University of Nevada, Reno

The Older Adults Lived Health Care Experience

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Nursing

By

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THE GRADUATE SCHOOL

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ABSTRACT

It is estimated that by 2020 there will be 55 million adults age 65 or older in the United States. This growing and important segment of the population is living longer, dealing with more chronic health conditions, seeking more medical services, and paying more for those services than any other age group. This group also experiences ageism which can directly impact those health care services. Research has been conducted evaluating the older person's experiences with specific disease states (i.e. cancer, hypertension, diabetes), specific patient settings (i.e. inpatient, skilled nursing facilities), and even specific providers (i.e. physicians, PAs, NPs). However, there is paucity in the literature regarding the older person's general lived experience with health care services.

The purpose of this phenomenological study was to determine the meaning and significance of the lived experience of the older person receiving health care services. The aim of this study was to explore, describe, interpret and gain a deeper understanding of that lived health care experience, which will contribute to the science of nursing and medicine. This study was guided utilizing van Manen's six activities of qualitative inquiry. Participants were recruited through purposeful sampling until data saturation occurred. Semi-structured, face-to-face, audio recorded, interviews were conducted. Colaizzi's 7-step approach was implemented for data analysis. Knowledge acquired from this study may be utilized to provide a more holistic approach to patient care for older adults by all health care providers.

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CHAPTER I

INTRODUCTION

Background and Significance

According to the U.S. Census Bureau (2011) more people were age 65 or older in 2010 than any previous census. The older population has increased from 35 million in 2000 to 40.4 million in 2010 and is projected to increase to 55 million in 2020 (Administration on Aging [AOA], 2012). Americans are living longer and those who survive to age 65 can expect to live an average of 19.2 more years (Federal Interagency Forum on Aging-Related Statistics [Forum], 2012). As individuals are living longer they are faced with more chronic diseases and long-term illnesses. More than three-quarters of adults over the age of 65 have at least one chronic medical condition that requires on going medical treatment (Institute of Medicine of the National Academies [IOM], 2008).

Heart disease, stroke, cancer and diabetes are among the most common and costly chronic diseases affecting older adults (Forum, 2012). From 2009 to 2010, 30.4% of people age 65 and older reported heart disease, 55.9% hypertension, 8.6% stroke, 20.5% diabetes, and 24% any type of cancer (Forum, 2012). Additional health concerns for this age group include vision and/or hearing limitations, oral health problems, depressive symptoms, functional limitations, and cognitive changes. These chronic conditions and long-term illnesses are rarely cured and are being managed in both outpatient and inpatient settings.

Older Americans have health insurance through Medicare which covers a variety of services including inpatient hospital care, physician services, hospital outpatient care, skilled nursing care, hospice services, and prescription drugs (Forum, 2012). These same authors identify that in 1999, the hospitalization rate was 320 per 1,000 Medicare enrollees and in 2009 the average length of stay was 5.4 days. Skilled nursing facility stays increased from 28 per 1,000 in 1992 to 80 per 1,000 in 2009 for Medicare enrollees. AOA (2012) cites in 2007, older persons averaged more office visits with doctors than persons aged 45 to 65 (7.1 office visits compared to 3.7 office visits that year). For Medicare enrollees, age 65 and over, the number of physician visits increased from 11,395 per 1,000 in 1999 to 15,437 per 1,000 in 2009 (Forum, 2012). Older persons are utilizing more medical services and are spending more on those services than other age groups.

In 2010, 13.2% of total expenditures by older American's were on health, more than twice the proportion spent by all consumers (AOA, 2012). Those older persons with no chronic conditions spent, on average, \$5,520 per year on health care costs while those with five or more chronic conditions spent \$24,658 per year in 2008 (Forum, 2012). The Dartmouth Atlas of Health Care (2013) reports that the last two years of life account for approximately 32% of total Medicare spending for patients with chronic illness and from 2003 to 2007 the national average of Medicare reimbursements per decedent in the last two years of life was \$53,441.

Another issue that the older person faces is ageism, which is the prejudice or discrimination against a particular age group, particularly the elderly (Kagan & Melendez-Torres, 2013). A majority of older adults report experiencing ageism, such as people assuming they have a memory or physical impairment due to their age (Dittmann, 2003). Health care professionals often view older patients has "set in their ways" and "unable to change their behavior" (Dittmann, 2003, p. 50) and a study focused on the

attitudes of physicians-in-training toward older patients resulted in a mix of both positive and negative views about caring for the older adult (Higashi, Tillack, Steinman, Harper, & Johnston, 2012). These negative stereotypes have been linked with a shortened life span and a study conducted by Levy, Slade, Kunkel, and Kasl (2002) found that older adults with more positive self-perceptions of aging lived 7.5 years longer than those with less positive self-perceptions of aging.

The IOM (2008) found that more health care providers need to be educated in the basics of geriatric care and should be capable of caring for older adults. The IOM published recommendations in 2008 that proposed a concurrent three-pronged approach 1) enhance the geriatric competence of all providers, 2) increase the recruitment and retention of geriatric specialists and caregivers, and 3) improve the quality of care that is given. In addition, the Affordable Care Act is focused on improving quality and lowering health care costs while increasing access to health care (U.S. Department of Health & Human Services [HHS], 2013). The Affordable Care Act strengthens Medicare, offers eligible seniors a range of cost-free preventative services, and provides new protections for seniors by decreasing waste, fraud, and abuse of the program (HHS, 2013). Now, and in the immediate future, primary care providers (PCPs) will be charged with providing increased health care services to this growing segment of our population. Having a greater understanding of what that health care experience is for the older person will aid the PCP to treat this population more holistically.

Definition of Terms

For the purpose of this study the following terms are defined:

Ageism. Social and interpersonal discrimination and stereotypes based on advancing age (Kagan & Melendez-Torres, 2013).

Primary care. The level of a health services system that provides entry into the system for all new needs and problems provides person focused care over time, provides care for all but very uncommon or unusual conditions, and coordinates or integrates care (Johns Hopkins University, 2014).

Primary care provider (PCP). A health care practitioner who sees people that have common medical problems (National Institutes of Health [NIH], 2013). This person is usually a doctor, but may be a physician assistant (PA) or a nurse practitioner (NP) (NIH, 2013).

Older person. Any person age 65 or older (Cipher, Hooker, & Sekscenski, 2006; Federal Interagency Forum on Aging-Related Statistics, 2012; Karlsson, Edberg, Jakobsson & Hallberg, 2013; U.S. Census Bureau, 2011).

Holistic. Treating the whole person rather than simply managing disease; focuses on how the physical, mental, emotional, and spiritual elements of a person are interconnected to maintain health (American Cancer Society, 2013).

Problem Statement

The 65 and older group is a growing and important segment of the United States populace that is living longer, dealing with more chronic conditions and long-term illnesses, seeking more medical services and is paying more for those services than other age groups. Research has been conducted evaluating the older person's experiences with specific disease states (i.e. cancer, hypertension, diabetes), specific patient settings (i.e. inpatient, skilled nursing facilities), and even specific providers (i.e. physicians, PAs, NPs). However, the older person's general lived experience with health care services has not been explored. PCPs have a responsibility to treat each patient as an individual, setting aside their own preconceived notions and biases. It is vital that PCPs, and all health care workers, have a deeper understanding and knowledge of the older person's health care experience so as to provide a holistic plan of care.

Purpose of Study

The purpose of this phenomenological inquiry was to explore, describe, interpret, and gain a deeper understanding of how the older person experiences health care services. This qualitative study has contributed to the current literature that is lacking a deeper understanding of what health care means to older persons and how they experience those health care services. This study benefits all PCPs, including physicians, PAs and NPs, by providing increased knowledge and understanding of this special growing population. In addition, older persons may benefit from this study, as they explore what health care means; they will gain valuable insight into their expectations and satisfaction with our current health care system.

Research Question

The main question that guided this study was: What is the lived experience of the older person receiving health care services?

Chapter Summary

This chapter provided the background and significance of health care concerns/issues affecting older Americans. Included is the purpose of the study along with the research question that guided this phenomenological inquiry to better understand the perspectives of older adults receiving health care services. Chapter II will provide a discussion and analysis of the current literature.

CHAPTER II

LITERATURE REVIEW

A literature review was completed using the most common research databases CINHAL, Pub Med, Academic Search Premier and GoogleTM. Included in the search criteria were articles from 2003 to the present and a total of 12 journal articles were obtained from the searched databases that proved to be relevant to the topic of interest (Appendix A). This search resulted in various studies focused on patient satisfaction and/or experiences with various providers, health care settings, disease processes, or a combination of these. This search found a paucity of literature related to the older person's health care experience, specific to the primary care setting, thus the following studies reviewed will provide basic comparative knowledge for analysis of this research study.

Provider Preference

Cipher, Hooker, and Sekscenski (2006) examined the Medicare Satisfaction Survey and Consumer Assessment of Health Plans Survey section on Fee-for-Service, from 2000 to 2001. The findings of this cross-sectional, national survey indicated PAs and NPs were rated as favorably as physicians with Medicare patients over the age of 65. An unexpected finding of this study was that a disproportionate number of Medicaid patients reported their primary care providers were NPs oppose to PAs or physicians. Conversely, a significantly higher number of patients who had supplemental insurance reported their primary care providers to be physicians. These researchers suggest that PAs and NPs may be taking care of the poor population of elderly more than physicians. This was the first national cross-sectional study on patient satisfaction comparing physicians, PAs and NPs. The results are consist with supporting that NPs and PAs provide health care that is indistinguishable, if not better, in quality from care provided by physicians (Brown, 2007; Horrocks, Anderson & Salisbury, 2002; Naylor & Kurtzman, 2010).

Budzi, Lurie, Singh, and Hooker (2010) examined patient satisfaction with care provided by physicians, PAs and NPs in the Veterans Health Administration (VHA). Data from the VHAs Survey of Health Care Experience of Patients was analyzed and the researchers concluded the majority of the outpatients preferred to see NPs, compared to physicians and PAs, for primary care. Limitations of this study include that a majority of the NPs were also veterans, possibly resulting in patient satisfaction being affected by the PCPs gender and military experience. In addition, due to confidentiality and information protection, survey respondents could not be linked to his or her health care provider and details regarding geographical regions of the providers and patients could not be defined. Finally, this study concluded that veteran patients are more satisfied with care provided by NPs than physicians and PAs.

Brown (2007) examined the feasibility and sustainability of independently managed nurse practitioner (NP) practices, identified the characteristics on consumers who would likely use an independent NP practice, assessed consumer needs, and defined a target market for competitively positioning NPs. Data for this descriptive study was collected in June 2005 using a convenience sample of the entire population of 1000 employees at a large nonprofit organization in King County, Washington. An anonymous survey of the 1000 employees was conducted and 206 surveys were completed. Of the 206 surveys completed most respondents knew about NPs and a majority had seen an NP previously. Most were satisfied or extremely satisfied with NP care. Research results indicate that NP users were more likely to be female and younger. Limitations of this study include the small sample size and non-generalizability of these results.

Mayer, Gropper, Neville, Partridge, Cameron, Winer and Earle (2012) developed a questionnaire to evaluate breast cancer survivors' comfort with different clinician types or with a telephone/Internet-based virtual visit as components of survivorship care. A total of 547 questionnaires were sent to breast cancer survivors seen at the Dana-Farber Cancer Institute who were English speaking, more than 2 years since diagnosis, and not undergoing chemotherapy-based treatment at the time of identification. Of the 547 questionnaires that were sent, 218 eligible breast cancer survivors were considered participants in this study based on eligibility criteria. Most patients favored medical oncologist follow-up visits over those with primary care physicians or nurse practitioners in terms of reduced worrying about cancer, reduced stress around the visit, and improved effect on cancer survival. However, the majority also displayed substantial comfort with both primary care physicians and nurse practitioners in the same domains. Patients rated a virtual visit as having a less favorable impact on cancer survival and cancer-related worrying compared with in-person visits with clinicians. The generalizability of the results was limited because the breast cancer survivor cohort surveyed may not reflect the larger population of patients with breast cancer in terms of education, income and race/ethnicity.

Health Care Settings

Hess, Lynn, Conforti, and Holmboe (2011) evaluated the older patients' experience of care in internal medicine and family medicine residency program clinics compared to the experience of care provided by practicing physicians. This quantitative study obtained patient experience data from an American Board of Internal Medicine Practice Improvement Module focused on care of vulnerable elderly (patients aged 65 or older), which is a web-based self-evaluation tool based on nationally recognized guidelines that uses chart abstraction, patient surveys, and a practice system survey to generate a performance report. The residency clinic sample included 46 programs that were geographically diverse and representative of academic and community-based programs. The practice physician sample included 144 physicians certified by the American Board of Internal Medicine who completed the Practice Improvement Module focused on care of vulnerable elderly. Data from 2,213 patient surveys received from the residency clinics and 4,204 patient surveys received from the practicing physician settings were analyzed using descriptive statistics. Patients cared for in residency clinics were less likely to report receiving each process of care important for older adults (i.e. fall prevention or treatment of problems with balance or walking, screening for memory or hearing concerns, or discussion of medication side effects) than practicing physicians. The overall quality of care was rated lower for residency clinics than practicing physician offices, however practicing physician offices also failed to perform some processes at a desirable rate. Limitations included; variations in resident performance cannot be detected, some residency clinics were performing higher than others and these differences have not been studied in detail, and information about how participants from either study group distributed the survey or how their patients completed the survey was not captured.

In a study that evaluated data from the Hospital Consumer Assessment of Health care Providers and Systems (HCAHPS) survey, Jha, Orav, Zheng, and Epstein (2008) concluded that although most patients were generally satisfied with their care in a hospital setting, there was room for improvement. Patient experiences at more than 2400 U.S. hospitals were examined and patients who received care in hospitals with a high ratio of nurses to patient-days reported somewhat better experiences than those who received care in hospitals with lower ratio. Although the strength of the relationship was modest, hospitals that performed well on the HCAHPS survey generally provided higher quality of care across all measures of clinical quality than did those that did not perform well on the survey. HCAHPS highlighted several areas of improvement such as nursing care, communication about medications, pain management, and providing clear discharge instructions. A limitation of this study is nearly 40% of U.S. hospitals failed to provide HCAHPS data and the data presented in this article only represented a snapshot of patients' experiences.

Hasson and Arnetz (2011) used cross-sectional surveys to compare care recipients' and their relatives' perceptions of quality of care in nursing homes and homebased care. This study was conducted in two municipal older people care organizations in Sweden. All of the older people receiving home help services, home care or living in nursing homes in these two municipalities were considered eligible for the study. The only exclusion criteria were older people not capable of expressing their perceptions due to severe dementia. The questionnaires were distributed by the nursing staff who discussed each care recipient's capability to reply to the questionnaire with their supervisors. Care recipients were permitted to receive assistance reading the questions and/or writing their responses from a friend or relative. Only one relative per care recipient was registered as the primary family member and all individuals who were registered as a primary family member to care recipients were included in the study. Relatives received the questionnaires by mail. A total of 541 care recipients responded to the survey for an overall response rate of 46%. A total of 780 relatives responded to the survey for an overall response rate of 50%. The study results suggest that home-based older people care appears to be in greater need, compared to nursing homes, of development of staff competence, staff interaction with families and activities offered to older adults. In both settings, nursing staff behavior influences the care recipients' and their relatives' satisfaction with care. Limitations of this study include; low response rates by care recipients and relatives, possible selection bias by the supervisors' and nursing staff in care recipient selection and limited generalization.

Karlsson, Edberg, Jakobsson, and Hallberg (2013) examined care satisfaction of people 65 years and older, in relation to place of living, health-related quality of life, functional dependency, and health complaints who were receiving public care and service (formal care from the municipality). The study included 166 individuals who received public care and services in five municipalities in southern Sweden. Participants were identified and recruited by their 10 digit personal number when they were registered in a national longitudinal and multi-purpose study initiated in 2001 in Sweden. Included in the study were older persons who had been granted public care and service at home, who were living in a special accommodation (equivalent to a nursing home) or who had at least two visits per month from home nursing care or rehabilitation. Excluded from the study were older people granted only a bodily-carried alarm (alarm equipment to call for help from staff), meals on wheels, or transport services (subsidized transport with assistance). Between October 2002 and June 2003, specially trained registered nurses, not involved in the care and services received by the older persons, conducted personal interviews with the study participants. Respondents who had impaired communication or cognitive ability, as assessed by the registered nurse, had a proxy, the next of kin or the contact person, that was interviewed instead. There were only 9 study participants who required a proxy to answer interview questions. Those older adults at home rated an overall higher care satisfaction and were more satisfied with care continuity and personal relations. They thought the staff had more time and were more respectful and quiet than the ratings by those in a special accommodation. Care satisfaction and health-related quality of life was also more associated with functional impairment and health complaints than to whether care and service was received at home or in a special accommodation. Those individuals with dependency in Instrumental Activities of Daily Living self-rated care satisfaction lower than those with dependency in Personal Activities of Daily Living who self-reported high care satisfaction. Limitations of the study discussed by the researchers included the skewed distribution regarding the older person's place of residency. This study identified that there were more, older people living in special accommodations compared to the official statistics. This may limit the results transferability to the group of older adults receiving public care and services at home. The participants' dependency on care and services may have also influenced their responses, which may have resulted in underreported dissatisfaction.

Satisfaction Related to Care of Disease Processes

Stein et al. (2011) evaluated the quality of and patient satisfaction with primary health care for anxiety disorders. The authors utilized baseline data from the Coordinated Anxiety Learning and Management study, which was a randomized controlled trial of 1004 subjects that were referred by their primary care provider for collaborative management of their anxiety disorder(s). They determined that approximately 57% of participants received appropriate anti-anxiety medication within the previous 6 months, but only about 29% at adequate dose and duration; approximately 46% of participants had received some counseling, but only 21% with a cognitive-behavioral therapy focus; only about 41% of participants received quality pharmacotherapy and/or psychotherapy; and few patients, about 45%, were at least somewhat satisfied with their mental health care. Limitations of this study include a purposively selected sample of outpatients that cannot be expected to be representative of U.S. outpatients with anxiety disorders and the patients may have been more difficult treat and as a result were referred by their primary care provider for the trial.

Kuluski et al. (2013) used a mixed method and reports study design to investigate what is important in care delivery from the perspective of hospital inpatients with complex chronic disease. Between February and July 2011, one-on-one semi-structured interviews were conducted using a convenience sample of inpatients at a continuing care/rehabilitation hospital in Canada. Excluded from the study were patients who could not provide informed consent including individuals with severe cognitive impairments. Of the 158 patients eligible for participation 116 participated in interviews and 110 commented on the aspects of care delivery that were important to them and were captured in the qualitative analysis. Three overarching themes were gleaned from the data and represented areas that the respondents felt needed to be addressed to improve the care delivery experience: 1) components of the care plan (a comprehensive assessment, supported transitions and bio-psycho-social care package), 2) care capacity and quality (optimal staff to patient ratios, quicker response times, better patient-provider communication and consistency between providers), and 3) the patient-provider relationship (characterized by respect and dignity. A limitation discussed by the researchers is the use of one hospital-based population with complex chronic disease which limits the transferability of the study findings.

Care Preferences and Disease Processes

A qualitative investigation conducted by Bayliss, Edwards, Steiner and Main (2008) explored processes of care desired by elderly patients who have multimorbidities that may present competing demands for patients and providers. One-on-one interviews of 26 community-dwelling Health Maintenance Organization (HMO) members age 65 or older and had at the minimum the conditions of diabetes, depression, and osteoarthritis were completed. Themes from the interviews that reflected the participants' preferred process of care included the following: 1) the need for convenient access to providers (telephone, internet, or in person), 2) continuity of care (knowing and being known by their providers for a period of time), 3) clear communication of individualized care plans (with supplemental, usually written, communication), 4) individual and coordinated care (support from a single coordinator of care who could help prioritize their competing demands), and 5) being heard (having providers who listened and included the patient in diagnosis and treatment plans). This investigation was limited in that all of the

respondents were members of a single HMO, however the researches believed that their findings are likely generalizable to many older adults with multiple chronic conditions. Also, some of their reported care preferences may reflect the participants' age and functional level rather than purely their disease burden.

Financial Impact and Chronic Disease

Jeon, Essue, Jan, Wells and Whitworth (2009) completed a secondary analysis of the qualitative data focusing on the economic hardship based on the experiences of those who are affected by chronic illness. Between March 2007 and January 2008, semistructured interviews were conducted in the Australian Capital Territory and Western suburbs of Sydney, Australia. Patients were recruited through referrals from general practices, local hospitals, community health services, specialist clinics, health care consumer organizations, and Aboriginal health services and purposive sampling resulted in 52 patient participants. Carers (the most centrally involved family member or close friend providing practical and emotional assistance to the patient) were recruited using convenience sampling, primarily through their care participant and through health care professionals at the previously mentioned centers, which resulted in 14 carer participants. Participants experienced the economic impact of chronic illness in terms of affordability of treatment (ability to pay for any treatment, service and care required to manage their chronic conditions and its consequences) and affordability of other things (ability to pay for additional necessities required for the management of the illness, such as health food, exercise and gym memberships and joining social activities). Factors that influenced economic hardship included eligibility for pensions, other government subsidies or allowances, and/or a concession card. The researchers concluded that economic hardship requires households to make difficult decisions between basic living expenses and health care in managing chronic illness. These decisions may cause less than optimal health outcomes and increased cost to the health care system. The limitations outlined by the researchers include the lack of generalizability of the data obtained, a small sample size, and convenient sampling of the carer participants.

Chapter Summary

Understanding the lived experiences of older adults receiving primary care services gives insight into the challenges and emotions faced by this populace. There is paucity in the literature in regards to the older person's primary health care experience. The current literature has an emphasis on patient satisfaction and/or experiences with various providers, health care settings, disease processes, or a combination of these. The literature review provided the reader basic comparative knowledge for analysis of this research study.

CHAPTER III

METHOD OF INQUIRY: GENERAL

Phenomenology was the method of inquiry utilized for this research. There has been much confusion surrounding the definition of phenomenology (Dowling, 2007; Maruna & Butler, 2005) however, phenomenology is simply the study of human consciousness and an understanding of subjective experience (Maruna & Butler, 2005). Phenomenology seeks to understand how humans experience and make sense out of their existence. The word phenomenon comes from the Greek word "*phanesthai*, to flare up, to show itself, to appear" (Moustakas, 1994) and thus the motto of phenomenology "*Zu den Sachen*" means both "to the things themselves" and "let's get down to what matters!" (van Manen, 1990, p. 184). In its most basic form, phenomenology is "illuminating the perspectives of others" (Maruna & Butler, 2005, p. 50).

According to van Manen and Adams (2010) phenomenological research aims to "lead us to suddenly see or grasp a human phenomenon in a way that enriches our understanding of everyday life experience" (p. 449). It is from a first-person perspective that we are able to make detailed descriptions of consciousness and inner experiences (Maruna & Butler, 2005).

History of Phenomenology

Phenomenology is a philosophical movement closely associated with the German philosopher Edmund Husserl (1859-1938), who is widely regarded as the founder of phenomenology. Husserl defined phenomenology as the science of pure consciousness and his philosophy was conceptualized in the idea that the "lifeworld" is understood without interpretations and is simply learning the experiences of individuals. Heidegger, a student of Husserl, distanced himself from the focus of consciousness and intentionality in favor of a more hermeneutic perspective founded on the ontological view that lived experience is an interpretive process (van Manen & Adams, 2010) thus, Heidegger is considered the "prime instigator of modern hermeneutics" (Annells, 1996, p. 706). Heidegger dismissed the notion of intentionality in favor of an existential phenomenological account of the meaning of the world (Moran, 2005) and emphasized the notion of *temporality*, or time, as the basic existential of existence (Keller, 1999). He also rejected the concepts of bracketing and reduction and believed that understanding is never without presuppositions (McConnell-Henry et al. as cited in Earle, 2010).

Phenomenology, as described by Husserl and Heidegger was philosophical in nature and no rules or procedures for conducting phenomenological research was discussed (Earle, 2010). Max van Manen appears to combine the descriptive phenomenology of Husserl with an argument that it is also interpretive (Dowling, 2007) and offers a contemporary approach to researching the lived experience through hermeneutic phenomenology. Like Heidegger, van Manen does not embrace the concept of bracketing but acknowledges that our experiences influence our reflections (Dowling, 2007). The approach of van Manen (1990) is an active and ongoing interplay of six distinct research activities: "(1) turning to a phenomenon which seriously interests us and commits us to the world; (2) investigating experience as we live it rather than as we conceptualize it; (3) reflecting on the essential themes that characterize the phenomenon; (4) describing the phenomenon through the art of writing and rewriting; (5) maintaining a strong and oriented pedagogical relation to the phenomenon; and (6) balancing the research context by considering parts and whole" (p.30). These activities will further guide this phenomenological inquiry.

Phenomenological Activities Related to this Study

The first activity, as outlined by van Manen (1990), is turning to a phenomenon which seriously interests us and commits us to the world which is fundamental for a researcher interested in understanding human experience. Questioning whether it is possible for a researcher to put aside any preexisting knowledge or assumptions they may have about the phenomenon, van Manen encourages a responsibility to make their knowledge of the subject explicit (Earle, 2010). "We must come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character" (van Manen, 1990, p. 46). This researcher's interest in the subject began with a self-reflection of how health care is experienced in today's society of modern technology. Family medicine has moved away from the time of house-calls to a computerized era of on-line appointment scheduling and digital communication with providers. As a family nurse practitioner it is important to understand how patients experience health care services, particularly the older generation which is a rapidly growing segment of our population.

The second activity, *investigating experience as we live it*, suggests that the researcher becomes immersed in the phenomenon in order to develop an understanding of the lived experience and not take anything for granted (van Manen, 1990). The three ways of collecting data, as noted by van Manen, include writing, interviewing and observation. Earle (2010) posits that through interviewing the researcher can collect data

in order to discover a rich understanding of a phenomenon while also creating a dialogue between the researcher and the participant about the meaning of the experience. This phenomenological inquiry examined the health care experience of older adults in order to develop an enriched understanding of that experience through conversational interviewing.

The third of van Manen's (1990) activities has the researcher *reflect on essential themes* which is integral in distinguishing between the appearance and the essence of the lived experience. Themes give structure to the phenomenon and ultimately meaning to the experience under investigation, once common themes have been identified the researcher must then select phrases from the data that are particularly relevant and capture the meaning of the themes (Earle, 2010). By identifying and analyzing themes found among older peoples health care experience, a rich and deeper understanding was revealed about the nature of this lived experience.

Describing the phenomenon through *the art of writing and rewriting* is the fourth activity (van Manen, 1990). Through this activity, the researcher gives appearance and body to thought through the artistic process of creating phenomenological text through writing and rewriting (Earle, 2010). As the older person shared their individual and unique experiences with health care the essence of the lived experience was discovered.

The fifth activity is *maintaining a strong and oriented relation* (van Manen, 1990) which requires the researcher to aim for the strongest possible interpretation of the phenomenon through their awareness of the lived experience. Although the researcher has personal knowledge and experience with the phenomenon under study, personal biases were separated and the researcher maintained openness to the participants'

experiences. In doing so, the researcher externalized the lived experience of the older adult's health care experience by writing a deep, rich, and meaningful text.

The sixth, and final, activity *balancing the research context by considering parts and whole* (van Manen, 1990) encourages the researcher not to be consumed with the details of the methodology, until the study has been completed. The power of the text comes from the participant's experiences and van Manen suggests that specific details can and should be worked out during the research study process (1990). This activity guided this researcher to achieve a deeper understanding of the phenomenon by stepping back to evaluate and examine how each part contributed to the overall study by maintaining openness to the participant's experiences.

Research Plan

Participant Selection

Qualitative research is the investigation of phenomena, in an in-depth and holistic fashion, through the collection of rich narrative materials (Polit & Beck, 2012). These same authors identify that inquiry of real-life experiences of people with first-hand knowledge of the phenomenon typically takes place in the naturalistic setting. In order to meet the conceptual and substantive needs of this research, purposeful sampling was utilized to recruit participants who are knowledgeable of the phenomena. In particular, participants who are over the age of 65, and who have had a health care experience with in the previous two years, were recruited to share their personal health care experiences. There are no fixed rules in qualitative sampling and sample size was based on informational need (Polit & Beck, 2012). A guiding principle of sampling is data

saturation or "sampling to the point that no new information is obtained and redundancy is achieved" (Polit & Beck, 2012, p. 521).

After approval from the Institutional Review Board (IRB) participants were recruited, via flyer, from a local Starbucks Coffee Company, Arthur Murray Dance Studio, and the Osher Lifelong Learning Institute. Inclusion criteria included: any English speaking person age 65 or older, who had a health care experience within the previous two years.

Data Generation and Analysis Procedures

Data Generation

"The relationship between the researcher and the participant is based on mutual respect and a position of equality as human beings" (Holloway & Wheeler, 2013, p. 97). These authors identify, by the virtue of professional expertise and skill in interviewing, the researcher is in a position of power and therefore an unequal relationship between the interviewer and the person interviewed exists. Furthermore, the researcher can empower participants by listening to their perspective and giving voice to their concerns. The researcher can also respect the way in which participants develop and phrase their answers (Marshall & Rossman, 2006). By empowering and respecting the participants the researcher is able to gain and maintain a high level of trust and become an active participant in the interview and thus takes part in co-constructing meaning (Holloway & Wheeler, 2013).

Qualitative data collection using a phenomenological approach primarily uses indepth interviews of individuals with first-hand knowledge and experience of the phenomenon being studied (Polit & Beck, 2012). The purpose of the interview was to discover the participants' feelings, perceptions and thoughts about their lived health care experience. Semi-structured interviews, utilizing an interview guide, helped the researcher to focus on the issues or topics that were covered and lines of inquiry followed. This ensured that the researcher collected similar types of data from all participants while encouraging the participant to talk freely about all the topics on the guide, and tell their stories in their own words (Polit & Beck, 2012). The most critical interviewing skill is active listening and it is the researchers' obligation to listen intently to the participants' stories. In order to protect participants' privacy, the interviews were conducted at an agreed upon location of choice. This placed the participant in some position of control which allowed for the participant to be at comfort and ease with the interview.

Analysis Procedures

Qualitative data analysis is a non-linear, complex process but is also systematic, orderly and structured (Holloway & Wheeler, 2013). These authors further assert data analysis is an iterative activity meaning that the researcher moves back and forth from collection to analysis and back again. Three techniques are suggested by van Manen (1990) to uncover themes in the data, the holistic approach, the selective reading approach, and the detailed reading approach. These techniques consist of listening and observing during interviews and reading and re-reading the transcripts, while reflecting on the essential themes which characterize the phenomena. Colaizzi's (1978) 7-step method of data analysis was utilized and is identified here. Colaizzi encourages researchers to be flexible with these as many of the steps overlap in the analysis process.

1) Read all transcripts to acquire a feeling for them and to make sense out of them. The researcher must preserve the participants' words as accurately as possible and the fullest and richest data can be gained from transcribing verbatim (Holloway & Wheeler, 2013) therefore the use of transcriptions from audio recordings is a technique often employed to record and store data appropriately. The participant interviews were professionally transcribed for further review by the researcher. The holistic approach employed by van Manen (1990) in reviewing transcripts suggests they should be read and re-read several times to gain a sense of the whole content.

2) Review each transcript and extract significant statements from them. Using van Manen's (1990) selective reading approach the transcripts were read several times to identify statements or phrases that seem particularly essential or revealing about the experience being described. Colaizzi (1978) suggests that repetitions in the transcripts can be eliminated and furthermore, specific statements can be transposed to a more general formulation.

3) Meanings are formulated from significant statements. The identification of themes requires the researcher to move beyond a description of the range of categories to an explanation or even better, interpretation of the phenomenon (Green et al., 2007) requiring the researcher to have creative insight (Colaizzi, 1978). Utilizing van Manen's (1990) detailed reading approach every single sentence or sentence cluster was evaluated to identify what is revealed about the phenomenon.

4) Meanings are organized into themes, and these themes evolve into theme clusters and eventually theme categories. Steps 1through 3 were repeated for each transcription and then organized into clusters of themes. These clusters of themes were then referred back to the original transcripts in order to validate them. It is possible that discrepancies may be noted among and/or between the various clusters and Colaizzi (1978) advises the researcher to refuse the temptation to ignore data or themes that do not fit the research findings thus far. All participants had different and unique experiences which were placed into different categories producing explanations for all data received.

5) Integrate results into an exhaustive description of the phenomenon under study. The researcher then constructs emerging themes as a generative guide for writing the research study (van Manen, 1990). The researcher allowed the themes to guide the written research study moving beyond a description toward an explanation and understanding of the lived health care experience of older adults.

6) Formulate an exhaustive description of the phenomenon under study in as unequivocal a statement of identification as possible. The notion underlying van Manen's (1990) approach is that phenomenological research cannot be separated from the practice of writing. Through writing the results of the study the researcher participated in an active struggle to understand and recognized the meanings of the lived experience (Polit & Beck, 2012).

7) As a final step, validation is sought from the participants to compare the researcher's descriptive results with their lived experience. An important part of verifying that the researcher has interpreted and presented the participants' lived experience accurately is to have the participant review the transcripts. This permits the participant and opportunity, if necessary, to clarify and elaborate on their lived experience and any relevant new data must be worked into the final product of the

research (Colaizzi, 1978). All transcripts and themes were reviewed by the participants for accuracy.

Ensuring Trustworthiness

Holloway & Wheeler (2013) describe trustworthiness as a methodological soundness and adequacy. Qualitative researchers must consider the true value of their studies and demonstrate that those studies are credible and valid. Guba (1981), purposes that trustworthiness of qualitative research is possible through developing credibility, transferability, dependability and confirmability.

Credibility, in preference to internal validity, seeks to ensure that the study measures or tests what is actually intended (Shento, 2004). Qualitative research can be valid through intersubjective knowledge and it is expected that "its readers will have learned something of the human condition as well as recognize and grasp the essence of the phenomenon under study" (Holloway & Wheeler, 2013, p. 302). Credibility can be achieved through: citing the key writers of related works in the literature review, specifying the particular data analytic methods used and corroboration of data analysis with the participants themselves (Saldana, 2011). Transferability, in preference to external validity/generalizability, suggests that the findings of the researcher can be transferred to similar situations or participants (Holloway & Wheeler, 2013). Guba (1981) cites that in order to ensure dependability of qualitative research, the research findings must be consistent and accurate, thus providing reliability of the study. The readers should be able to follow the appropriateness of the analysis through the decisionmaking process outlined by the researcher (Holloway & Wheeler, 2013). Confirmability, in preference to objectivity, judges the research by the way the findings and conclusions

were achieved and ensuring they were not the result of the researcher's prior assumptions and preconceptions (Holloway & Wheeler, 2013).

Chapter Summary

This chapter began with a history of phenomenological research and its importance as a methodology for qualitative research. A description of van Manen's approach to hermeneutic phenomenology utilizing Colaizzi's steps of data analysis and the process for data collection and management were explained. Finally, a description of ensuring trustworthiness within the study was provided.

CHAPTER IV

METHOD OF INQUIRY: APPLIED

Sample Participant Recruitment and Selection

Participants who were knowledgeable in the content of this study were selfselected through purposeful sampling. Purposeful sampling allowed the researcher to seek information-rich participants who have had a previous health care experience for the purpose of understanding that phenomena. The goal was to recruit approximately 10 participants with recruitment cessation once data saturation had occurred. Data saturation was achieved when the narratives revealed no new information and redundancy occurred (Polit & Beck, 2012).

The inclusion criteria for this study were: At the time of recruitment the participant must have been an English speaking adult, age 65 or older, who had a previous health care experience in the prior two years. Participants who were primarily non-English speaking, under the age of 65, who had not had a health care experience in the prior two years were excluded from this study.

Participants agreed to a face-to-face, audio taped interview, which was conducted at a private location mutually agreed upon by the researcher and the participant. Participants also agreed to follow-up communication via face-to-face, telephone, or mail for review of their narratives. Each participant was provided a copy of their transcription for review. This allowed the participants to make any corrections, clarify any points, and ensure accuracy of their experience. Participants were asked then to provide any additional thoughts on their lived health care experiences.

Gaining Access

Protection of Human Subjects

The Institutional Review Board (IRB) at the University of Nevada, Reno reviewed and approved this research (Appendix B). Additionally, approval from the recruitment sites was obtained prior to posting a recruitment flyer.

Recruitment

Following approval from the IRB and selected businesses, recruitment flyers were posted in highly visible areas at each location (Appendix C). Participants were also recruited by word of mouth from other participants who self-selected for this research and met the inclusion criteria.

Interested participants contacted the researcher via telephone. The researcher determined inclusion criteria, further explained the purpose of the research, structure of the interviews, maintenance of confidentiality, consent to audio-taped interviews, transcription of the data verbatim, handling of the data, reporting of the data at the end of the research, and answered any questions the participant may have had regarding the research. This information was included in the consent form (Appendix D). All participants were informed that participation in this research study was completely voluntary and that they may refuse participation or withdraw from the study at any time without penalty or risk. All participants who met the inclusion criteria were treated fairly, equally, and without discrimination. Individuals who agreed to participate in this research were contacted regarding a time and location for formal consenting and interview.

Privacy and Confidentiality

All of the information obtained in this study was and continues to remain confidential. Participants were given a pseudonym and any identifying information was removed from the transcripts to maintain confidentiality. In the researcher's field notes and transcripts, the participant was referred to by their pseudonym. A key for participant contact information and the recorded interviews were stored in a locked file cabinet accessible only to the researcher. A confidentiality statement was signed by the transcriptionist who had access to the interview data (Appendix E).

Consent

Consent forms were developed to meet the requirements of the participating university's IRB. The consent form included the purpose of the research and a discussion of the inclusion criteria. It was made clear that participation in the study was on a volunteer basis and that the participants could withdraw from the research at any time, should they choose. Research procedures were clearly stated, along with the details related to the maintenance of confidentiality and the risks and benefits of participation. All participants completed the consent process prior to beginning the interview.

Data Generation and Analysis Procedure

Data Generation

Data for this study was collected through in-depth, face-to-face guided interviews lasting approximately one hour. The interviews were conducted at an agreed upon, private location where confidentiality was maintained throughout the length of the interview. An interview guide was prepared and utilized to help facilitate the discussion (Appendix F). Initial questions included basic demographic information to identify the age of the participants. The interviews were recorded with a digital voice recorder, transcribed verbatim by a professional transcriptionist, who signed a confidentiality statement, within a week of the interview and reviewed for accuracy by the researcher. In addition, a field journal containing notes was maintained by the researcher to help described aspects of the physical environment, participant body language, demeanor, dress, and other observations not discernible from the transcripts.

Data Analysis

The initial step in data analysis consisted of listening to the recorded interviews of each participant's experience. The verbatim transcripts were then read and re-read multiple times to analyze the data. Thematic statements were isolated utilizing van Manen's (1990) three techniques (the holistic approach, the selective reading approach, and the detailed reading approach). The researcher demonstrated these techniques through observation and listening to each participant, reading and re-reading the verbatim transcripts, and through thoughtful reflection and analysis on the essential themes which characterize the phenomena. Finally, Colaizzi's (1978) 7-step approach that operationalizes van Manen's (1990) techniques was utilized in analyzing the data.

1) Read all transcripts to acquire a feeling for them and to make sense out of them. Each interview was conducted, in person, by the researcher. After each interview the researcher spent time reflecting on the discussion and re-reading the interview notes. Each recorded interview was transcribed verbatim by a professional transcriptionist who

had signed a confidentiality agreement. The transcripts were reviewed and listened to multiples times to ensure accuracy and provided time for additional notes to be taken by the researcher. The holistic approach of listening to, reading, and re-reading the interviews allowed the researcher to immerse themselves into the data in order to gain a sense of the whole content (van Manen, 1990).

2) Review each transcript and extract significant statements from them. Using van Manen's (1990) selective reading approach, the transcripts were read several times to identify statements or phrases that seem particularly essential or revealing about the experience being described. The transcripts were coded by hand, through highlighting, circling, or underlining and compared with the field notes from the interviews.

3) Meanings are formulated from significant statements. The identification of themes requires the researcher to move beyond a description of the range of categories to an explanation or even better, interpretation of the phenomenon (Green et al., 2007) requiring the researcher to have creative insight (Colaizzi, 1978). Utilizing van Manen's (1990) detailed reading approach every single sentence or sentence cluster was evaluated to identify what was revealed about the phenomenon. Common words, phrases, or thoughts, which were significant to the participants' experiences, were analyzed by the researcher.

4) Meanings are organized into themes, and these themes evolve into theme clusters and eventually theme categories. Steps 1 through 3 were repeated for each transcription and then organized into clusters of themes. These clusters of themes were then referred back to the original transcripts in order to validate them.

5) Integrate results into an exhaustive description of the phenomenon under study. The researcher then constructed emerging themes as a generative guide for writing the research study (van Manen, 1990). The researcher allowed the themes to guide the written research study moving beyond a description toward an explanation and understanding of the lived health care experience of older adults. Commonalities within various descriptions created a meaningful explanation of the phenomena (van Manen, 1990).

6) Formulate an exhaustive description of the phenomenon under study in as unequivocal a statement of identification as possible. Through writing the results of the study the researcher participated in an active struggle to understand and recognized the meanings of the lived experience (Polit & Beck, 2012). As the researcher began writing the results of the study, themes and theme clusters were easily identified. The struggle occurred when the researcher tried to identify the essence of those themes and theme clusters in a concise, and as an unequivocal statement as possible.

7) As a final step, validation is sought from the participants to compare the researcher's descriptive results with their lived experience. An important part of verifying that the researcher interpreted and presented the participants' lived experience accurately was to have each of the participants review their transcripts. This permitted the participant an opportunity, if necessary, to clarify and elaborate on their lived experience. All transcripts were provided to the participants for review. The participants then had an opportunity to verify the transcripts and the researcher's interpretation of the data for accuracy and true expression of their health care experience.

Ensuring Trustworthiness

In qualitative research, Holloway & Wheeler (2013) define trustworthiness as methodological soundness and adequacy. Qualitative researchers must consider the true value of their studies and demonstrate that those studies are credible and valid. Guba (1981) proposes that trustworthiness of qualitative research is possible through developing credibility, transferability, dependability and confirmability.

Credibility

In this phenomenological study, credibility was obtained by utilizing the reputable qualitative research methods developed by van Manen. Credibility seeks to ensure that the study measures or tests what is actually intended (Shento, 2004). It is expected that in qualitative research "its readers will have learned something of the human condition as well as recognize and grasp the essence of the phenomenon under study" (Holloway & Wheeler, 2013, p. 302). The researcher cited key writers of related works in the literature review, specified the particular data analytic methods used, and corroborated the data analysis with the participants themselves all in an attempt to ensure credibility of the research study.

Transferability

Transferability suggests that the findings of the researcher can be transferred to similar situations or participants (Holloway & Wheeler, 2013). The findings of this study are specific to older adult's health care experiences. While this data cannot be generalized to the entire population; this research does serve as an example of an important and growing segment of the American population. The researcher's goal was to provide a rich and thick description of the phenomena to give readers a deeper understanding of the older population's health care experience.

Dependability

Guba (1981) cites that in order to ensure dependability of qualitative research, the research findings must be consistent and accurate, thus providing reliability of the study.

The readers should be able to follow the appropriateness of the analysis through the decision-making process outlined by the researcher (Holloway & Wheeler, 2013). To maintain dependability, the processes within this research are described in detail. An indepth description of the planning process, execution of the study, details of the field experience, and evaluation of inquiry are provided.

Confirmability

Readers are able to judge this research by the way the findings and conclusions were achieved and ensuring they were not the result of the researcher's prior assumptions and preconceptions (Holloway & Wheeler, 2013). A detailed description of the methodology, along with ongoing reflective commentary created an audit trail. In this study, the researcher discussed with the committee chair and members, the researcher's biases based on personal experiences with older adults receiving health care services. Acknowledging these biases allowed the researcher to produce a text which accurately reflects the participants' lived health care experience and not that of the researcher.

Chapter Summary

This chapter provided the application process of van Manen's phenomenological approach to research with a description of Colaizzi's steps for data analysis. The researcher identified specific areas of the study where credibility, transferability, dependability and confirmability were demonstrated to ensure trustworthiness within the research.

CHAPTER V

FINDINGS

The purpose of this phenomenological study was to determine the meaning and significance of the lived experience of the older person receiving health care services. The aim of this study was to explore, describe, interpret and gain a deeper understanding of that lived health care experience, which will contribute to the science of nursing and medicine. The question guiding this research was: What is the meaning and significance of the lived experience of the older person receiving health care services? The following accounts come from older persons who have had a recent health care experience and the insight they share gives the reader "a view of the world in which we live as human beings" (van Manen, 1990, p. 5).

Description of the Participants

A total of eight participants were recruited and participated in this study; five men and three women. The ages of the participants ranged from 65 to 75 years. Two participants were married to each other; two other participants were living together; two participants were widowed; one participant was divorced; and one participant was married.

Data Collection

All eight interviews were conducted between December 2013 and January 2014. Five of the participants were known to the researcher, as family friends, and three were unknown to the researcher. The interviews were held in a private location, which was convenient for the participant. Three of the interviews were conducted at the participants' private residence, two were conducted at the researcher's private residence, and two were conducted in a private, small meeting room at the Redfield Campus extension of the University of Nevada, Reno.

Each of the chosen interview locations provided a quiet, private, comfortable space for the participants. The participants sat in chairs or couches next to or across from the researcher. All cell phones were turned off or silenced to avoid distraction.

Each participant was given the consent form for review. The researcher allowed adequate time for the participant to read the consent form. The researcher then reviewed the consent form with each participant and answered any questions the participants might have regarding the consent form. The researcher reminded each participant that involvement in the study was completely voluntary and if they chose, they could withdraw from the study at any time without risk or consequences. The consent form was then signed and a copy provided to each participant.

To assist the participant with being at ease during the interview, a time of open dialogue occurred prior to each interview. This process lasted approximately 10 to 15 minutes and allowed the researcher time to build rapport with each participant. Following this time of discussion the researcher announced the formal interview was about to proceed and asked if the participant was ready. When the participant acknowledged "yes" the recorder was started and the formal interview process commenced. Before ending each interview, the researcher asked, "Is there anything else you'd like to share?" When the participant indicated there was no additional information they would like to share, the researcher thanked the participant and the recorder was turned off.

The participants were contacted, after the transcripts were reviewed by the researcher, and asked to review the verbatim transcript for accuracy and to ensure the participant answered the interview questions as they intended to. Participants were provided the transcripts, with the researcher's comments and notes, and asked to review these as well as to ensure the researcher was interpreting the participants' story as they intended to tell it. All eight participants who began this study completed the study.

Data Analysis

All of the digitally recorded interviews were transferred to a thumb drive and given to the transcriptionist within one week of the original interview date. The transcripts were then returned to the researcher within 1 to 2 weeks. The data was then hand coded by the researcher using Colaizzi's 7-step method of data analysis.

Immersion

After the completion of each interview the researcher recorded field notes regarding any thoughts, feelings, emotions, attitudes, and ideas that were identified. Once the transcription was completed, the verbatim transcript was reviewed, while listening to the interviews, to verify accuracy. The researcher then read and re-read the transcripts multiple times to become more familiar with the data and gain a deeper understanding of each experience.

Extraction of Significant Statements and Phrases

Each transcript yielded 7 to 32 pages of interview material for a total of 44,943 words. Through hand coding by the researcher, 8888 significant words, statements and/or phrases, which described their health care experience, were identified. A word document was created to compile these significant statements.

Formulation of Meanings

The researcher formulated meanings for each significant word, statement or phrase. Diligence was taken to ensure each formulated meaning provided a relationship to the participants' original thoughts and statements.

Organizing Clusters of Themes

The formulated meanings were analyzed and organized for likeness; which resulted in clusters of themes that emerged. The themes represented the individual and groups health care experiences. This step was validated by returning to the original transcripts to search for additional information that was not included into the developing themes.

During analysis of the data, discrepancies and contradictions were noted, which Guba (1981) states are an expected finding in qualitative research. To ensure complete understanding by the researcher, each transcript was returned to the participants who were asked to validate the researcher's findings in the themes and to clarify or add any additional thoughts to their health care experience. Some of the following statements were made by the participants during this process.

Charles and I agree that we have no changes to your transcripts. They are exactly as we intended. (Barbara)

Yes, I have reviewed the transcripts, and they look very accurate to me. I don't see anything that is different from what I remember. (David)

I think it is very accurate of the experiences I've had. Didn't know I said so many ums. Will have to watch that. (Erica)

Sat and looked at the transcripts last night. Did I really talk that much? As far as I am concerned do what you wish with it like using only what you felt was important, the underlined thoughts. (Gail)

Returning to the participants allowed the researcher to validate that the findings were interpreted correctly and they were a true account of the participant's experience.

Essence, Themes and Subthemes

The researcher identified five themes, which reflected the health care experiences of the older person. These themes include (1) time (2) personal connection (3) communication (4) adjusting to change and (5) having an advocate. The theme time was further broken down into four subthemes, which were time waiting to see the provider, actual time spent with the provider, time spent waiting on referrals, and convenience of services. The theme communication was also further broken down into two subthemes, which were communication between the provider and the participant, and communication between the providers with each other. These themes and subthemes contributed to the overall essence of the health care experiences of older adults.

Theme: Time

This theme was apparent throughout each interview as one of the greatest frustrations for older adults and their health care experiences. Each participate was either greatly dissatisfied with the length of time spent waiting for health care services or they were satisfied with the short amount of time spent receiving health care services. As the participants were sharing their stories, it became apparent that time could be further broken down into four subthemes (1) time waiting to see the provider, (2) actual time spent with the provider, (3) time spent waiting on referrals, and (4) convenience of services.

Subtheme: Time Waiting to see the Provider

The following excerpts describe the frustrations with the length of time it takes

from arrival at the office to seeing the provider.

And I've been to some really [bad] places that I wouldn't want (laughs) to go and waited for an hour, hour and a half. One place, they told us to go to lunch and come back, we waited so long. (Erica)

Waiting is, is an issue. You know? Where ah, they always say, 'you know if its 15 minutes or 20 minutes beyond your appointment, please remind us.' I don't see any doctor's office that, that makes a point themselves. I mean, they're relying on, on the customer, the patient to come up and say, 'you know, it's been 30 minutes' and you know, why, why don't they keep track of that rather than the patient? ... Sometimes they're busy, you know? You understand why it might be necessary to spend more time, and you'd want that more time if it were you. Um, and you don't want to feel rushed. And that's often, you know, you do feel rushed now a days. More so I think than ever, where you're only with the doctor 8 or 9 or 10 minutes and you've waited an extra 40 minutes, and you've got other things to do in life besides sit in a doctor's office and wait. So I think there's a tendency to either overbook, or not to manage their time. I think that is an inconvenience to the patient. (Henry)

Um, well, it's adequate, it's just not very ah, it's real business like and their running people through that office so fast. They have so many people waiting, it's just in and out as quick as I can get you in and out. (David)

Waiting, waiting, waiting. And ah, sometimes they apologize for the wait. You know? Sometimes they don't. You know, they just ignore it. Well, again, I'm not overly sensitive, but because I've been in business so many years, and, you know, you, you experience so many things, and you have to put them into perspective. But, it doesn't show professionalism. (Henry)

One participant shared her experience waiting for a provider to discharge her from

the hospital. This was her experience:

...I mean, it took me I think six hours to be released finally for them to track him [doctor] down. I'm just sitting on that bed, waiting...so they've been not so great experiences. And I'm pretty patient most of the time. When he finally did show up, um, some of the medication hadn't been

followed up with. He basically said to me (sighs) something like um, 'well I have other patients to see.' And I said, 'you know, I fully understand that, but six hours sitting here waiting to go home?' (Gail)

The following excerpts describe the participant's satisfaction being able to see

their providers quickly, resulting in a decreased amount of time waiting.

I'm greeted immediately and brought into the back [lounge], it's like a lounge in the back so you're not sitting in the waiting room up front, but you will see people back there. And they all, you know, [offer you] water? Whatever. Whatever. And, within I would say five minutes, one of the nurses has me in an examination room. And does the BP and, you know, the oxygen and all of that good stuff. And, ah, I would say within five minutes, and I'm always given the choice of waiting there 'til I can get in his office, or going back into the other room, ah, usually, within five minutes I see him. Which is, you know, quite amazing. (Gail)

Um, over there it's real easy because there is hardly anybody there. So you walk in, you sign in, and within usually 5 - 10 minutes, then you go back to the back and um, I don't know if it's a nurse or an assistant or what she is, but she takes your blood pressure, does your weight, um, asks you some questions, does stuff on the computer, and then the physician's assistant or, I don't know if she is a nurse practitioner or physician's assistant, she'll come in and, it's been very good over there. (Erica)

Subtheme: Actual Time Spent With the Provider

This subtheme describes the limited amount of time that the participants felt they

had with their providers and their perceptions of their health care as a result of that

limited time. The following statements from the participants are provided to illustrate

this theme.

Well, I just wonder if I'm getting the advice and the care that sometimes I think I need because, he checks my cholesterol once a year cause I do have that, and it's a real busy office where you're just sort of, you know, I don't know. I wait a long time usually, and then when I go in, I see the nurse, and she does everything, and then the doctor comes in and I see him for a couple of minutes and, and it's, it's real ah, business like. It's not that comfortableness that I had with Dr. X and like still have with the other two doctors. (David)

Ah, we usually have to wait 10 to 15 minutes. Ah, we get in to the, then they call us into the doctor's office, another 10 to 15 minutes wait, and then a quick in and out with the doctor. I'm a little disappointed at, I'm not, I don't have the feeling that he's really that worried about me, that means, I'm just a check mark, and, but, I'm in pretty good shape so I'm not too worried about that right now. (Charles)

Um, well, it's adequate, it's just not very ah, it's real business like and their running people through that office so fast. They have so many people waiting, it's, you know, it's just in and out as quick as I can get you in and out. I don't, I don't really have any problem with the care I'm getting or the advice and that kind of thing. It's just the atmosphere is a lot different than it used to be. (David)

Subtheme: Time Spent Waiting on Referrals

This subtheme became very common throughout several of the interviews. The

participants were having difficulty with the referral process dictated by the insurance

companies which, in some cases, resulted in prolonging treatment to the participants.

The following excerpts demonstrate this theme.

I just assume I could make the appointments myself. I don't need them to do it for me, but I guess they have to send all the x-rays and her findings and those things to the person they are referring you to. So, you do wait for that. And then, the first time I went was cause of my back, and then they referred me to an Nephrologist and I said, 'but it's my back that's really bothering me.' Well, I had a little bit of an elevation of my GFR, which isn't, was nothing because it went back to normal because I was taking too many ibuprofens for my back. So, at that point, I never even got the orthopedist referral. It wasn't until the second time I went back that they actually referred the, me to the orthopedist. So it's like a middleman that you could do without. (Erica)

Well, you're lucky if they'll [referrals office] call you within 3 to 4 days. And at the time I went, it was my back and it was really hurting, so waiting 3 or 4 days just to get the referral, then you still had to wait to get an appointment, and if you're not here to answer the phone, they leave you a message, and you call back and there's nobody there and then you still wait for them to call you back again, and, I just can't sit here for 3 or 4 days waiting for my phone to ring. (Erica) And with the pulmonary, I had to make several phone calls to them. Also, to the office again and they had sent the referral. It was the other end that wasn't good about getting to me. And trying to set something up. So, sometimes it works really quick, and sometimes it doesn't. I think we all want to get stuff over with. Ok, well maybe that test will give us another answer, I'm not unreasonable that I'd like it yesterday. (Gail)

One participant was able to make his own appointments with specialists without

waiting on the referral process. This was his experience:

I don't have to wait, you know, for the doctor to request a referral from the insurance company and then after that get an appointment, I mean, I have had some appointments that they say, well, we'll see you in two months. That bothers me. If there is a need for me to be seen, then I need to be seen in a relatively quick time. Two weeks would be about the extent. And by being able to call in, I've been able to make an appointment within a couple of weeks. Very upset. Because I don't know if I'm gonna get better or not, am I gonna get worse, which I could. I don't know. And that feeling of not knowing bothers me. (Charles)

Subtheme: Convenience of Services

This subtheme highlights the participants' satisfaction of having multiple services

available at one location, decreasing the amount of time the participants were required to

spend on their health care visits. The following statements demonstrate this theme.

You'd walk into his office, and I mean he was shoe-horned into his office; the area that you'd walk into was maybe 10 foot by 10 foot, that's all. One little old couch there...the front desk person would be right there, and you'd know her, she knew you, you'd talk and be friendly. The doctor's assistants were all there, he had two assistants in the office, and they'd, when we got into a room, you weren't there more than five minutes before the doctor would come in, or if you were having some type of procedure, the nurse and/or assistant would come in and help. And he did everything in his office. He had x-rays. We did the stress test. He did ultra- sounds. Everything was right there in his office. Made me feel good because I could get everything done right there. It wasn't, now wait three weeks to get an appointment here, and two weeks there, you know? He'd say, if he couldn't do it that day, it was no more than a day or two that it could happen. And the results were right back. I really enjoyed that doctor. (Charles)

She does that, and normally, depending upon if it's for a bi-annual visit, you'll go in, first thing in the morning, you go in at 7 o'clock. You get your blood drawn, by 10:30 when you'd normally go in 10:30 or 11:00 o'clock, you go in for your meeting with your doc, and by then they've already gotten your labs to them, so the labs are all there. It's all computerized so that um, like for me, because I have so much stuff in my neck, they generally have the x-rays there and the x-rays are right in the computer. It's kind of cool because then we can sit there and look at them. (Fred)

They have x-ray and they have lab right there, so you can get it done. (Erica)

Theme Summary

The first theme "time" with the subthemes "time waiting to see the provider, actual time spent with the provider, time spent waiting on referrals, and convenience of services" identifies one of the most difficult aspects of health care for older adults. There is a significant amount of time spent waiting throughout their health care experiences. When the amount of time waiting was prolonged this resulted in frustration and uncertainty where as if the amount of time waiting was decreased participants were satisfied with their providers and services.

Theme: Personal Connection

This theme emerged as participants discussed what characteristics they liked or disliked about their health care experience. The participants sought a personal connection, not only with their provider, but also with the office staff involved in their care. The following excerpts are provided to illustrate this theme.

First encounter is the front desk person. Ah, the girl there. I am embarrassed because I don't remember her name, but she remembers us. Very nice. Very friendly. And always takes care of us. (Charles)

She [the provider] talks to you like a friend would talk to you. She asks how your day is going. She asks how you've been, and then she gets into the other stuff, ah,

in the more medical field. She's just, she's very personable. I would love to have her as a friend. (Barbara)

Um, this is a service they are providing, and a service um, no matter whether it's at the grocery store or the dry cleaners, or where ever you are, they are providing a service for you, and this is a very personal service. So therefore, they are making it personal is to me very important. (Barbara)

The receptionists all know me by name, and they'll say hi to me when I go in there, and it's a good experience for me and Dr. X is the same way. I've been going there so long that, occasionally he'll have a new employee, and I'll meet them, but pretty much, it's the same folks and I usually don't have to wait. (David)

Um, it's been overall really good with both of them [two providers]. I trust them, and when I go see them, we're sort of like friends. I mean, we'll be talking about sports or something else while I'm in there and he's, you know, doing, both of them doing things, I'm lucky I have two good doctors that I'm really happy with and, that, you know, feel like friends with. (David)

Not everyone told a story of being or feeling connected to their health care

providers as identified in the following excerpts.

But again, they're not, the receptionist, other than at Dr. X and Dr. XX's office who know me, there's a couple I know, are not, they don't seem to be trained in customer service. It's automatic. It's mechanical. (Henry)

Ah, we'll see some people in the back area. I guess, the assistants and everything, but again, very quick in and out, not, I don't know who they are...we had a very good doctor and everything. I feel a little neglected. (Charles)

I haven't been back there for some while, but even though you're a regular patient, you're not often recognized as someone they know. ..but Dr. X' office, having been there for so many years, even though there was a lot of turn-over, there was always someone that, you know, you could say hi to and, and visit just like a normal environment..., but you don't see that in a lot of doctor's offices. It's either turn-over, or it's more ok, you know, ah, 'I wanna see your insurance card,' and 'fill out forms,' forms, forms, constantly filling out forms. I mean it's, from a patient's standpoint, it's absolutely ridiculous. (Henry)

Theme Summary

The theme of "personal connection" describes the participants desire to feel and be significant to their provider and office staff. The participants felt confident in their provider and content with the environment when there was a personal connection made between the provider and/or office staff and the participant. Participants were unsatisfied with their care when that personal connection was lacking.

Theme: Communication

This theme arose throughout each interview as a significant concern for older adults. Two subthemes emerged as participants described the types of communication that were important for them. The participants desired open and honest communication between (1) the provider and the participant and (2) the providers with each other.

Subtheme: The Provider and the Participant

This subtheme described the significance of communication, whether good or bad, between the provider and the participant, along with the feelings experienced through positive and negative interactions. Not only that the providers communicated information to the participants effectively, but also that the providers took the time to listen and acknowledge the needs of the participants as well. The following excerpts describe the desire for communication and listening.

> And I had done my homework on it, and I had my blood pressure readings and I had all this stuff and I was ready, really ready to go, I mean I'm gonna tell this doctor I don't need to take this anymore and he didn't want to hear any of it. It was like we'll do a blood pressure for you right now and we'll do some other tests, but just come back in another month or so. He didn't want to hear anything about me. And this is one of the major points that I want to make, is that the expert, the cardiologist expert, you know, has no people skills. Ah, and, and, and doesn't want to know anything about you. You know? You're just a patient. You're just a

patient that he can go on his computer and read, read your readouts and, and then decide what to do to you. You know? He doesn't want to know about you. He doesn't want to know about anything about, about, you know, how you live, or what your lifestyle is, or, or anything, you know, because if you start bringing that up, he doesn't want, he's, he's turning it off, you know. (Alan)

Now I don't know whether it's because I'm on blood thinners or I've always had low blood pressure, and the blood thinners occurred about two weeks after I was out of the hospital after having the brain tumor removed. I was having cramps in my legs when I was in the hospital and I told the doctor that was on duty at the time and she paid no attention to me. Once we got home I told [Frank], look this is just like when I had the breast tumor before, and they put me on blood thinners. My legs are hurting me. He took me back in and they ended up putting the green field filter in me....I was very upset and she had come in to see me when I had the green field filter put in and she said to me I'm so sorry I missed that, and I said you just didn't listen to me. And she says I guess I didn't. (Barbara)

The office clerk was supposed to call me about something, I'd asked her to call me because the doctor had made a suggestion at that time in Southern California, and she never called me back. ...you really ought to get the name of the neurologist and we'll go see him. I called her back and she said well I'll have to check with the doctor. But she never called me back. (Laughs) I was uncomfortable after that. I was glad we were moving. That I wouldn't go see him anymore, because it's really important that your health care people follow up with what they are supposed to do. (Barbara)

I have to call in and find out what the results are. Again, I don't care for that. (Charles)

... so he, he's extremely knowledgeable and he's really good at explaining things and showing me little diagrams of the eye and so forth like that. (David)

Well, I wanted a little bit of explanation and I didn't get it when they called me with a result of one of my tests, they just told me to make another appointment to talk to the physician's assistant. (Erica)

He is very open and tells you exactly what's going on and you don't have to worry about going and digging and looking to find out what about this, what about that, because he's normally right up front with you. (Fred) When there's a test that comes through and Dr. Smith sees something he doesn't like he will follow up on it. The first time I saw him and I'd had my blood work done, he called me at 11 o'clock at night because my potassium was so low. So I'm feeling like I'm getting a bit more attention. He's paying more attention to paperwork that comes through and follows up if he thinks he needs to. (Gail)

I would say that health care needs to continue to concentrate on the socalled bedside manner. I think that's probably the wrong terminology anyway because, it's more than that, you know? It's just this whole ability to communicate, to explain what the process is going to be, explain what you're doing when you're doing it, and explain what happens afterwards, including your results. I think you ought to be able to get your simple test results, if they're ok, over the phone, or e-mail. I do not think you should have to pay for another appointment just to go back and say 'everything's fine,' 'thanks for coming in,' you know? That's an hour or two of your time and \$30 or \$40 co-pay, and insurance pays more than that. I don't think you should have to do that. (Henry)

Subtheme: The Providers with Each Other

It also became apparent that the participants expected that their different providers

would communicate with each other regarding the participants' health care. One

participant expressed his frustration with the lack of communication between providers.

The following statement highlights that frustration.

I'm in the emergency room, and I'm having to fill out all the forms and everything, and sign my life away, and trying to remember all the stuff I've been doing and what I haven't done and how I felt and all this kind of thing, and I'm telling them, Dr. X is her name, she is my main physician. Could you call her? Could you let her know, you know, that I'm having this heart attack, or had a heart attack or I'm in the hospital, and all that kind of thing and I had the phone number for her message machine, her answering service. I'm assuming that's gonna be done, you know? Well, when I go I'm in ICU for a day and then I'm in the regular hospital, and I'm sitting there in the hospital room, having this other little problem that I had, you know, and I'm thinking well, Dr. X needs to know about this. I'm thinking as I'm laying there that she needs to know about this, this other issue that's come up and so I get on my cell phone and call her. I say I'm at XXX Hospital and she says, you're in XXX Hospital? I didn't know about that. I'm thinking, you didn't get a call from the emergency room or from the cardiology people? No, I haven't heard from anybody.

And I, I just thought are you kidding me? That's inexcusable. ...if you ask the person's name, then you have to follow through. You have to at least make a phone call. That's only ethics, or morals or whatever, you know. ...and she said, well what are you in the hospital for? (Laughs) She didn't have any idea. Because they had never talked to her ... that was really irritating, I felt like I had been abandoned. (Alan)

One participate describes the use of electronic medical records and a positive

form of communication between her providers.

I like the XXX chart sharing, My Chart, the fact that most of the doctors I see are into that. My skin doctor, my heart doctor, now the pulmonary people...it's connected so that when I visit my regular doctor, he can just pop in there. They all know what meds I take. I kind of like that. (Gail)

One participant was sharing a health care experience that she had while caring for

a friend and their frustration with the lack of communication between providers.

Well, like if she's in the hospital, which she is frequently because she gets cellulitis. The physicians in the hospital will not call her main physician, her attending, primary care physician, to find out anything about her. They just look at her, and, they, they won't even consider calling her primary care to find out what they should be doing for her, because her primary care is in Truckee. (Erica)

Theme Summary

The theme "personal connection" with the subthemes "communication between

the provider and the participant, and communication between the providers with each

other" demonstrates how older persons are seeking open and honest communication.

Older persons feel that this lack of communication can impair their health and that

effective communication between providers can assist in improving their health.

Theme: Adjusting to Change

This theme emerged as participants described life before and after a significant

health event. Participants describe concerns with not being able to perform activities like

they used to and adjusting current activities to accommodate that change. The following

excerpts highlight this theme.

I still don't have quite the stamina that I wanted to have, so I'm not doing as much as I want to do. I'm not playing golf, but the cardiologist says just play a couple holes, you know? Well, you aren't going to get me to just play a couple holes. So I play four or five holes and then I'm tired and the next time I play six holes, and I'm working up to it and I'm walking the golf course. I'm doing pretty well, but I'm still feeling that the stamina is down. I'm not hitting the ball as far as I used to and all of these things that are really important, you know? I'm not able to do as many things during the day as I used to. (Alan)

I haven't been driving since I had the brain tumor. I will drive in D to go and get my nails done, but I don't drive outside of D. ...after I had the brain tumor, I had a seizure and although I'm on medication...I would just float on that. It was just a real narcotic for me. And I just, I never, I didn't drive after that. ...now I'm on a half..., but I still don't want to take somebody out with me. (Barbara)

It's, I don't wake up every morning raring to go. So, I've cut back a little bit on my involvements. (Gail)

Dr. X told me just the other day when I was there that what they can do now is when it comes time to do the cataract surgery, they essentially replace the lens and put another lens in, and he said you probably won't have to wear contact lenses anymore, but you'll have to wear reading glasses for anything probably closer than about 5 or 6 feet. I do that anyway already. I have reading glasses. That was neat. I didn't know there was a possibility I wouldn't have to wear the hard lenses cause your eyes are really sensitive to dirt and dust and you ride a bike and work in the yard and play tennis and those kind of things like I do, I have a lot of trouble with hard lenses. You have to take them out and I wash my eyes out a lot if I'm outdoors. It would be nice not to have to do that again. (David)

Theme Summary

As older persons experience adverse health events they are faced with "adjusting

to change." They are faced with the inability to perform activities as they previously did

and they find themselves making accommodations to manage those limitations.

Theme: Having an Advocate

As participants described their health care experiences it became apparent that they rely on the support of others. They depend not only on friends and family but health care providers to advocate for their best interest. The following excerpts describe the significance of this theme.

That night I couldn't sleep and I had sweats and I was going back and forth to the bathroom and was getting very hot and cold. I didn't really think too much about it. So I just went to bed and tried to, felt like I could sleep it off and I couldn't go to sleep, so I got up and thought about it a little bit and thought 'God, maybe I've got to do something. Maybe I ought to call somebody or do something because I live at home, so there's nobody there that would look at me and say 'well you need to go to the hospital. (Alan)

You know? Where somebody is going to have to take care of me, cause nobody was there to take care of me. Nobody went with me to the emergency room. I have two people that I do have great reliance on, but they both have their own family. ...they weren't going to be there at the emergency – I didn't even attempt to call them. ...but I felt like I had the paperwork in order so that, so that the medical people would do the right thing. (Alan)

They [the office staff and provider] are very important to me. Um, not only because of my medical problems, but also because of the fact that I know they are there. Just knowing that they are there, ready to help me at any time is really important. (Barbara)

Well, it's, it's the availability. There's that 100%. ...the availability, their knowledge of what's going on with me, their staying on top of it. It just as I said, the only thing I can say is there is somebody in my corner that I can go to and that will keep an eye out. (Gail)

This participant was sharing her friends experience in choosing which facility she

sought medical care and the importance of support from friends.

...so she lives here, so she goes usually to XXX. Now she's so sick of them, she wants to go to Truckee whenever she, but that's a long way to go and then nobody visits her because all her friends are here. (Gail)

Theme Summary

The theme "having an advocate" demonstrates that the older person finds security in knowing that someone is advocating for their best interest. That person could be friends or family but also includes their health care providers.

Chapter Summary

The lived health care experience of older adults was explained through five themes and six subthemes, which were collected through participant interviews. Older adults value their time and have expectations on how long it should take to see their providers, how long they should spend with their providers, how long it should take for referrals to be processed, and they appreciate when they are able to complete several health care services at one location, decreasing the amount of time they need to spend on health care services in general. They also are seeking a personal connection with their providers and office staff which greatly impacts their satisfaction or dissatisfaction with their providers and care received. All older adults seek open and honest communication between their provider and themselves and their providers with each other. This communication helps alleviate fears and uncertainty while providing a sense of security in knowing they are receiving expert health care. Adjusting to change after a significant health event can be a challenge for the older adult. Many older adults find themselves accommodating for certain limitations that they previously hadn't experienced. Finally, older adults desire an advocate, whether it is family, a friend, or their provider. They want the security of knowing "someone" is looking out for them if they are unable to do so themselves.

CHAPTER VI

DISCUSSION AND INTERPRETATION

The purpose of this phenomenological inquiry was to explore, describe, interpret, and gain a deeper understanding of how the older person experiences health care services. In this research five themes were identified with six subthemes from each older person's intriguing experiences.

As each participant shared their compelling story, common themes emerged interconnecting each experience. Although each individual story was unique, their experiences shared common desires and frustrations. The themes which arose became essential to the understanding of the older persons health care experiences. The thick, rich description provided by the participants, offers insight into the older person's health care experience.

Findings as They Relate to the Current Literature

The current literature has an emphasis on patient satisfaction and/or experiences with various providers, health care settings, disease processes, or a combination of these. However, there is paucity in the literature in regards to the older person's primary health care experience. With this in mind, the findings of this phenomenological research study are compared to what is available in the current literature.

Although the results of this phenomenological inquiry may support or expand on the current findings in the literature, the stories and experiences in this study are unique to this particular group of older adults.

Demographics

A total of eight participants were recruited and participated in this study; five men and three women, and all were Caucasian. The ages of the participants ranged from 65 to 75 years. Two participants were married to each other; two other participants were living together; two participants were widowed; one participant was divorced; and one participant was married.

Main Theme: Time (Subthemes: time waiting to see the provider, actual time spent with the provider, time spent waiting on referrals, and convenience of services)

Andersen's behavioral model of the 1960's "suggests that people's use of health services is a function of their predisposition to use services, factors which enable or impede use, and their need for care (Andersen, 1995). The findings of this study show older persons experience a variety of emotions and reactions while receiving health care services. Each of the participants expressed frustration with the lengthy amount of time spent on their health care services and the limited amount of time spent with their providers. When participants described decreased wait times (to see their provider or receive services) and the ability to spend an adequate amount of time (determined by the participant) with their providers they reported increased satisfaction with their health care experiences.

Wait times are experienced in all areas of health care. Bascetta (as cited in Pizer & Prentice, 2011) identified the Veteran Administration has waiting times up to 90 days for some services. Higher wait times are unpopular and waiting for weeks to months for the next available appointment results in adverse effects on patient health (Pizer & Prentice, 2011) specifically a higher incidence of mortality (Prentice & Pizer, 2007).

Press Ganey (2009) studies show that patients are least satisfied with the amount of time they spend waiting and that the average time they spend waiting to see their provider is 24 minutes or longer.

Older adults experience natural physical changes and the speed of which information is encoded, stored, and received may decrease resulting in memory loss (American Psychological Association [APA], 2014). Additionally, these same authors identify that the rate at which new information is learned can be slower for those over age 65. As a result older adults often have a greater need for repetition of new information. It is important health care providers acknowledge this and take the additional time when providing health care education to their older patients. Finally, Bastiaens, Van Royen, Pavlic, Raposo, and Baker (2007), in a qualitative study, examined older people's preferences for involvement in their own care throughout eleven European countries. Findings indicated that some participants felt time was more important to older people than younger people due to physical barriers and decreased consultation times.

Main Theme: Personal Connection

The theme "personal connection" spoke to the participants' desire to feel important and connected to their providers and the office staff they encountered while receiving health care services. Participants appreciated being remembered and identified by name. Several participants acknowledged that even with staff turn-over at their provider's offices, they enjoyed seeing a familiar face that recognized and acknowledged them. It was important to be identified as an individual and not just a check mark on a list or a box to be completed. These findings are similar to those found in Bayliss et al. (2008) and Kuluski et al. (2013) related to the patient and provider relationships that are fostered through continuity of care. Two participants were deeply dissatisfied with the automatic, robotic process that some providers and offices use resulting in a disconnection between themselves and the participants.

A study conducted by Cornwell and Waite (2009) found that social disconnectedness is associated with worse physical health for older adults. These authors also reported that older adults who develop a subjective sense of isolation suffer from a decline in both their physical and mental health. Older adults will have better health outcomes as a result of establishing and maintaining a personal connection with their health care providers and staff.

Main Theme: Communication (Subthemes: the provider and the participants, and the providers with each other)

The theme communication speaks to the older person's desire and expectation that information will be shared between the provider and themselves and the providers with each other. Participates described trust and confidence in their providers who answered the participants questions and provided understandable rationales and explanations for treatment choices. Most participants voiced frustration in the apparent lack of communication between providers with each other. Participants expected that information would be shared freely between providers and described the lack of communication as unprofessional and unethical. Similar results were reported by Bayliss et al. (2008) detailing the older person's need for clear communication and feeling heard. A qualitative study by Calvin, Frazier, and Cohen (2007) examined older adults' perceptions of health care providers and found similar results that highlighted the participants desire to have information shared about their health condition in terms they could understand.

The Gerontological Society of America (2012) reported that "breakdowns of communication have been cited as contributors to health care disparities and other counterproductive variations in rates of health care utilization by all patients, not just older adults" (p. 5). As discussed earlier, older adults suffer from physical changes related to aging that include hearing deficits, decline in vision, and changes in cognitive function (APA, 2014). All of these changes directly affect communication between the health care provider and the patient and require the health care provider to learn and practice effective communication skills with older adults to improve patient satisfaction and health outcomes.

Yorkston, Bourgeois, & Baylor (2011), further suggest a relationship between communication problems and dissatisfaction with health care including overall quality, accessibility, and receipt of information. These same authors further identify that health care providers need to be well versed in appropriate strategies for communicating effectively with older adults.

Main Theme: Adjusting to Change

Older adults experience normal, age-related changes that may affect their normal lifestyle. As previously mentioned, common physical changes experienced by the older adult include hearing impairment, weakening vision, along with the increased probability of heart disease, hypertension, diabetes, arthritis, osteoporosis, and memory loss (APA, 2014). As age increases so does the need for assistance with everyday activities. Approximately 9% of those age 65 to 69 need personal assistance, while up to 50% of

older adults age 85 and older require assistance with everyday activities (APA, 2014). As the older person experiences a significant health event they are faced with adjusting to change and are faced with the fear of aging and mortality. In this study, several participants described a frustration with not being able to complete activities they were accustomed to and the necessity to adapt their current lifestyle after such an event. Feelings of fear and uncertainty accompany these changes and it is important for health care providers to listen to the older adults concerns, acknowledge these emotions and set realistic, mutually agreed upon goals.

Main Theme: Having an Advocate

The theme "having an advocate" highlights the older person's reliance on family, friends, and health care providers to look out for the participants' best interest with regards to health care. Many of the participants described consulting with family or friends prior to seeking health care services or having that friend or family accompany them to those health care services. These findings are consistent with the current literature in that assistance and support from family and friends are linked with positive health outcomes (DiMatteo, 2004). Older adults expect their provider will monitor and provide care that is in their best interest, as well as assist them in navigating the health care system.

Nelms, Johnson, Teshuva, Foreman, and Standley (2009) found that many older people received considerable support from family such as shopping, preparation of meals, housekeeping and assistance with banking and finances. These authors examined social and health factors affecting the use of community services by vulnerable older adults. They found that older adults who were less connected with family and community had the most difficulty accessing the support they needed to remain in their home.

Implication for Health Care

The findings from this research study offer a perspective of health care services experienced by older adults for the health care community. This phenomenological study contributes to the current literature by providing health care providers, including physicians, physician assistants, nurse practitioners, nurses, and other medical professionals a better understanding of the older adults health care experiences. There is a paucity of qualitative research examining older adult's health care experiences and this study provides a synopsis of how older adults interpret and perceive those experiences.

Apparent through this research is that older adults have certain expectations regarding their health care services. There were very strong feelings of frustration and dissatisfaction if those expectations were not being met. The process of "time" stood out as a significant factor for the older person's satisfaction or dissatisfaction with health care services. Providers and health care workers need to acknowledge this as important to older adults and be cognizant of the time older adults spend on those services. Implementing strategies to decrease the amount of time older adults are waiting to see the provider, or receive services, will greatly improve satisfaction and compliance (Press Ganey, 2009). Primary care practices need to examine their appointment "check in" processes, rooming the patients in the exam rooms, conducting the visit with the provider, and discharging the patients at the end of the visit. Each step of the process should be efficient and focused on meeting the patient's needs. It is reported that physicians spend less time providing health education to patients older than age 64 in comparison to younger patients (Keeler, Solomon, Beck, Mendenhall, & Kane, 1982). However a more recent study, conducted by Callahan et al. (2000), had findings that markedly conflicted with prior reports and stated that older patients had significantly longer visits than did the youngest group of patients. Either way, providers schedules must allow for adequate face to face time with older adults as this research demonstrates a great dissatisfaction when older adults feel rushed or that their concerns were unheard by their providers. Decreasing the amount of time it takes for older adults to receive health care services and increasing the amount of time they are able to spend with their providers will result in increased patient satisfaction and positive health outcomes (Press Ganey, 2009).

Health care in general could benefit from improved customer service. Older adults seek a personal connection with their providers and other health care professionals. It is important for health care providers to slow down and acknowledge the older adult as an individual and connect with them as another human being. As previously discussed, social disconnectedness is associated with worse physical outcomes and the perception that one lacks social resources also takes a toll on physical health (Cornwell & Waite, 2014). These authors also found socially isolated older adults have worse mental health to the extent that they feel isolated. Patient satisfaction has been shown to increase when caring is expressed by the health care providers (Greene, Adelman, Freidmann, & Charon, 1994; Lee & Kasper, 1998). All health care professionals need to communicate honestly and openly with older adults and each other. Research has shown that older adults appear to be less involved during medical consultations and participate less in decisions than younger people (Tennstedt, 2000). Older adults give more decisionmaking authority to physicians and younger patients have been described to have a consumerist attitude and therefore ask more questions than older patients (Beisecker as cited in Tennstedt, 2000). Bastiaens et al. (2007) found that older European adults thought that general practitioners should actively enable patient involvement and communication training for practitioners would be a good strategy to enhance that involvement. It is also essential for health care providers to communicate with each other for the benefit of the older adult. An interdisciplinary and collaborative approach to providing health care services for older adults will directly result in positive health outcomes (Institute for Healthcare Communication, 2011).

As this population continues to age and experience significant health events, it is important for health care providers and professionals to acknowledge this adjustment and change as important for the older adult. Change can elicit feelings of fear and uncertainty which may negatively impact health outcomes for older adults. By acknowledging these emotions health care professionals can assist the older adult in coping with these feelings and make the transition as easy as possible.

Health care providers and professionals must recognize their importance as an advocate for older adults. Negotiating health care systems can be overwhelming for older adults, especially if they do not have family or friends that are willing or able to provide help. The use of advocates, assists the older adult in overcoming practical barriers (i.e. access, forgetfulness) to health services and support active involvement during the consultation (Bastiaens et al., 2007). Providers can improve older adult satisfaction and compliance by ensuring they are connected with resources and tools needed to maximize their health care benefit.

The themes ("time," a "personal connection," "communication," "adjusting to change", and "having an advocate") identified in this research express the older adult's health care experience and contribute to the current body of literature. These themes contribute to the overall satisfaction with health care services and improved health care outcomes for patients. It is particularly important that health care providers and professionals acknowledge that older adult's satisfaction and compliance with health care services will directly impact the provider and health care organizations reimbursement from insurance companies. According to Press Ganey (2008) the use of performance measurement data has become the basis for quality improvement programs of health care organizations across the country. In addition, this same source identifies that pay for performance programs, utilized by medical practices, adds an additional component by measuring not only performance but then linking performance to incentives. Pay for performance programs have already been implemented by Medicare and private insurers and the Center for Medicare and Medicaid Services have numerous projects underway to pilot these programs in a range of care settings from primary care to hospitals (HHS, n.d.).

Limitations

Qualitative phenomenological research provides an individual interpretation of a phenomenon with the understanding of the possibility of further research building a deeper and even richer description of the experience (van Manen, 1990). It is therefore the hope of this researcher that further inquiry into the health care experiences of older adults will occur as a result of this study. The themes yielded in this study are a result of this population alone and should be tested with other groups for further comparison and validation. This research is limited also by recruiting a self-selected group of participants confined to one geographical location.

Given the limited qualitative research of older adult's health care experiences, more research is needed with other variables taken into account. For example, examining the health care experiences of older adults with varied ethnic backgrounds might produce results for comparison with this study. Addressing specific ethnic groups would explore differences in health care experiences across cultures. In addition, researching older adults without health care insurance could offer additional means for comparison. Replications of this study can offer different and new health care experiences of other older adults.

Chapter Summary

This chapter provided a description and interpretation of the themes found in this research. Much of the research findings add to the current literature and overall this research provides new information and insight into the health care experiences of older adults. Implications for health care providers and professionals and recommendations for further research are also discussed.

Conclusion

Eight older adults voluntarily participated in this research in which five themes and six subthemes emerged. The themes provide a rich, thick description of the health care experiences of older adults. Findings were validated through participant review and provide the overall interpretation of the older adult's health care experience. Realizing the significance and meaning of the health care experience for older adults is beneficial for health care providers and future researchers. This research adds to the current literature by examining the health care experience for older adults and provides the first step examining this significant population. While this research provides one interpretation of the phenomena, it opens the door for further investigation into an important and growing segment of our population.

Reference	Description of Study	Results/Conclusions		
Provider Preference				
<u><u><u> </u></u></u>				
Cipher et al., 2006	A cross-sectional national	Patients are generally		
	survey of Medicare recipients from the 2000 and 2001	satisfied with their medical		
		care and do not have		
	Medicare Satisfaction Survey, Consumer Assessment of Health	preferences based on types		
		of providers. Regardless of		
	Plans Survey section on Fee-for- Service, who identified a	patient characteristics, PAs, NPs, and physicians in		
	primary care provider were	primary care seem to be		
	evaluated to determine how	viewed similarly.		
	satisfied older American			
	consumers are with physician			
	assistant (PA) and nurse			
	practitioner (NP) care.			
Budzi et al., 2010	Secondary data was obtained	This study showed that a		
20021 00 000, 2010	from the Veterans Health	majority of the primary care		
	Administration's (VHA's)	clinic patients prefer to see		
	Survey of Health care	NPs as compared with PAs		
	Experience of Patients (SHEP)	and physicians. NPs focus		
	to examine the differences in	on health promotion,		
	patient satisfaction with care	disease prevention, health		
	provided by nurse practitioners	education, attentiveness,		
	(NPs), physician assistants	and counseling.		
	(PAs), and physicians in the			
	VHA system.			
Brown, 2007	An anonymous electronic	Most respondents knew		
	survey of 1000 employees at a	about NPs and a majority		
	large nonprofit organization in	had previously seen an NP		
	King County, Washington was	for their care. Most were		
	completed to determine the	satisfied or very satisfied		
	feasibility and sustainability of	with their care provided by		
	independently managed nurse	an NP. Patients utilizing		
	practitioner (NP) practices, to	NP services tend to be		
	identify the characteristics of	female and younger.		
	consumers who would choose			
	an independent NP practice, to			
	assess consumer needs and			
	define a target market for NPs.			

APPENDIX A – LITERATURE REVIEW

Mayer et al., 2012	A quantitative study that evaluated breast cancer survivors' comfort with different clinician types or with a telephone/Internet-based virtual visit as components of survivorship care.	Most patients favored medical oncologist follow- up visits over those with primary care physicians or nurse practitioners in terms of reduced worrying about cancer, reduced stress around the visit, and improved effect on cancer survival. However, the majority also displayed substantial comfort with both primary care physicians and nurse practitioners in the same domains. Patients rated a virtual visit as having a less favorable impact on cancer survival and cancer-related worrying compared with in- person visits with clinicians.
Hess et al., 2011	An American Board of Internal Medicine Practice Improvement Module focused on care of vulnerable elderly was used to obtain patient experience data regarding the receipt of guidance or interventions for important aspects of older adults. A focus was placed on older patients' experience of care in internal medicine and family medicine residency program clinics, compared with the experience of care provided by practicing physicians.	Patients from residency clinics were less likely to report receiving guidance and interventions for important aspects of care than patients from the practice physician setting. Patients from the residency clinics were also less likely to rate their overall care as high.
Jha et al., 2008	A quantitative study that used data from the Hospital Consumer Assessment of Health care Providers and Systems (HCAHPS) survey to provide a	Hospitals that were large and private not-for-profit, hospitals with ICUs, teaching hospitals, and hospitals located in urban

	portrait of patients' experiences	areas and in the Northeast
	in U.S. hospitals.	were more likely to report HCAHPS data than not to report the data. Overall, patients were generally satisfied with their care but there was room for improvement.
Hasson & Arnetz, 2011	A quantitative study using cross-sectional surveys in two municipal older people care organizations in Sweden to compare care recipients' and their relatives' perceptions of quality of care in nursing homes and home-based care.	Home-based older people care appears to be in greater need, compared to nursing homes, of development of staff competence, staff interaction with families and activities offered to older adults. In both settings, nursing staff behavior influences the care recipients' and their relatives' satisfaction with care.
	This cross-sectional study, including comparison and correlation, utilized personal interviews performed by specially trained registered nurses between October 2002 and June 2003 to explore care satisfaction in relation to place of living, health-related quality of life, functional dependency and health complaints among people, age 65 or older, receiving public care and service. This study was conducted in southern Sweden.	For older adults, care satisfaction and health- related quality of life was more associated with functional impairment and health complaints than to whether care and services was received at home or in a special accommodation.
Satisfaction Related to Care of Disease Processes		
Stein et al., 2011	This study evaluated quality of and patient satisfaction with primary health care for anxiety disorders by surveying outpatients with anxiety	Approximately 57% of participants received appropriate anti-anxiety medication within the previous 6 months, but only

	disorders that were referred by the primary care physician for participation in a therapeutic trial.	about 29% at adequate dose and duration. Approximately 46% of participants had received some counseling, but only 21% with a cognitive- behavioral therapy focus. Only about 41% of participants received quality pharmacotherapy and/or psychotherapy. Few patients, about 45%, were at least somewhat satisfied with their mental health care.
Kuluski et al., 2013	This mixed methods and reports study investigated what is important in care delivery from the perspective of hospital inpatients with complex chronic disease. Semi-structured interviews were conducted with inpatients at a continuing care/rehabilitation hospital in Canada between February and July 2011.	On average, patients had 5 comorbidities and several illness symptoms including impairments with activities of daily living, physical pain and emotional disturbance. Three broad themes (each with subthemes) were generated from the data. Each represented important components of care delivery: components of the care plan; care capacity and quality; and the patient- provider relationship.
Care Preferences and Disease Processes		
Bayliss et al., 2008	This qualitative investigation explored processes of care desired by elderly patients who have multiple comorbidities that may present competing demands for patients and providers. One-on-one interviews of 26 community- dwelling HMO members aged 65-84 who had a minimum	Desired process of care included: 1) the need for convenient access to providers (telephone, internet, or in person), 2) continuity of care (knowing and being known by their providers for a period of time), 3) clear communication of

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APPENDIX B – IRB APPROVAL



Research Integrity Office 218 Ross Hall / 331, Reno, Nevada 89557 775,327,2368 / 775,327,2369 fax

DATE: November 18, 2013

TO: Stephanie DeBoor, PhD Dianna Hein FROM: Social Behavioral Education IRB

 PROJECT TITLE:
 The older adults lived health care experience

 REFERENCE #:
 2014S031

 SUBMISSION TYPE:
 New protocol

ACTION: APPROVED APPROVAL DATE: November 18, 2013 EXPIRATION DATE: October 29, 2014 REVIEW TYPE: Expedited

REVIEW CATEGORY: Expedited review category # 6 & 7

Approved documents: Protocol 11/08/13, flier 11/12/13, Consent form 11/18/13, interview guide 11/12/13

The above-referenced protocol was reviewed and approved by one of UNR's Institutional Review Boards in accordance with the requirements of the Code of Federal Regulations on the Protection of Human Subjects (45 CFR 46 and 21 CFR 50 and 56). This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission. This submission has received expedited review based on applicable federal regulations.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Problems Researchers Must Report to the Research Integrity Office or IRB Staff (to be reported as soon as possible, but within 10 business days)

 New or additional risks: Outcomes that the principal investigator believes are unexpected, related to the research, and suggest the research may place participants or others at greater risk of harm than was previously known or recognized
 Changes to expected harms or benefits: Any report indicating the frequency or magnitude of harms or benefits may be different than initially presented to the IRB
 Privacy: Any invasion of privacy related to an individual's participation in research
 Confidentiality: Any breach of confidentiality involving research data
 FDA Changes: Any change in FDA labeling or approval for a drug, device or biologic used in a research protocol

1|Page

Immediate harm: Any change to the protocol to eliminate an apparent immediate hazard to a research participant, prior to seeking IRB review and approval •Prisoner: Any incarceration of a participant in a protocol not approved to enroll prisoners

Sponsor: Any event that requires prompt reporting to the sponsor Sponsor: Any sponsor-imposed suspension for risk Protocol change: Any accidental or unintentional change to the IRB approved protocol

that harmed participants or others, indicates participants or others may be at increased risk of harm, or has the potential to recur

•Device: Any unanticipated adverse device effect •Department of Health: Any non-compliance identified by Department of Health audit or monitoring

•Federal agency: Any investigation or report by federal agency related to the research •Medical license or practice changes: Any loss of license or hospital privileges by any researcher on the study

·Complaints: Any complaints that suggest participants or others may have been harmed or placed at increased risk of harm

PI Responsibilities

·Maintain an accurate and complete protocol file.

·Submit continuing projects for review and approval prior to the expiration date. ·Submit proposed changes for review and approval prior to initiation, except when necessary to eliminate apparent immediate hazards to subjects. Such exceptions must be reported to the IRB at once.

·Report any unanticipated problems which may increase risks to human subjects or unanticipated adverse events to the IRB within 5 days.

·Submit a closure request 10 days after project completion to the IRB.

If you have any questions, please contact Valerie Smith at 775.327.2368.

Sincerely,

M	my	11-19-13	
IRB Chair or Designee	0	Date	

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APPENDIX C – RECRUITMENT FLYER

Are you over 65? Want to tell your health care experience story?



My name is Dianna Hein and I am a master's student at the University of Nevada, Reno.

I am researching the health care experiences of adults age 65 or older.

- The title of my study is The Older Adults Lived Health Care Experience (Protocol Number 2014S031).
- Participants will agree to a face-to-face audio-taped interview to be conducted at an agreed upon private location.
- All participants must have had a health care experience within the past two years.
- A follow-up interview will be conducted so you may clarify your experiences and add any additional remarks.

I hope you will consider being a part of this research. To participate, or for additional questions, please contact me at (775) 762-2494.

Dianna Hein - 1664 N Virginia Street - University of Nevada, Reno/0134 - Reno, NV 89557-0184 - (775) 762-2494

Dianna (775)	Dianna (775)	Dianna (775)	Dianna (775)	Dianna (775) 7	Dianna (775) 7	Dianna (775)	Dianna (775)	Dianna (775)	Dianna (775)
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APPENDIX D – CONSENT FORM

UNIVERSITY OF NEVADA, RENO SOCIAL BEHAVIORAL INSTITUTIONAL REVIEW BOARD CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE OF STUDY: The Older Adults Lived Health Care Experience **INVESTIGATOR(S):** Dianna Hein, 775-771-4348; Stephanie S. DeBoor, PhD, RN, CCRN, 775-682-7156 **PROTOCOL #:** 2013S031 **SPONSOR:** None

PURPOSE

You are being asked to participate in a research study. The purpose of this study is to achieve a better understanding of what older adults experience when they receive health care services. Understanding your experiences might help physicians, physician assistants, nurse practitioners and all health care providers to better support other older adults using health care services.

PARTICIPANTS

1) You are being asked to participate because you are an English-speaking older adult (age 65 or older), who has used health care services now or in the past.

2) It is expected that there will be 10 participants enrolled in this local study.

PROCEDURES

If you volunteer to participate in this research study, you will be asked to take part in a face-to-face, audio-taped interview, with the student researcher, lasting approximately one hour. The interview will be held at a mutually agreed upon, convenient location. During the interview you will be asked questions related to your health care experience. Following the initial interview, you will be asked to read the transcript from the interview and the student researcher's interpretation to make sure it is a good description of your experience. Follow-up communication will be conducted either by telephone, post office mail or face-to-face. Review and discussion of the transcript is expected to take no more than one additional hour of your time. It is important for you to remember that your participation in this study is voluntary and all information shared will be kept confidential.

DISCOMFORTS, INCONVENIENCES, AND/OR RISKS

There are risks involved in all research studies. This study may include only minimal risks. There may be some discomfort answering some of the questions related to your health care experience. You may refuse to answer any question that makes you feel uncomfortable. You may withdraw from the study at any time. There are no risks for refusing to participate.

BENEFITS

You may not experience any direct benefit from participating in this study other than the satisfaction of having participated in research. However, we hope that learning about your health care experiences will help us better understand how to support other older adults receiving health care services.

CONFIDENTIALITY

All information gathered during this research study will be kept completely confidential. All participants will be given an alias to keep all material confidential. Interviews will be audio taped and transcribed by a private transcriptionist who has signed a confidentiality statement. Your identity will be protected to the extent allowed by law. All personal identifiers will be removed before the transcriptionist receives the audio tapes. You will not be personally identified in any reports or publications that may result from this study.

The Department of Health and Human Service (HHS), other federal agencies as necessary, the University of Nevada, Reno Social Behavioral Institutional Review Board may inspect your study records. The study records will be securely stored in a locked file cabinet in the researcher's office and destroyed following completion of the study in May 2014.

COSTS/COMPENSATION

There will be no cost to you nor will you be compensated for participating in this research study.

DISCLOSURE OF FINANCIAL INTERESTS

The researcher, researcher's spouse and children have no financial interest. <u>RIGHT TO REFUSE OR WITHDRAW</u>

You may refuse to participate or withdraw from the study at any time and still receive the care you would normally receive if you were not in the study. If the study design or use of the data is to be changed, you will be so informed and your consent re-obtained. You will be told of any significant new findings developed during the course of this study, which may relate to your willingness to continue participation.

QUESTIONS

If you have questions about this study or wish to report a research-related injury, please contact Dr. Stephanie S. DeBoor, PhD, RN, CCRN at (775) 682-7156 or Dianna Hein, BSN, RN at (775) 771-4348 at any time.

You may ask about your rights as a research subject or you may report (anonymously if you so choose) any comments, concern, or complaints to the University of Nevada, Reno Social Behavioral Institutional Review Board, telephone number (775) 327-2368, or by addressing a letter to the Chair of the Board, c/o UNR Office of Human Research Protection, 205 Ross Hall / 331, University of Nevada, Reno, Reno, Nevada, 89557.

CLOSING STATEMENT

I have read () this consent form or have had it read to me (). [Check one.]

has explained the study to me and all of my questions have been answered. I have been told of the risks or discomforts and possible benefits of the study.

If I do not take part in this study, my refusal to participate will involve no penalty or loss of rights to which I am entitled. I may withdraw from this study at any time without penalty [or loss of other benefits to which I am entitled].

I have been told my rights as a research subject, and I voluntarily consent to participate in this study. I have been told what the study is about and how and why it is being done. All my questions have been answered.

I will receive a signed and dated copy of this consent form.

Signature of Participant	Date
Signature of Person Obtaining Consent	Date
Signature of Investigator	Date

APPENDIX E - TRANSCRIPTION AGREEMENT

Transcriber's Confidentiality Agreement

Title of Study: The Lived Health Care Experience of Older Adults

Principle Investigator: Stephanie S. DeBoor, PhD, RN, CCRN

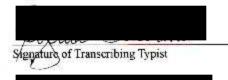
Student Investigator: Dianna Hein, BSN, RN

Contact Phone Number: (775) 771-4348

As a transcribing typist of this research study, I understand that I will be hearing taped, confidential interviews. The information on these tapes has been revealed by research participants who participated in the project on good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement.

I hereby agree not to share any information on these tapes with anyone except the principal investigator and student researcher of this project. Any violation of this agreement would constitute a serious breach of ethical standards and I pledge not to do so.

This acknowledgement is governed by HIPAA as well as other applicable federal, state, university and local laws, rules and regulations.



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Date

Printed Name of Transcribing Typist

APPENDIX F - INTERVIEW GUIDE

INTERVIEW QUESTIONS

Demographics

- 1) Please state your name. This will not be reported in my data as you will be given a pseudonym. This is for my use only.
- 2) What is your age?

Semi-Structured Interview Questions

- 1) Tell me about the type of provider or providers (i.e. physician, physician assistant, or nurse practitioner) you see for your health care.
- 2) Tell me where you typically see them.
- 3) Tell me about a typical [health care experience].
 - A) Describe getting to your appointment.
 - B) Describe the waiting area.
 - C) Describe the room you see your provider in.
 - D) Who do you encounter when you go to the office?
 - E) Is there any communication after you have left the office?
- 4) What was the [health care experience] like compared to what you thought it would be like?
- 5) How did you feel after your [health care experience]?
- 6) If you would like to share, tell me about the financial aspects of your [health care experience].
- 7) What aspects of your [health care experience] were you satisfied with and why?
- 8) What aspects of your [health care experience] were you unsatisfied with and why?
- 9) If you could sum up your [health care experience] what would you say?

Additional Cue Questions

- 1) Can you tell me more about that?
- 2) How did that make you feel?

References

- Administration on Aging (AOA). (2012). A profile of older Americans: 2011. Retrieved from http://www.aoa.gov/aoaroot/aging_statistics/Profile/2011
- American Cancer Society. (2013). Holistic medicine. Retrieved from www.cancer.org/treatment/treatmentsandsideeffects/complementaryandalternative medicine/mindbodyandspirit/holistic-medicine
- American Psychological Association (APA). (2014). What practitioners should know about working with older adults. [Executive summary]. Retrieved from www.apa.org/pi/aging/resources/guides/practitioners-should-know.aspx
- Andersen. R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of health and social behavior 36*(1), 1-10. Retrieved from http://www.globalhealth.stanford.edu/resources/Revisiting_Behavioral_Model_an d_Access.pdf
- Annells, M. (1996). Hermeneutic phenomenology: Philosophical perspectives and current use in nursing research. *Journal of Advanced Nursing 23*(4), 705-713.
- Bastiaens, H., Van Royen, P., Pavlic, D. R., Raposo, V., & Baker, R. (2007). Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries. *Patient Education and Counseling* 68(1), 33-42.
- Bayliss, E. A., Edwards, A. E., Steiner, J. F., & Main, D. S. (2008). Process of care desired by elderly patients with multimorbidities. *Family Practice* 25(4), 287-293. doi: 10.1093/fampra/cmn040

- Brown, D. J. (2007). Consumer perspectives on nurse practitioners and independent practice. *Journal of American Academy of Nurse Practitioners*, *19*(10), 523-529.
- Budzi, D., Lurie, S., Singh, K., & Hooker, R. (2010). Veterans' perceptions of care by nurse practitioners, physician assistants, and physicians: A comparison from satisfaction surveys. *Journal of the American Academy of Nurse Practitioners*, 22(3), 170-176. doi: 10.1111/j.1745-7599.2010.00489.x
- Callahan, E. J., Bertakis, K. D., Azari, R., Robbins, J. A., Helms, L. J., & Chang, D. W.
 (2000). The influence of patient age on primary care resident physician-patient interaction. *Journal of the American Geriatrics Society* 48(1), 30-35.
- Calvin, A. O., Frazier, L., & Cohen, M. Z. (2007). Examining older adults' perceptions of health care providers: Identifying important aspects of older adults' relationships with physicians and nurses: Older adults want to feed cared for, respected, and informed. *Journal of Gerontological Nursing 33*(5), 6-12.
- Cipher, D. J., Hooker, R. S., & Sekscenski, E. (2006). Are older patients satisfied with physician assistants and nurse practitioners? *Journal of the American Academy of Physician Assistants*, 19(1), 36-44.
- Colaizzi, P. R. (1978). Psychological research as the phenomenologist views it. In R. S.
 Valle & M. King (Eds.), *Existential phenomenological alternatives for* psychology, (pp. 48-71). New York: Oxford University Press.
- Cornwell, E. Y., & Waite, L. J. (2009). Social disconnectedness, perceived isolation, and health among older adults. *Journal of Health and Social Behavior 50*(1), 31-48.
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology 23*(2), 207-218.

Dittman, M. (2003). Fighting ageism: Geropsychologists are striving to stop negative age stereotypes and meet the growing mental health needs of older adults. *Monitor on Psychology 34*(5), 50. Retrieved from

http://www.apa.org/monitor/may03/fighting.aspx

- Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44(1), 131-142.
- Earle, V. (2010). Phenomenology as research method or substantive metaphysics? An overview of phenomenology's uses in nursing. *Nursing Philosophy 11*(4), 286-296.
- Federal Interagency Forum on Aging-Related Statistics (Forum). (2012). Older Americans 2012: Key indicators of well-being. Retrieved from http://www.agingstats.gov
- Green, J., Willis, K., Hughes, E., Small, R., Welch, N., Gibbs, L., & Daly, J. (2007).
 Generating best evidence from qualitative research: The role of data analysis. *Australian and New Zealand Journal of Public Health 31*(6), 545-550.
- Greene, M. G., Adelman, R. D., Freidmann, E., & Charon, R. (1994). Older patient satisfaction with communication during an initial medical encounter. *Social Science & Medicine 38*(9), 1279-1288.
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Education Communication and Technology*, 29(2), 75-91.
- Hasson, H., & Arnetz, J.E. (2011). Care recipients' and family members' perceptions of quality of older people care: A comparison of home-based care and nursing

homes. *Journal of Clinical Nursing 20*(9-10), 1423-1435. doi: 10.111/j.1365-2702.2010.03469.x

- Hess, B. J., Lynn, L. A., Conforti, L. N., & Holmboe, E. S. (2011). Listening to older adults: Elderly patients' experience of care in residency and practicing physician outpatient clinics. *Journal of the American Geriatric Society 59*(5), 909-915. doi: 10.111/j.1532-5415.2011.03370.x
- Higashi, R. T., Tillack, A. A., Steinman, M., Harper, M., & Johnston, C. B. (2012). Elder care as "frustrating" and "boring": Understanding the persistence of negative attitudes toward older patients among physicians-in-training. *Journal of Aging Studies 26*(4), 476-483.
- Holloway, I., & Wheeler, S. (2013). *Qualitative research in nursing and healthcare* (3rd ed.). Oxford, United Kingdom: Wiley.
- Horrocks, S., Anderson, E., & Salisbury, C. (2002). Systematic review of whether nurse practitioners working in primary care can provide equivalent care to doctors. *British Medical Journal*, 324, 819-823.
- Institute of Healthcare Communication. (2011). *Impact of communication on healthcare*. Retrieved from http://healthcarecomm.org/about-us/impact-of-communication-in-healthcare/
- Institute of Medicine on the National Academies (IOM). (2008). *Retooling for an aging America: Building the health care workforce* [Consensus Report]. Retrieved from http://www.iom.edu/reports/2008/retooling-for-an-aging-america-building-thehealth-care-workforce.aspx

- Jeon, Y., Essue, B., Jan, S., Wells, R., & Whitworth, J. A. (2009). Economic hardship associated with managing chronic illness: A qualitative inquiry. *BMC Health Services Research* 9(1), 182-193. doi: 10.1186/1472-6963-9-182
- Jha, A. K., Orav, E. J., Zheng, J., & Apstein, A. M. (2008). Patients' perception of hospital care in the United States. *The New England Journal of Medicine 359*(18), 1921-1931.
- Johns Hopkins University. (2014). What is primary care? Retrieved from www.jhsph.edu/research/centers-and-institutes/johns-hopkins-primary-carepolicy-center/definitions.html
- Kagan, S. H., & Melendez-Torres, G. J. (2013). Ageism in nursing. *Journal of Nursing Management*, 1-7. DOI: 10.1111/jonm.12191
- Karlsson, S., Edberg, A., Jakobsson, U., & Hallberg, I. R. (2013). Care satisfaction among older people receiving public care and service at home or in special accommodation. *Journal of Clinical Nursing* 22(3-4), 318-330. doi: 10.111/jocn.12115
- Keeler, E. B., Solomon, D. H., Beck, J. C., Mendenhall, R. C., & Kane, R. L. (1982). Effect of patient age on duration of medical encounters with physicians. *Medical care 20*(11), 1101-1108. Retrieved from http://0www.jstor.org.innopac.library.unr.edu/stable/3764671
- Keller, P. (1999). *Husserl and Heidegger on human experience*. Cambridge, UK: Cambridge University Press.
- Kuluski, K., Hoang, S. N., Schaink, A. K., Alvaro, C., Lyons, R. F., Tobias, R., &Bensimon, C. M. (2013). The care delivery experience of hospitalized patients

with complex chronic disease. *Health Expectations 16*(3), 1-13. doi: 10.1111/hex.12085

- Lee, Y. & Kasper, J. D. (1998). Assessment of medical care by elderly people: General satisfaction and physician quality. *Health Services Research* 32(6), 741-758.
- Levy, B. R., Slade, M. D., Kunkel, S. R., & Kasl, S. V. (2002). Longevity increased by positive self-perceptions of aging. *Journal of Personality and Social Psychology* 83(2), 261-270.
- Marshall, C. & Rossman, G. B. (2006) *Designing qualitative research* (4th ed.). Thousand Oaks, CA: Sage Publications.
- Maruna, S., & Butler, M. (2005). Phenomenology. In K. Kempf-Leonard (Ed.), Encyclopedia of social measurement (p. 49-52). St. Louis, MO: Elsevier.
- Mayer, E. L., Gropper, A. B., Neville, B. A., Partridge, A. H., Cameron, D. B., Winer, E.
 P. & Earle, C. C. (2012). Breast cancer survivors' perceptions of survivorship care options. *Journal of Clinical Oncology 30*(1), 158-163. doi: 10.1200/JCO.2011.36.9264
- Moran, D. (2005). *Edmund Husserl: Founder of phenomenology*. Malden, MA: Polity Press.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage Publications.
- National Institutes of Health (NIH). (2013). Choosing a primary care provider. Retrieved from http://www.nlm.nih.gov/medlineplus/ency/article/001939.htm
- Naylor, M. D., & Kurtzman, E. T. (2010). The role of nurse practitioner in reinventing primary care. *Health Affairs*, *29*(5), 893-899.

- Nelms, L., Johnson, V., Teshuva, K., Foreman, P., & Stanley, J. (2009). Social and health factors affecting community service use by vulnerable older people. *Australian social work* 62(4), 507-524.
- Pizer, S. D., & Prentice, J. C. (2011). Time is money: Outpatient waiting times and veterans in the United States. *Journal of Health Economics 30*(4), 626-636.
- Polit, D. F., & Beck, C. T. (2012). Nursing research: Generating and assessing evidence for nursing practice (9th ed.). China: Wolters Kluwer Health, Lippincott Williams & Wilkins
- Prentice, J. C., & Pizer, S. D. (2007). Delayed access to health care and mortality. *Health Services Research* 42(2), 644-662.
- Press Ganey. (2008). The impact of patient satisfaction on pay-for-performance in medical practices. [White paper]. Retrieved from www.pressganey.com/researchResources/white-papers/white-papers-for-medicalpractices-ambulatory.aspx
- Press Ganey. (2009). *Keeping me waiting: Medical practice wait times and patient satisfaction* [White paper]. Retrieved from www.pressganey.com/Documents_secure/Medical%20Practices/White%20Papers /Keep_Me_Waiting.pdf
- Saldana, J. (2011). *Fundamentals of qualitative research*. Oxford, NY: Oxford University Press.
- Shento, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63-75.

- Smith, D. W. (2011). Phenomenology. In E. N. Zalta (Ed.), *The Stanford encyclopedia of philosophy* (Fall 2011 ed.). Stanford, CA: Metaphysics Research Lab. Retrieved from http://plato.stanford.edu/archives/fall2011/entries/phenomenology/>
- Stein, M. B., Roy-Byrne, P. P., Craske, M. G., Campbell-Sills, L., Lang., A. J., Golinelli,
 D., . . . Sherbourne, C.D. (2011). Quality of and patient satisfaction with primary
 health care for anxiety disorders. *Journal of Clinical Psychiatry* 72(7), 970-976.
 doi: 10.4088/JCP.09m05626blu
- Tennstedt, S. L. (2000). Empowering older patients to communicate more effectively in the medical encounter. *Clinics in Geriatric Medicine 16*(1), 61-70.
- The Dartmouth Atlas of Health Care. (2013). *Care of chronic illness in last two years of life*. Retrieved from http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=1

The Gerontological Society of America. (2012). *Communicating with older adults: An evidence-based review of what really works*. Retrieved from http://www.agingresources.com/cms/wpcontent/uploads/2012/10/GSA_Communicating-with-Older-Adults-low-Final.pdf

- U.S. Census Bureau. (2011). *The older population: 2010* [2010 Census Briefs]. Retrieved from http://www.census.gov/prod/cen2010/briefs/c2010br-09.pdf
- U.S. Department of Health & Human Services (HHS). (2013). *Services for seniors*. Retrieved from http://www.hhs.gov/healthcare/prevention/seniors/
- U.S. Department of Health & Human Services (HHS). (n.d.) *What is pay-forperformance?* Retrieved from www.hrsa.gov/healthit/toolbox/HealthITAdoptiontoolbox/QualityImprovement/w

hatispay4perf.html

- van Manen, M., (1990). Researching lived experience: Human science for an action sensitive pedagogy. Albany, NY: State University of New York Press.
- van Manen, M., & Adams, C. A. (2010). Phenomenology. In P. Peterson, E. Baker, & B. McGaw (Eds.), *International encyclopedia of education* (3rd ed.) (pp. 449-445). St. Louis, MO: Elsevier.
- Yorkston, K. M., Bourgeois, M. S., & Baylor, C. R. (2010). Communication and aging. Physical Medicine and Rehabilitation Clinics of North America 21(2), 309-319.