrality Lost

XIV. Preventing losing the patient as the centrality of care.

Humanistic Patient Narrative In-Service Part II

I Am Still Here

I see the fright in your eyes as you find me in our bed. I hear the panic in your voice as you cry out to God. No my darling husband, I cannot stand up. My head still hurts. My left side of my body feels as though a concrete cinder block is weighing down my arm and leg. I am trying to respond to your questions. Don't you hear what I am saying? No! I do not want to go to the hospital! Please let me stay home, I will get better. I do not want the police and ambulance to come to our home. Do not pick that telephone up! I hear what you are saying on the telephone. Listen to me! Can't you understand what I am saying? I do not want to go to the hospital! Please do not leave the room, stay with me.

Why is the room flashing in red light? The loud footsteps and voices approaching from the hallway are becoming closer. Who are you? You are looking so intently at my face. I cannot lift my left arm upon your request, but I can squeeze your hand with my right hand. I am smiling. You asked me to smile and I did so. Why are you saying my face is drooping? You are squeezing my arm too tight with that blood pressure cuff. Your reading must be wrong, my blood pressure has never been that high. I do not like that feeling in my nose. Take that off! It feels like air being blown up my nose. Why are there more people in my room? Please won't you all go home? Ouch that hurt! You are hurting my right arm. It feels so cold. I feel it travelling up my veins. Turn those loud radios off! It is so loud in the room with all of you talking at once.

Please don't drop me. The sheet is not strong enough to hold my weight. I feel as though I am going to fall. The landing could have been a little gentler. The straps are too tight. I cannot see where I am going. Everything looks backwards. Now I can see the direction we are going towards. How are you going to get me down the front steps? There are ten of them! This is so scary, I feel as though I am going to fall. Tilt to the right, tilt to the left. Please keep it straight. You look too small to carry my weight. Please do not drop me as you lift me up and lock me in place. Please slow down and lower all of the noise. My head is throbbing. Where is my husband?

Slow down! You are wheeling me too quickly through the doors. You are lucky you did not ram my foot into that door! What is that loud rattling sound you make as you walk around my bed? Yes dear, I see you and hear you. Can't you just keep that thing out of my nose? I hate that ticklish feeling. I just tried to squeeze their hand and push my foot against their hand. Don't put me through this again. I am smiling, can't you see it? They just put that blood pressure cuff on my arm. Please do not put it on as tight as they did. I cannot hold this in my mouth. You have to hold it there or don't do it at all. It is so cold and gooey. How come you are putting it on my chest, arms and legs? What a strange feeling. That beeping sound is so annoying. Ouch that hurts. What are you doing down there? Why does it burn? I don't like that pressure feeling. I am so cold. Where is my husband?

Who are you? You are very young. You cannot be the doctor. I am so embarrassed. Please close my gown up. I am breathing as you direct me to do. I just said my name. You asked my name and I said it. Why do you keep asking me to repeat words? Why do I have to keep showing everybody I cannot move my arm and leg? I am

so frustrated and scared. Yuck that tastes so dry and chemically. What are you talking to her about? What needs to get started in less than four hours? What are you connecting to my arm? It feels even weirder now. What are you looking at above my head? Can't you lower that annoying beeping sound? Ouch that is really painful! Do you need so many tubes? Leave some for me. Finally, you arrived! Where have you been? I want to go home. You shouldn't look so worried. I will be fine. Who is behind you? Why did you tell them?

Don't cry. I love you all. I will get better. I am so proud of all of you and so grateful that you are mine. No, I don't want to leave them. Can't they come with me? Where am I going? Don't worry everybody. I will be back in a little while. Go get coffee and then I will be back. I really don't want to go with this person. I wish I could just get up and leave with them. This metal enclosed room is freezing. You are both so rough. The table is so hard. What is my body going into? The thumping is so loud that it feels as though it is vibrating through my body. The low music does not help with drowning out the annoying thumping. It helps to hear your voice. Yes I am okay and understand it is almost done. I am moving down towards my feet. Finally, I am out of the casket like tunnel. That was much gentler, please drive it slowly.

I am back, are you all still here? I am so happy to see you all. I hear you all. Stop worrying. I can still see you even though I lean to my left side and see limitedly out of my left eye. My right eye sees you all clearly. Both ears can still hear. You all do not understand what I am trying to say. I am trying so hard to tell you all that I love you and want to hold each of you in my arms. They are moving me again. You don't all need to

come with me. I will be okay. Everybody should go home, it is late. The room is so quite. Goodnight. Get home safe. I will be fine.

Yes, it is me. You have the right person. Who are all the people with different colored outfits with funny tubes around their necks? There are so many mouths talking around the big centralized circular table. The continual shrill of telephone rings is somewhat musical. Through my crooked gaze, my right eye tells the story. My heavy left arm and leg begin to ache as the blood drains out of them. Painful tingling is taking over quickly. The person in the purple outfit is so nice. Thank you for talking to me first and telling me what you are doing to me. Yes, your smile is warm, your eyes kind and the words you speak comforting. I trust you. Thank you for telling me what you are giving me. I don't like medicines, but I trust you. You are gentle as you put on the stockings and also the plastic holder that straps down my puffy and pale cool hand. Yes, you are correct. It does keep the fingers curved away from the palm. I hope you don't see that my nails are long, dry and jagged. I wanted to get a manicure before all of this happened. I will need somebody to do this for me since an alien entered my body and stole my independence.

I am so tired just sitting here watching the circus outside my room. Ouch, couldn't you have waited until I was fully awake? That really hurt. How many tubes was it that time? I don't want to leave again. My bed is so comfortable. Why don't you get another person to help? I am too heavy for you to move with only two people. It is freezing, slow down. I feel a cool breeze on my face because you are going so fast. The metal room again! I hate this. At least there is no thumping with this test. I am not scared. It is almost over. Now where am I going? Not another room! Get that gooey stuff off my neck. My

neck is just fine. Leave me alone for goodness sake. Hopefully, I am going back to my room now.

Back in my room at last, now I can nap before my family comes. Yes, I am awake. I understand my blood work is getting better. Can I go back to sleep now? Oh, yes this is my family. I wish they would stop asking so many questions, they are going to drive you crazy. I am starting to feel stronger so I hope I can go home soon. I will get better quicker if I go home. You are back again, is there something wrong? Talk to me, not the family. I hear you, my CT scan is better. I am a person, I am still in here. Talk to me, not them. Goodbye everybody, go home and get some sleep.

I am glad that I am leaving here today. I wish I was going home but I understand that I need rehabilitation. You don't look as worried. I am glad. I will be fine. I will be home soon. Thank you for meeting me there. I will see you in a little while. The ride is so different. It is so solemn and calming. Finally arrived! The ride seemed so long. The atmosphere is busy. There are so many people in wheelchairs sitting at various tables. I am whisked by so quickly, I cannot see what they are doing. There are people in the hallway being helped to walk. Some look weak, barely able to stand as they hold the metal bars on wheels in front of them. Others look strong and walk with a stick. Many people smile at me as I get swooshed by them.

The room is bright yellow with flower print curtains. Many people come into the room all at once. A nice lady says hello and states her name to me. Thank you for telling me that everything will be alright. All of a sudden I am afraid again. There are so many new people around me. All of them are looking at me. I hear them counting loudly. On the count of three I am swept into the air and onto the bed. A safe landing, I always hate

that feeling of falling. I am nice and warm. Thank you for making me comfortable. It will take time to feel safe here. I hope they realize that this is only temporary until my family can take me home. My husband has arrived and nods in approval of the room. As tears swell in his eyes he smiles and reassures me that I will get better in this place. He hangs my clothes in the closet and places the afghan my daughter knit on the edge of the bed. With tears remaining in his eyes, he takes my hand and kisses it. I want to cry also and say I love him but the words just won't come out yet. I am still in here. Soon I will tell you how grateful I am for your support and love. Soon I will be able to prepare the holiday dinners. I so love having my family home with us. Go home. You don't need to sit in the chair beside my bed. I will be fine. It has been a long week and I can see you are tired. I will be home soon. Look at my eyes I am still in here. My eyes are telling you thank you and I love you.

Dear _____,

I am presently working on my doctoral dissertation at Drew University in Madison, NJ. My research focuses on the effects that "Humanistic Patient Narrative Theory" staff in-services has upon the staff provision and residents receipt of humanistic, ethical, quality, and dignified care in Long Term Care (LTC) facilities." I am writing to _____(LTC Facility)____ requesting permission for the performance of my research study to take place at your facility. Informed consent would be required from each interested participant. Research results will be published as a dissertation for completion of the Drew University Medical Humanities Doctoral Program.

If granted authorization to proceed with the research at your facility, I will be the principal investigator. The principal investigator will obtain quantitative data from three surveys of residents. The data collected by the first resident surveys will indicate the type of dignified care received prior to the healthcare provider staff (RN's, LPN's, and Nurses Aides) inservice training on Humanistic Patient Narrative Theory in relation to quality, ethical, humanistic, and dignified care. After the completion of the first resident surveys, the healthcare provider staff will receive a 75 minute in-service based upon humanistic patient narrative theory. After the staff in-service, the staff members will be assigned to provide routine care for the residents participating in the study. The staff members and residents will not know who is participating in the study. One week after the staff inservice, the participating residents will complete a second quantitative survey to determine the effects of the narration theory in-service training upon the staff deliverance and receipt of dignified care by the resident. One month after the staff has completed the in-service on humanistic patient narrative theory, the residents will complete a final third survey to determine the long term effects of healthcare provider staff Humanistic Patient Narrative Inservice training upon the provision of dignified care to the residents.

The anonymous research results will be distributed as a summary of results to each of the participating LTC facilities, nurses, nursing assistants, and residents. The LTC facilities, staff, and the residents may utilize the research results for enhancing dignified care provided at the LTC facilities. The benefits of participation are that your participation will help to identify and set a standard for the provision of dignified care for anybody that resides in a LTC facility. Your participation will help to determine new approaches which are beneficial for training LTC staff about the provision of quality, ethical, dignified, and humanistic care for residents.

Thank you very much for your time and consideration regarding this matter. Please do not hesitate to contact me with any questions in regards to the proposed research study. I will contact you on _____ to follow up with your decision as to whether I may conduct my research at your facility.

Kindest Regards,

Kathleen Kavanagh MSN, Ed RN

904-256-7949
Cell- 201-803-0567
kkavana2@ju.edu

Will humanistic patient narrative theory staff in-service produce positive outcomes in long term care facilities (LTC)?

RESIDENT CONSENT FORM

---

1. INTRODUCTION

You are invited to be a participant in a research study about your personal opinions about the type of care provided in regards to dignified care. You were selected by the unit nurse manager as a possible participant because you reside in the LTC facility. We ask that you read this document and ask any questions you may have before agreeing to be in the study. The study is being conducted by Kathleen Kavanagh MSN, Ed.

2. BACKGROUND

The purpose of this study is to identify the factors that affect the provision of dignified care in LTC facilities. The increased number of persons living past the age of sixty five correlates to a growing need, for long term care facilities to provide quality dignified care in the later years of their life.

3. DURATION

The length of time you will be involved with this study is four months starting ____ and ending _____..

4. PROCEDURES

If you agree to be in this study, we will ask you to do the following things: Take a total of three surveys. The research includes answering questions on several surveys in regards to receiving dignified care from the LTC healthcare provider staff. You will be asked to answer survey questions by selection on a grading scale.

A survey will be administered to each participating resident regarding their perception about receiving dignified care prior to a staff in-service. Once the first survey is completed, the healthcare provider staff (nurses and nursing assistants) will receive Humanistic Patient Narrative Theory in-service training. Upon completion of the in-services, the staff will continue to provide routine care for the residents participating in the study. After the completion of the staff in-service, the participating residents will be asked to complete a second survey comparing the care received from the healthcare staff prior to and after the in-services. One month after the staff in-service training, the residents will be asked to complete a final comparative survey to compare long term effects in the provision of care to residents after the staff in-service training. All information will remain anonymous.

5. RISKS/BENEFITS

This study has no identifiable risks that are foreseen.

The benefits of participation are that your participation will help to identify and set a standard for the provision of dignified care for anybody that resides in a LTC facility. Your participation will help to determine new approaches which are beneficial for training LTC staff about the provision of care for residents. No royalties related to participating in the study and/or for the publishing of any aspect of the research study will be awarded. Research results will be published as a dissertation for completion of the Drew University Medical Humanities Doctoral Program.

6. CONFIDENTIALITY

To maintain anonymity, participating residents will not have any identifiable data associated with their participation in the research study. Data collected by the principal investigator regarding a participant will always remain anonymous. Each long term care facility will have a letter A, B, C, or D. The resident's data for those who reside and participate in the study from each facility will remain anonymous. Any research study related data or electronic data will be stored in a locked, fire proof cabinet inside of a locked room. All electronic data will be stored on a password protected portable drive. Any data regarding the research study that is no longer in use shall be shredded to a non-identifiable state and disposed of.

7. VOLUNTARY NATURE OF THE STUDY

Your decision whether or not to participate in this research will not affect your relationship with your facility nor with the services you receive from this facility. If you decide to participate in this study, you are free to not answer questions related to the study or to withdraw from the study at any time without affecting those relationships and without penalty.

8. CONTACTS AND QUESTIONS

The survey results will indicate the resident's perception regarding the provision of dignified care after the provision of narrative theory in-service healthcare provider staff training. The anonymous research results will be distributed as a summary of results to each of the participating LTC facilities, nurses, nursing assistants, and residents. The LTC facilities, staff and the residents may utilize the research results for enhancing dignified care in the LTC facilities.

The researcher conducting this study is Kathleen Kavanagh MSN, Ed RN. You may ask any questions you have right now. If you have questions later, you may contact Kathleen Kavanagh at kkavanagh@drew.edu or at 201-803-0567.

If you have questions or concerns regarding this study and would like to speak with someone other than the researcher(s), you may contact, Allan Dawson, Chair IRB at adawson@drew.edu or 973-408-3292.

9. STATEMENT OF CONSENT

The procedures of this study have been explained to me and my questions have been addressed. I understand that my participation is voluntary and that I may withdraw at any time without penalty. If I have any concerns about my experience in this study (e.g., that I was treated unfairly or felt unnecessarily threatened), I may contact the Chair of the Drew Institutional Review Board regarding my concerns.

Participant signature_____
Date_____

Will humanistic patient narrative theory staff in-service produce positive outcomes in long term care facilities (LTC)?

HEALTHCARE PROVIDER STAFF CONSENT FORM

---

1. INTRODUCTION

You are invited to be a participant in a research study about the LTC facility resident's opinions regarding the type of dignified care provided. You were selected as a possible participant because you work in the LTC facility. We ask that you read this document ask any questions you may have before agreeing to be in the study. The study is being conducted by Kathleen Kavanagh MSN, Ed RN.

2. BACKGROUND

The purpose of this study is to identify the effect on the provision of care after in-service training. The increased number of persons living past the age of sixty five correlates to a growing need, for long term care facilities to provide quality dignified care in the later years of their life.

3. DURATION

you will be involved with this study is four months starting _ ___and ending _____.

4. PROCEDURES

If you agree to be in this study, we will ask you to do the following things: Participate in a 75 minute staff in-service training based upon the topic of Humanistic Patient Narrative Theory. After the in-service training, you will be assigned to perform routine care of the residents who participated in the study. The LTC residents will complete a survey prior to your participation in the in-service training and afterwards to determine if the narrative theory in-service resulted in an increased provision of dignified care. All information will remain anonymous and the residents will not be informed as to who has completed the in-service training.

5. RISKS/BENEFITS

This study has no identifiable risks that are foreseen.

The benefits of participation are that your participation will help to identify and set a standard for the provision of dignified care for anybody that resides in a LTC facility. Your participation will help to determine new approaches which are beneficial for training LTC staff about the provision of care for residents. No royalties related to participating in the study and/or for the publishing of any aspect of the research study

will be awarded. Research results will be published as a dissertation for completion of the Drew University Medical Humanities Doctoral Program.

6. CONFIDENTIALITY

To maintain anonymity, participating staff will not have any identifiable data associated with their participation in the research study. Data collected by the principal investigator regarding a participant will always remain anonymous. Each long term care facility will have a letter A, B, C, or D. Any research study related data or electronic data will be stored in a locked, fire proof cabinet inside of a locked room. All electronic data will be stored on a password protected portable drive. Any data regarding the research study that is no longer in use shall be shredded to a non-identifiable state and disposed of.

7. VOLUNTARY NATURE OF THE STUDY

Your decision whether or not to participate in this research will not affect your relationship with the LTC facility. If you decide to participate in this study, you are free to not participate in the staff inservice activities related to the study or to withdraw from the study at any time without affecting those relationships and without penalty.

8. CONTACTS AND QUESTIONS

The survey results will indicate the resident's perception regarding the provision of dignified care after the provision of narrative theory in-service healthcare provider staff training. The anonymous research results will be distributed as a summary of results to each of the participating LTC facilities, nurses, nursing assistants, and residents. The LTC facilities, staff and the residents may utilize the research results for enhancing dignified care in LTC facilities.

The researcher conducting this study is Kathleen Kavanagh MSN, Ed RN. You may ask any questions you have right now. If you have questions later, you may contact Kathleen Kavanagh at kkavanagh@drew.edu or at 201-803-0567.

If you have questions or concerns regarding this study and would like to speak with someone other than the researcher(s), you may contact, Allan Dawson, Chair IRB at adawson@drew.edu or 973-408-3292.

9. STATEMENT OF CONSENT

The procedures of this study have been explained to me and my questions have been addressed. I understand that my participation is voluntary and that I may withdraw at any time without penalty. If I have any concerns about my experience in this

study (e.g., that I was treated unfairly or felt unnecessarily threatened), I may contact the Chair of the Drew Institutional Review Board regarding my concerns.

Participant signature_____ Title_____
Date_____

Will humanistic patient narrative theory staff in-service produce positive outcomes in long term care facilities (LTC)?

DEBRIEFING FORM

1. PURPOSE OF THE STUDY

The study in which you just participated was designed to determine if residents who reside at long term care facilities (LTC) and employed healthcare providers perceive that residents receive quality, ethical, humanistic, dignified care in a home like setting. The results of the survey will contribute towards the development and implementation of healthcare provider training for the provision of better quality, ethical, humanistic, and dignified care in the participating LTC facilities. There is limited research regarding the use of humanistic patient narration staff in service training to increase the provision of humanistic care to LTC residents. The results of the provision of the training may be instrumental towards a future publication of a humanistic patient narrative workbook for healthcare provider training. Research results will be published as a dissertation for completion of the Drew University Medical Humanities Doctoral Program.

2. METHODOLOGY

The principal investigator observed residents and healthcare providers' interactions, during routine activities at each of the four long term care facilities prior to the administration of surveys to residents and healthcare providers. The randomized control group of Long Term Care Facility participants was comprised of sixty adult residents and thirty two healthcare providers. Two licensed nurses that were either an LPN or RN, and two nurse aides during each day and evening shift from four LTC facilities participated. The data collected by the surveys included questions in regards to the characteristics of a home like setting, quality, ethical, humanistic, and dignified care as designated by the participants. After completion of the surveys, staff in service training modules based upon narration theory was provided to each participating staff members. Upon the completion of training, staff members were assigned to provide care for the residents participating in the study. After the provision of care, residents and staff completed a survey to determine the effects of narration theory in service training upon the deliverance and receipt of care by the resident.

3. ADDITIONAL RESOURCES

For more information on the topic of this research, participants may reference:

The Centers for Medicare and Medicaid Services at 1-800-Medicare, http://www.medicare.gov.

Pellegrino, Edmund D. and Thomasma, David C. *For the Patients Good: the Restoration of Beneficence in Health Care.* New York: Oxford University Press, 1988.

Leading Age, "Expanding the World of Possibilities for Aging." at http://www.leadingage.org/

John Engel et al., *Narrative in Health Care: Healing Patients, Practitioners, and Profession, and Community.* UK: Radcliffe Publishing, 2008.

4. CONTACT INFORMATION

If you are interested in learning more about the research being conducted, or the results of the research of which you were a part, please do not hesitate to contact the principal investigator Kathleen Kavanagh DMHc, MSN, ED RN at 201-803-0567 or kkavanagh@drew.edu. The Drew University Associate Dean of the Caspersen School and IRB Chair, Bill Rogers may be contacted at 973-408-3110 or wrogers@drew.edu.

Thank you for your help and participation in this study.

RESIDENT SURVEY

Dear Resident,

Feedback from this survey will enable the identification of areas that you identify as important for a positive dignified care experience at (LTC Facility) . There is no right or wrong answers.

For each question below, mark an "X" in the survey box that fits your opinion on how often the healthcare provider (RN/LPN/Nursing Assistant) staff performs the actions in each of the questions.

Strongly Agree (5)	**Staff performs daily**
Agree (4)	**Staff performs five to six times per week**
Somewhat Agree (3)	**Staff performs four or less times per week**
Disagree (2)	**Staff does not perform at all**
No Opinion (1)	

Questions	Strongly Agree (5)	Agree (4)	Somewhat Agree (3)	Disagree (2)	No Opinion (1)
Quality Care					
1. The staff has a 15 minute conversation with me every day.					
2. The staff shows a true interest in me during our conversations.					
3. The staff have a positive attitude (smiles, pleasant) when providing care to me.					
4. The staff is highly trained and educated.					
5. The staff provides safe care to me.					
6. The staff teaches me about health prevention to keep me healthy.					

Questions	Strongly Agree (5)	Agree (4)	Somewhat Agree (3)	Disagree (2)	No Opinion (1)
7. The staff provides care for my emotional, spiritual, and physical needs.					
8. The staff communicates to each other and works as a team when providing care to me.					
9. The staff takes care of my needs in a reasonable amount of time.					
10. The staff does not appear rushed when speaking or providing care to me.					

Questions	Strongly Agree (5)	Agree (4)	Somewhat Agree (3)	Disagree (2)	No Opinion (1)
Dignity of Care					
1. The staff treats me with respect.					
2. The staff provides privacy when providing physical care to me.					
3. The staff provides privacy during personal conversations.					
4. The staff cares for my emotional, spiritual, social, and physical well being.					
5. The staff encourages me to be part of the residents' community.					
6. The staff includes my family in my care when I want them to be involved.					

Questions	Strongly Agree (5)	Agree (4)	Somewhat Agree (3)	Disagree (2)	No Opinion (1)
7. The staff encourages me to control my own sleep/wake patterns.					
8. The staff encourages me to participate in my decisions about my care.					
Questions	**Strongly Agree (5)**	**Agree (4)**	**Somewhat Agree (3)**	**Disagree (2)**	**No Opinion (1)**
Ethics					
1. The staff is respectful and supportive of my unique personal needs.					
2. The staff treats all residents equally and fairly.					
3. The staff respects my worth as a human being.					

Questions	Strongly Agree (5)	Agree (4)	Somewhat Agree (3)	Disagree (2)	No Opinion (1)
4. The staff supports my individual rights to accept or refuse care.					
5. The staff educates me about the patient bill of rights.					
6. The staff keeps my care confidential.					
7. The staff is non-judgmental about my personal values and beliefs.					
8. The staff encourages me to participate in decision making within my residence.					
9. The staff educates me about my care so that I can decide what care is right for me.					

Questions	Strongly Agree (5)	Agree (4)	Somewhat Agree (3)	Disagree (2)	No Opinion (1)
Humanistic Care					
1. The staff respects me.					
2. The staff maintains my dignity.					
3. The staff is trust worthy.					
4. The staff encourages me to live my life the way I want it to be lived.					
5. The staff advocates for my best interests.					
6. The staff treats me as a whole person not only as a person with a medical condition.					
7. The staff has a good and caring relationship with the residents.					

Thank you for completing this survey!

APPENDIX C

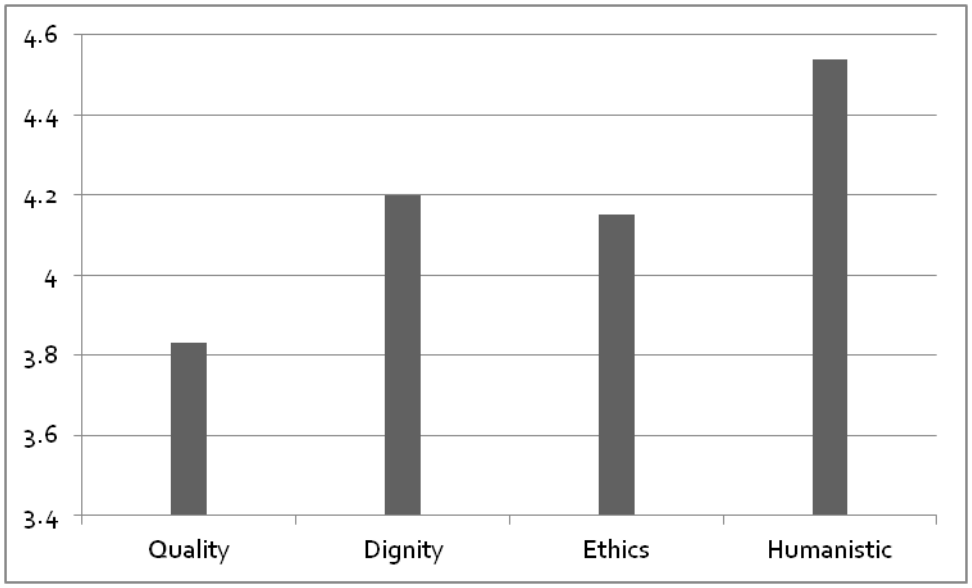

Figure 1.1 LTC A Survey 1 Mean Comparison All Categories

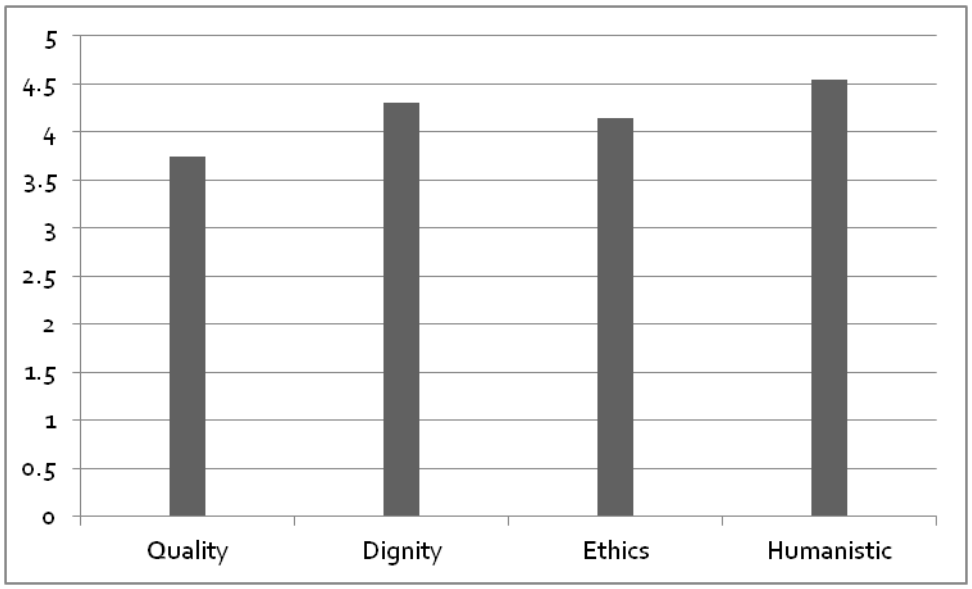

Figure 1.2 LTC B Survey 1 Mean Comparison All Categories

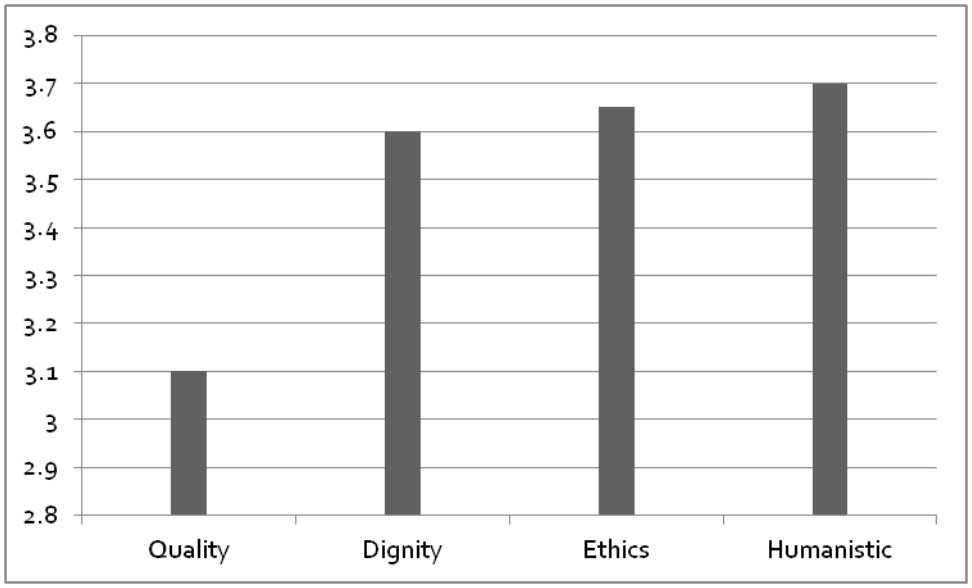

Figure 1.3 LTC C Survey 1 Mean Comparison All Categories

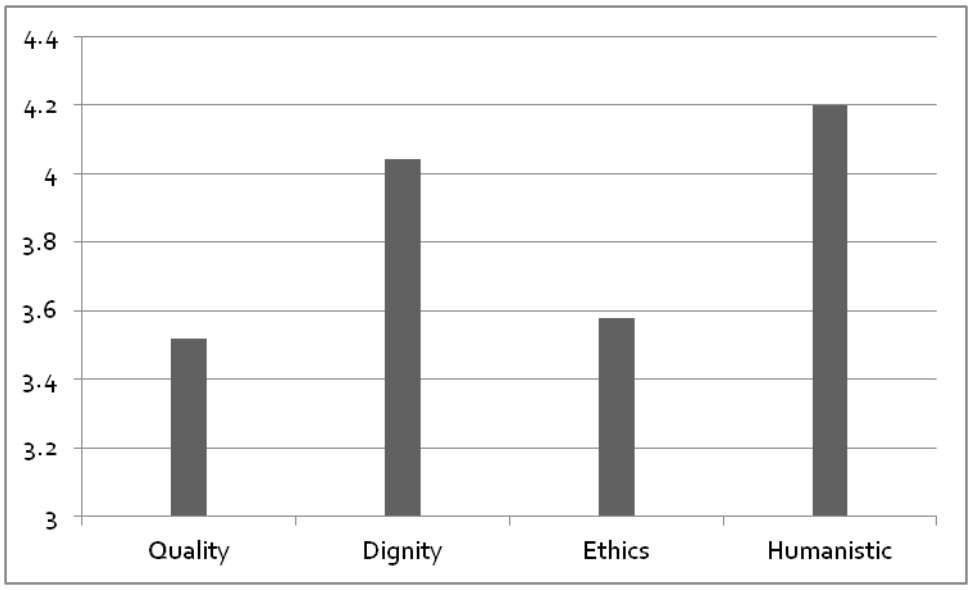

Figure 1.4 LTC D Survey 1 Mean Comparison All Categories

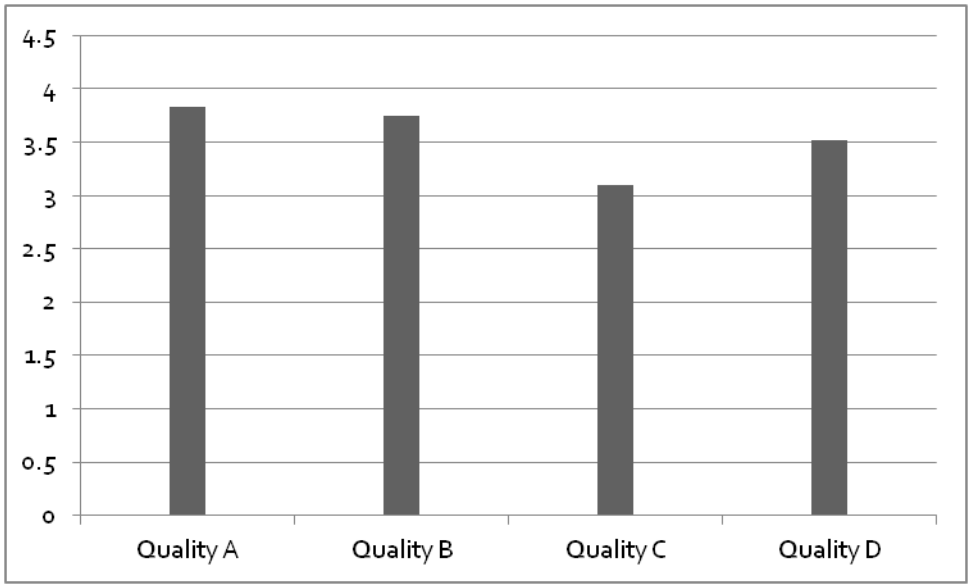

Figure 1.5 Survey 1 Mean Comparison of Individual LTC Facilities A, B, C and D Quality Category

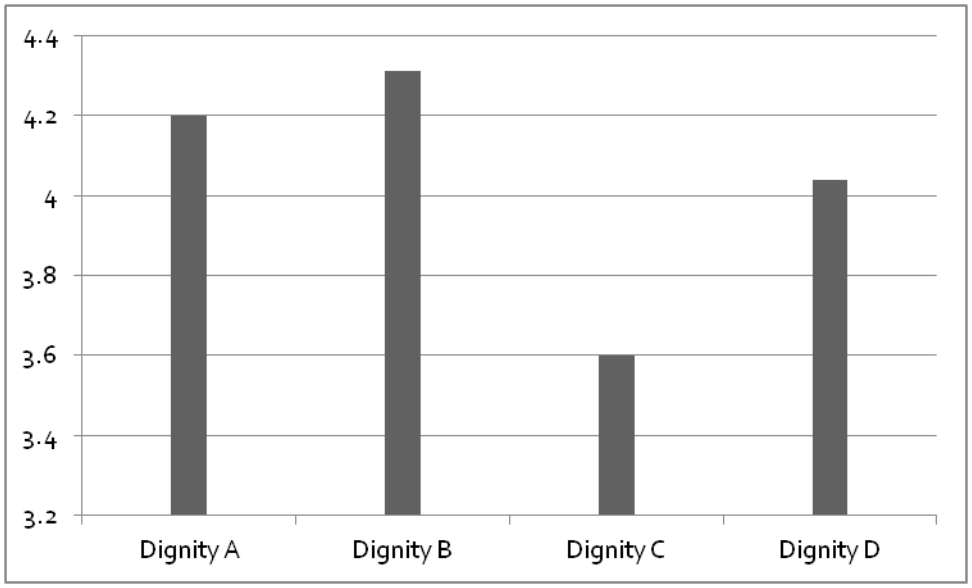

Figure 1.6 Survey 1 Mean Comparison of Individual LTC Facilities A, B, C and D Dignity Category

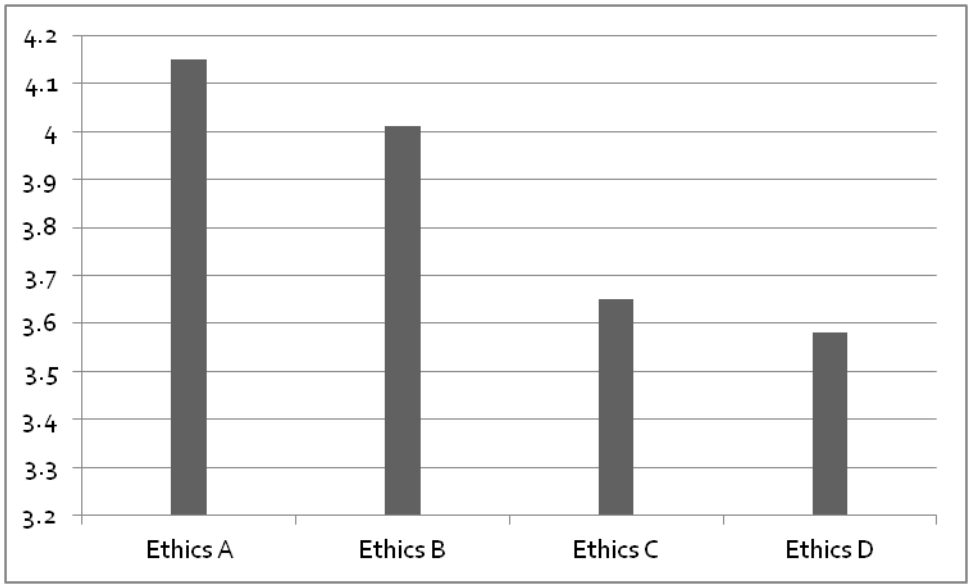

Figure 1.7 Survey 1 Mean Comparison of Individual LTC Facilities A, B, C and D Ethics Category

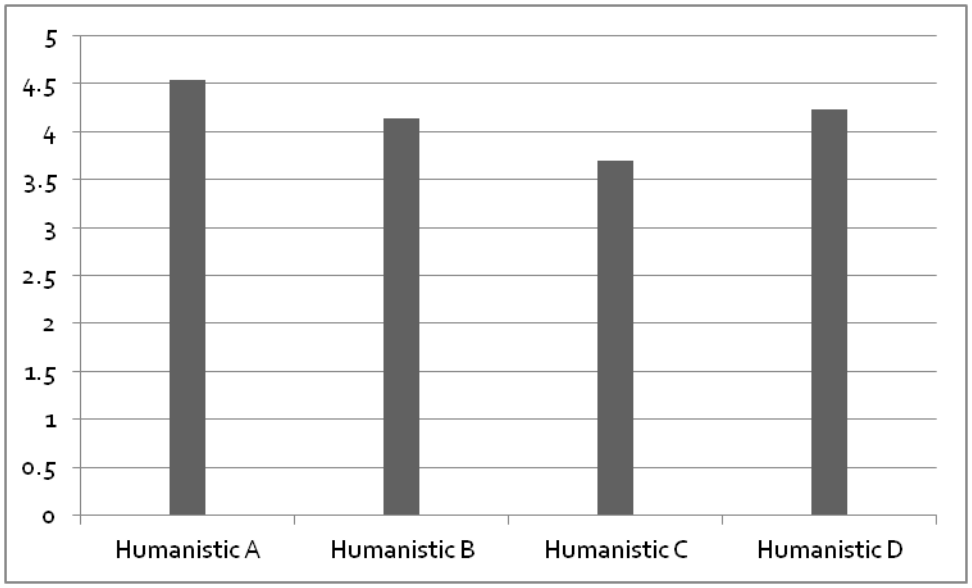

Figure 1.8 Survey 1 Mean Comparison of Individual LTC Facilities A, B, C and D Humanistic Care Category

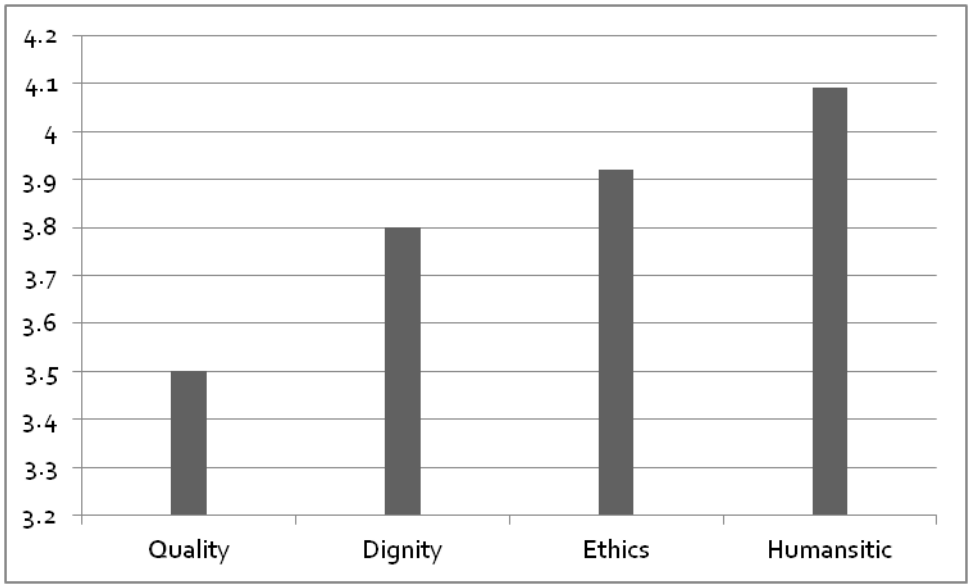

Figure 1.9 Survey 1 Combined LTC Facilities A, B, C, D Category Mean Comparison

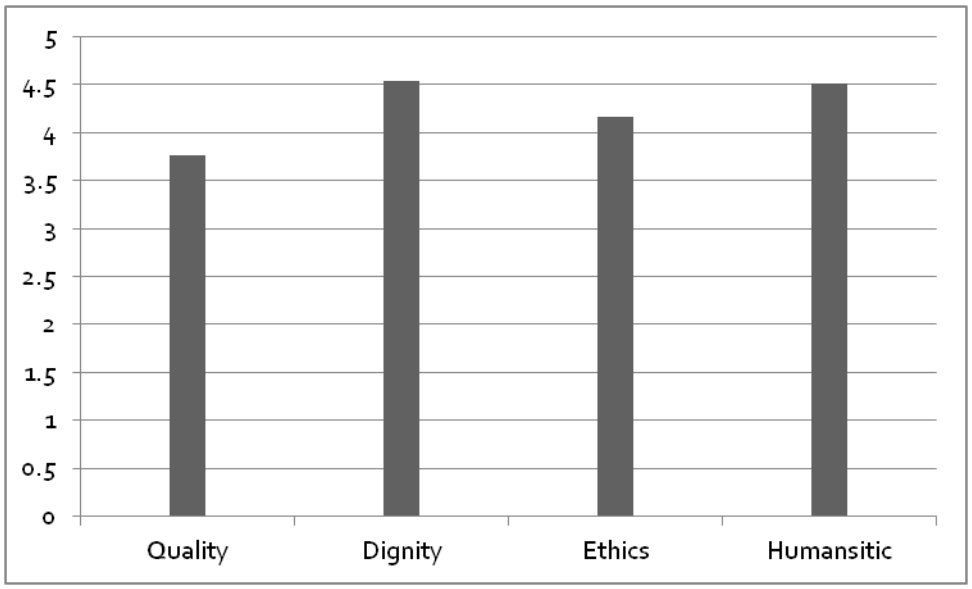

Figure 2.1 LTC A Survey 2 Mean Comparison All Categories

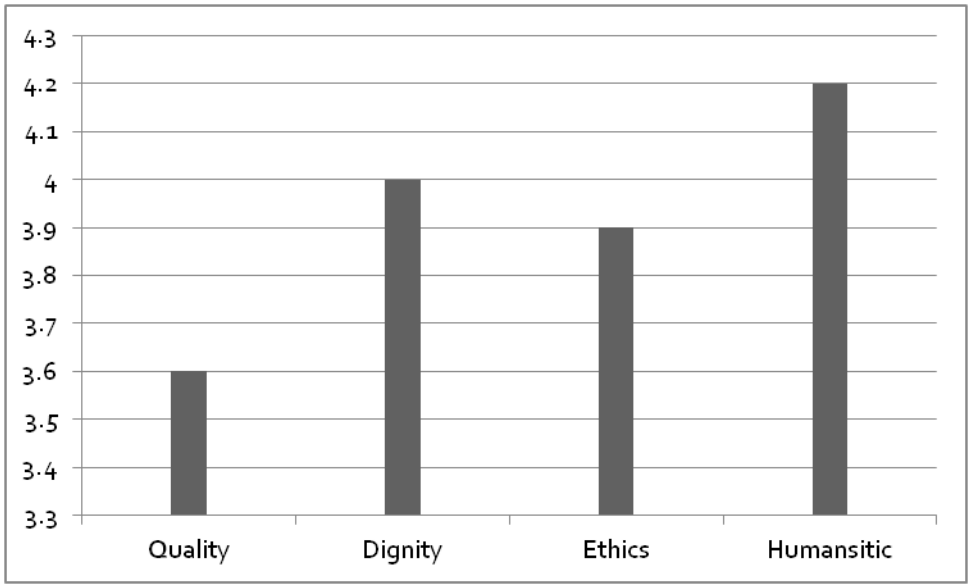

Figure 2.2 LTC B Survey 2 Mean Comparison All Categories

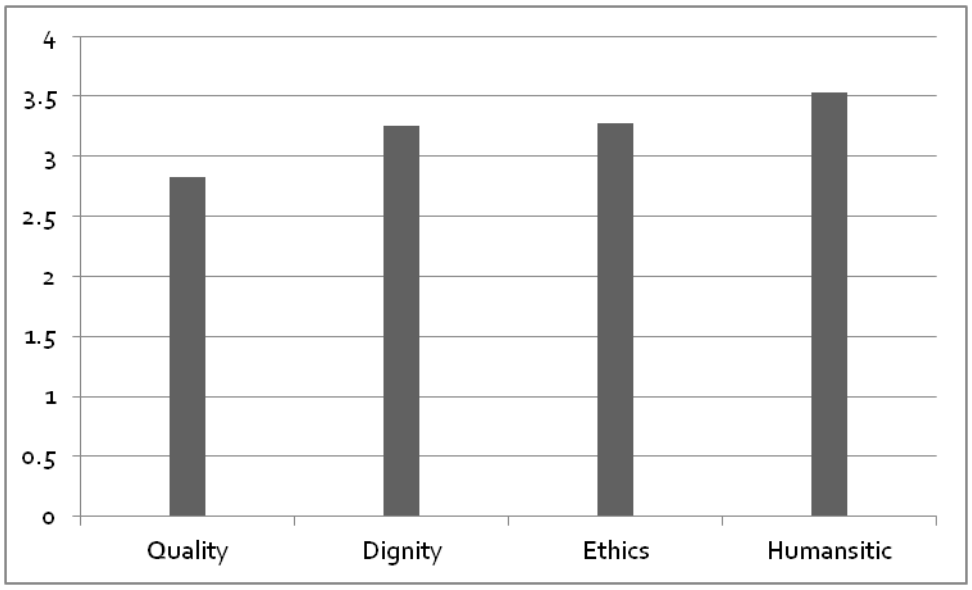

Figure 2.3 LTC C Survey 2 Mean Comparison All Categories

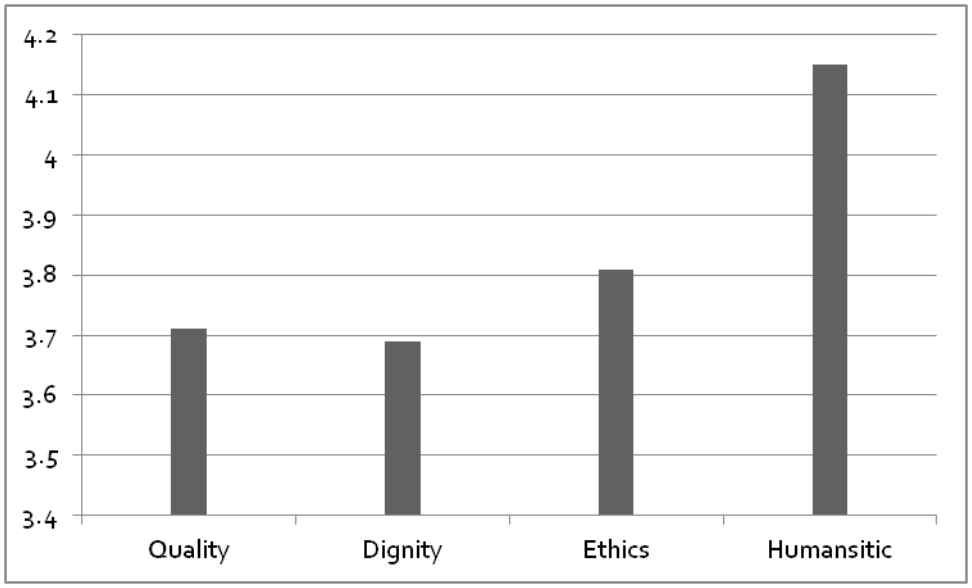

Figure 2.4 LTC D Survey 2 Mean Comparison All Categories

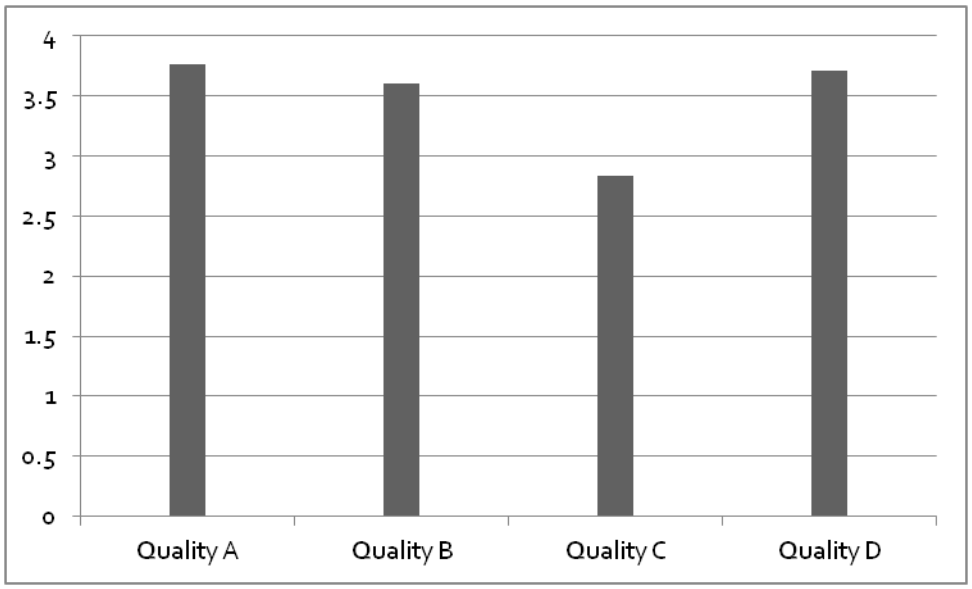

Figure 2.5 Survey 2 Mean Comparison of Individual LTC Facilities A, B, C and D Quality Category

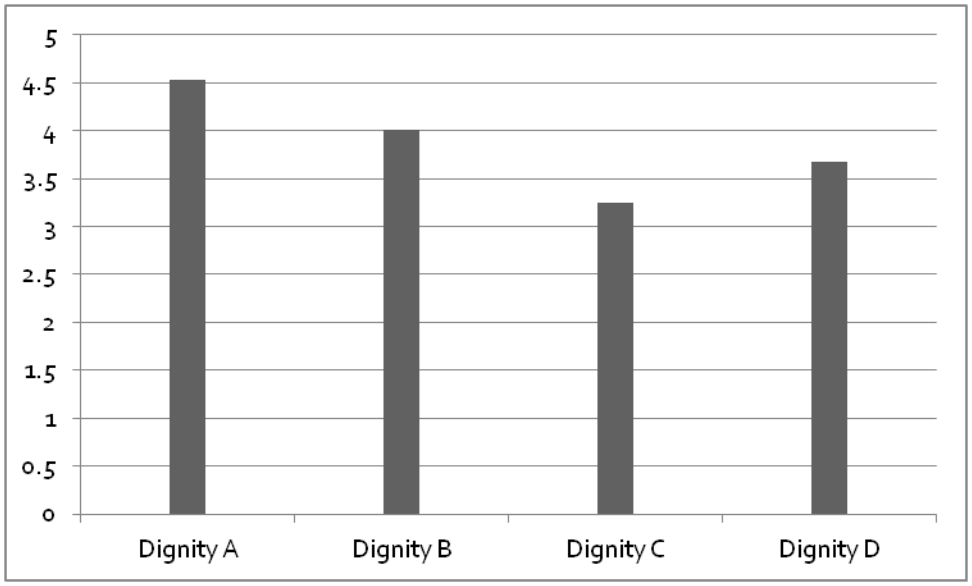

Figure 2.6 Survey 2 Mean Comparison of Individual LTC Facilities A, B, C and D Dignity Category

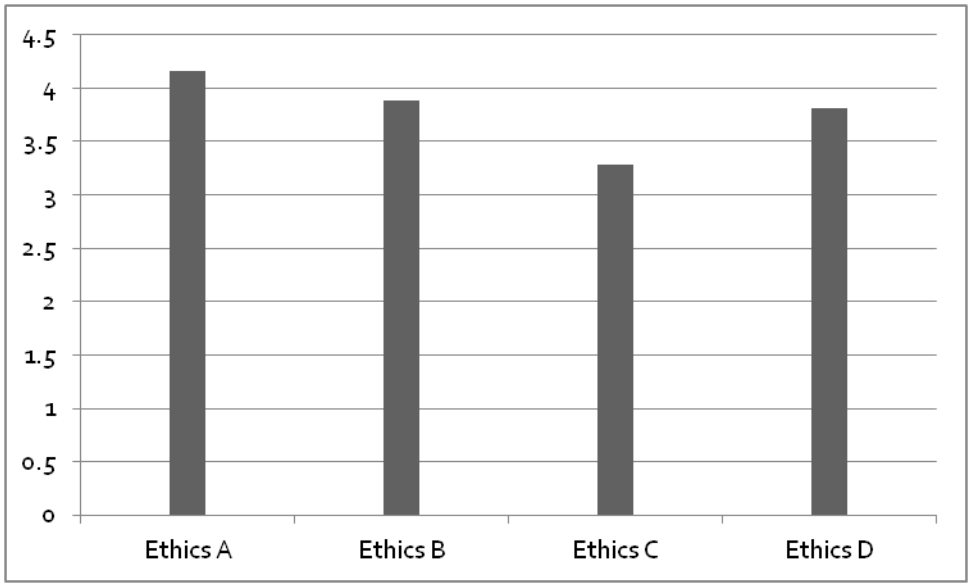

Figure 2.7 Survey 2 Mean Comparison of Individual LTC Facilities A, B, C and D Ethics Category

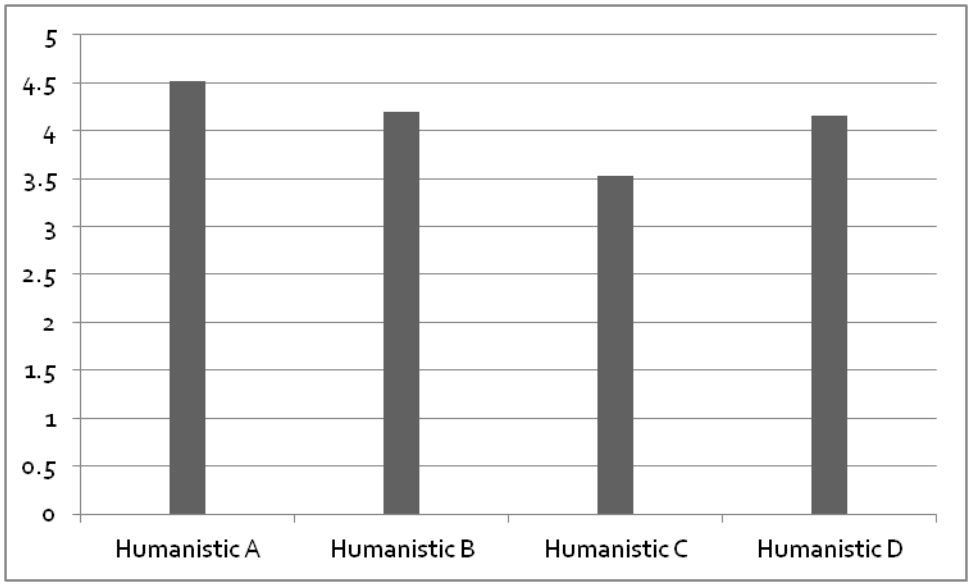

Figure 2.8 Survey 2 Mean Comparison of Individual LTC Facilities A, B, C and D Humanistic Care Category

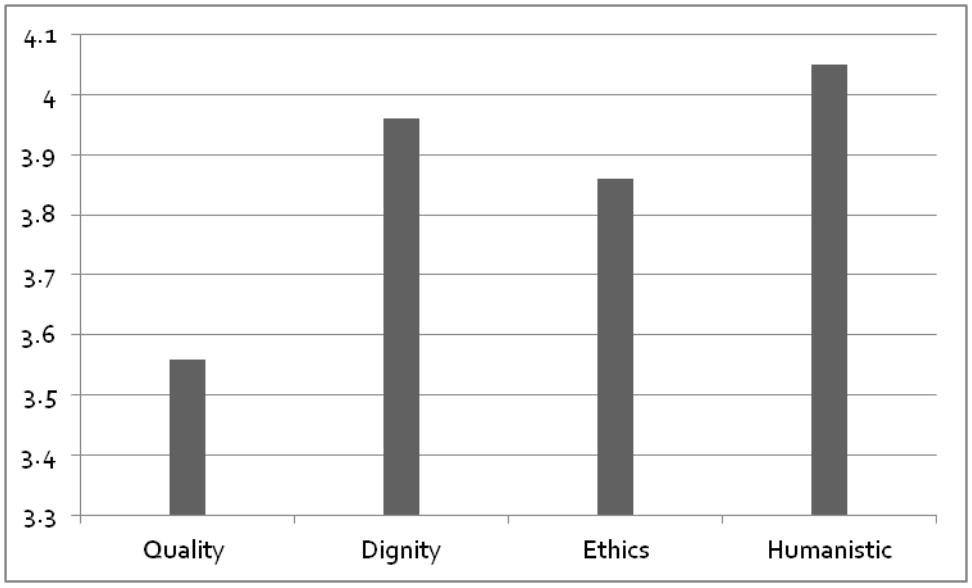

Figure 2.9 Survey 2 Combined LTC Facilities A, B, C, D Category Mean Comparison

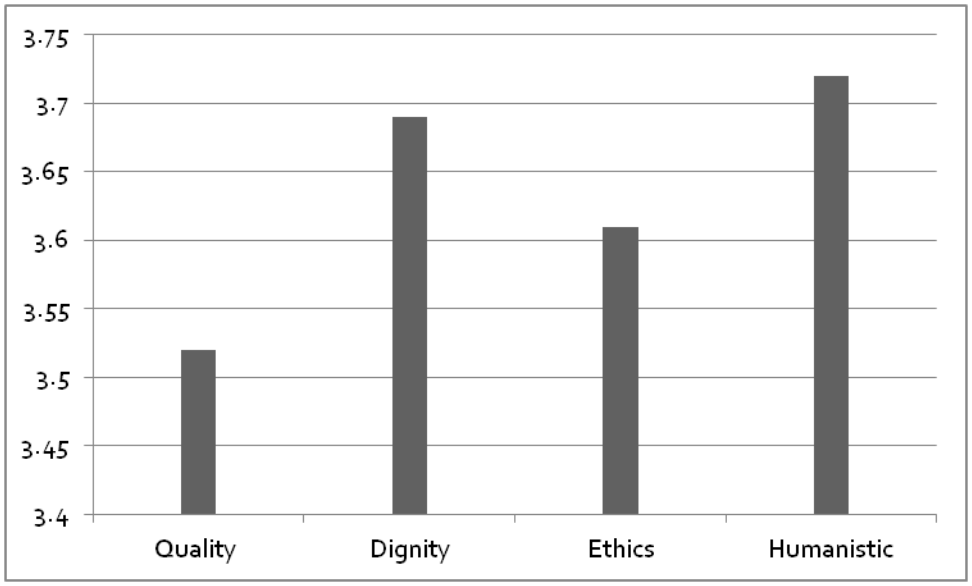

Figure 3.1 LTC A Survey 3 Mean Comparison All Categories

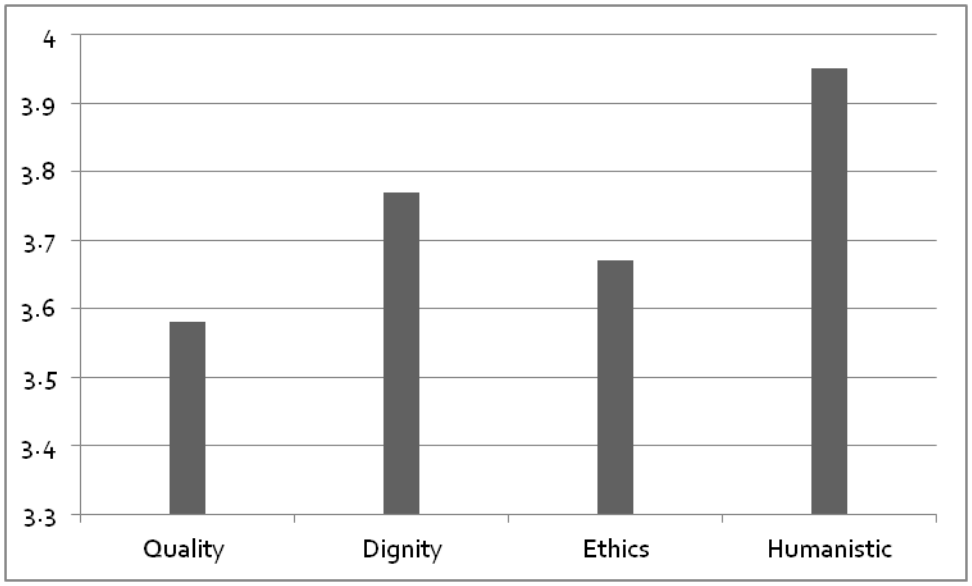

Figure 3.2 LTC B Survey 3 Mean Comparison All Categories

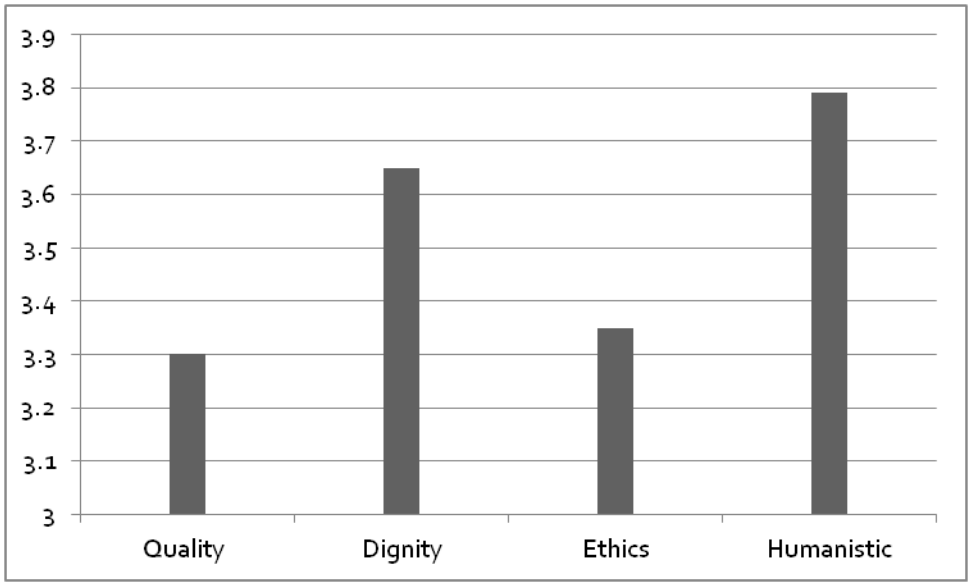

Figure 3.3 LTC C Survey 3 Mean Comparison All Categories

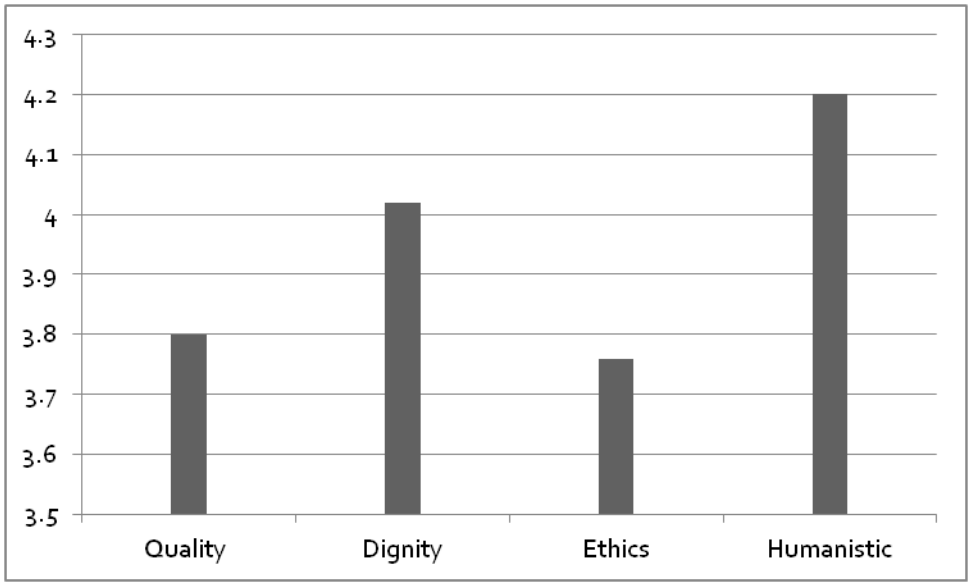

Figure 3.4 LTC D Survey 3 Mean Comparison All Categories

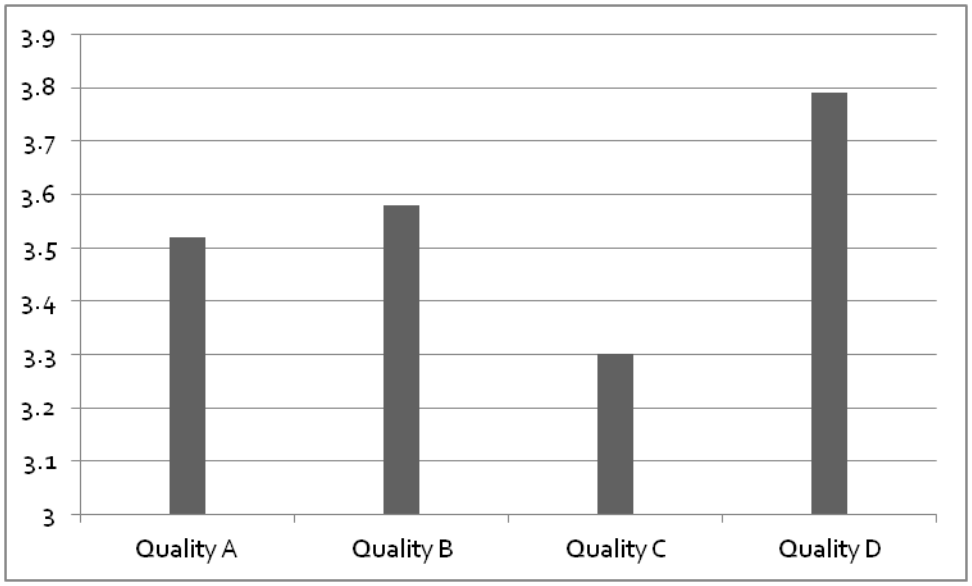

Figure 3.5 Survey 3 Mean Comparison of Individual LTC Facilities A, B, C and D Quality Category

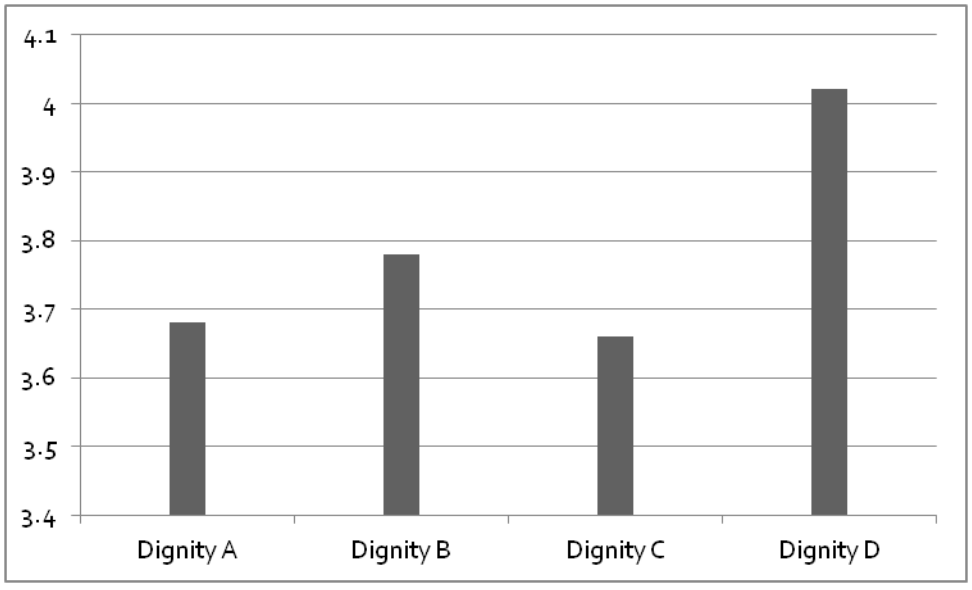

Figure 3.6 Survey 3 Mean Comparison of Individual LTC Facilities A, B, C and D Dignity Category

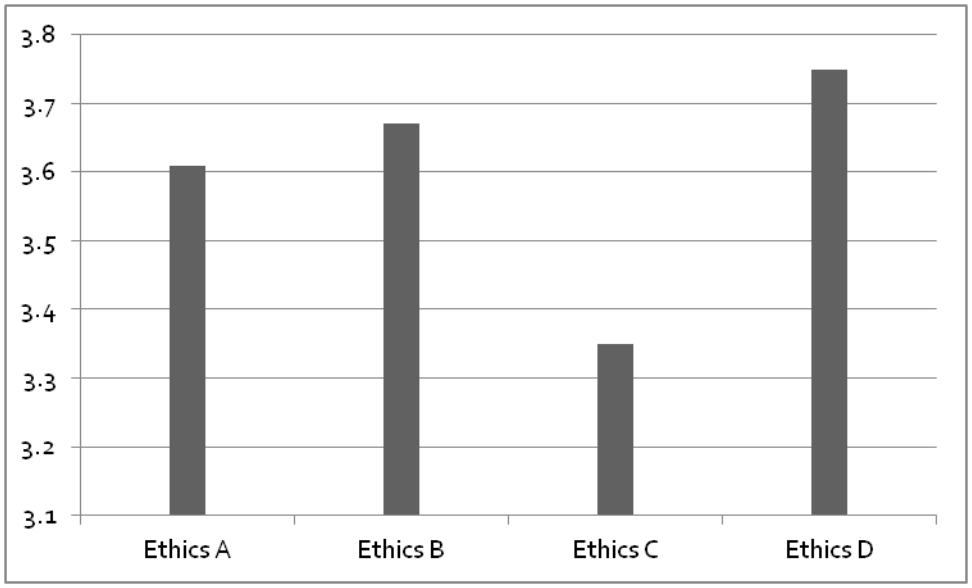

Figure 3.7 Survey 3 Mean Comparison of Individual LTC Facilities A, B, C and D Ethics Category

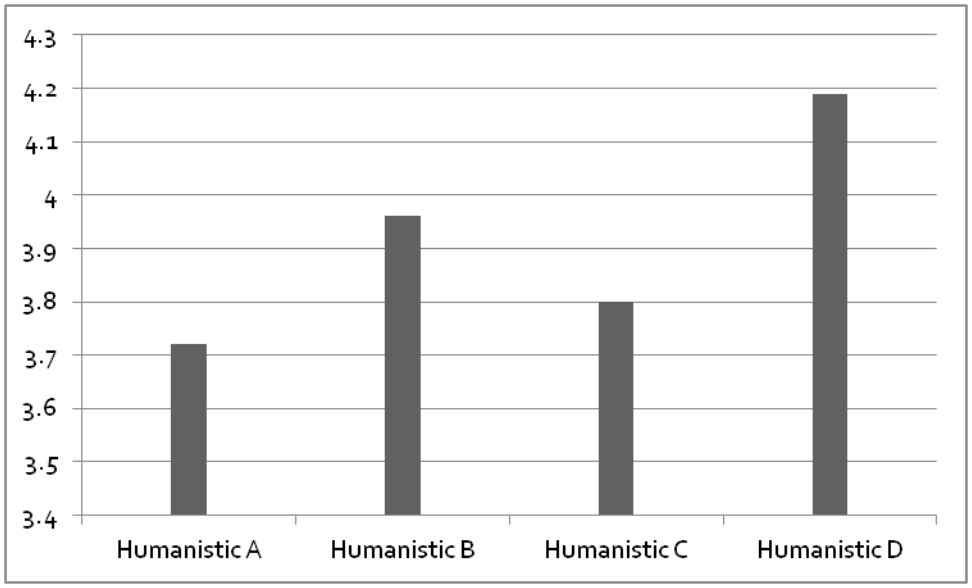

Figure 3.8 Survey 3 Mean Comparison of Individual LTC Facilities A, B, C and D Humanistic Care Category

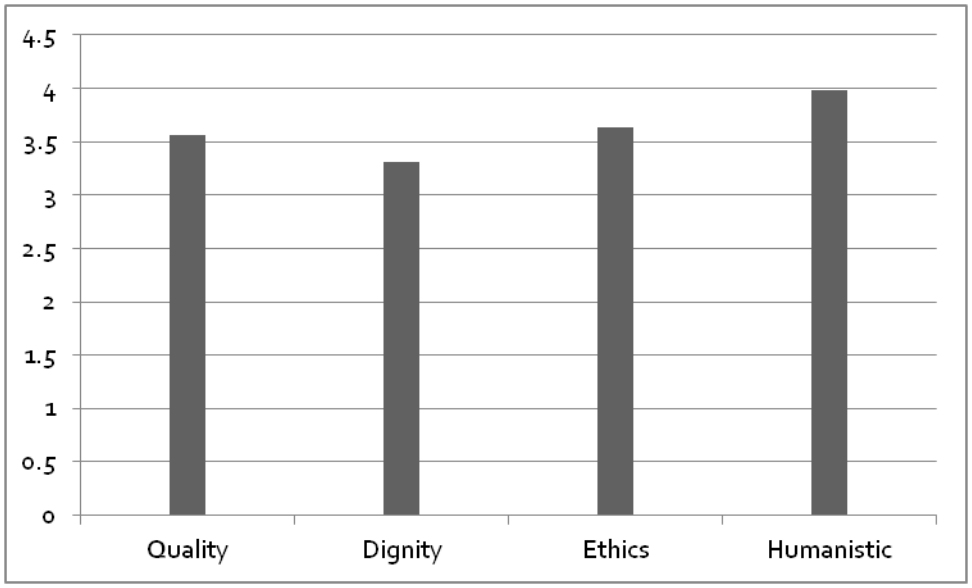

Figure 3.9 Survey 3Combined LTC Facilities A, B, C, D Category Mean Comparison

GLOSSARY

Malaria. A febrile hemolytic disease caused by infection with protozoa of the genus Plasmodium.[267]

Dysentery. Diarrhea containing blood and mucous, resulting from inflammation of the walls of the gastrointestinal tract, esp. the colon. Abdominal pain, rectal urgency, and sometimes fever are present. Dysentery is caused by bacterial, viral, protozoan, or parasitic infections and is most common in places with inadequate sanitation, where food and water become contaminated with pathogens.[268]

Influenza. An acute contagious respiratory infection marked by fevers, muscle aches, headache, prostration, cough, and sore throat. The disease usually strikes during the winter. In patients with serious pre-existing illnesses and people over 65, influenza frequently is fatal. The disease spreads primarily by inhalation of infectious aerosols.[269]

Pneumonia. Inflammation of the lungs, usually due to infection with bacteria, viruses or other pathogenic organisms. Clinically, the term "pneumonia" is used to indicate an infectious disease.[270]

Smallpox. An acute, highly contagious, and frequently fatal viral illness caused by the variola virus.[271]

Yellow fever. One of two forms of an acute, infectious disease caused by a flavivirus and transmitted by the Aedes mosquito.[272]

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[267] Donal Venes, ed., *Taber's Cyclopedic Medical Dictionary*, (Philadelphia: F.A. Davis Company, 2001), 1294.

[268] Venes, 648.

[269] Venes, 1102.

[270] Venes, 1694.

[271] Venes, 2016.

[272] Venes, 2364.

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