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THROUGH THE EYES OF THE ELDER: PERCEPTIONS AND EXPECTATIONS OF HEALTH CARE

by
Micaela Mare DeLashmit

A thesis submitted to the faculty of The University of Mississippi in partial fulfillment of the requirements of the Sally McDonnell Barksdale Honors College.

Oxford
May 2012

Approved by

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First, I would like to thank Dr. Robin Wilkerson for her devotion to my education. Her guidance and support made it possible for me to be successful. I am truly thankful for her interest in me, as my instructor, advisor, and mentor.

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Lastly, but most importantly, I extend my sincerest appreciation to God. Without You, nothing I do would be possible. Lord, make me understand what I can and cannot do to help others in the world today. Please show me the small actions I can take that will make a difference.

"Keep your face to the sunshine and you cannot see the shadows." – Helen Keller

ABSTRACT

Through the Eyes of the Elder: Perceptions and Expectations of Healthcare

The purpose of this study was to explore and describe elders' perceptions and expectations of healthcare. Qualitative in nature, this study was conducted in the methodology explicated by van Manen: hermeneutic phenomenology. Data was collected in the form of personal interviews. Demographic data was collected to provide context for the study. Three essential themes, the future, time, and trust, and 10 subthemes emerged from analysis and further reflection upon the interviews of the participants. The theme of the future included: concern for the future care of elders, financial concern, possible decline in the number or quality of healthcare providers, and fear of the unknown. Four subthemes of time were described by the elder participants: taking away time, taking the time, remaining time, and perseverance. The theme of trust was an important factor in the elders' perception of healthcare. Trust was expected to be reciprocal between elders and their healthcare providers, including respect and meeting expectations. Elders' expectations of healthcare were also identified. The participants discussed a wide variety of expectations, particularly pertaining to characteristics of healthcare providers. The elders' perception of experiencing all three themes and having their expectations met or exceeded was associated with descriptions of satisfactory outcomes and the reception of good care.

TABLE OF CONTENTS

Chapter 1.	Introduction	1
	Purpose	2
	Research Questions	2
	Significance	3
	Phenomenological Approach	3
	Operational Definitions	4
	Assumptions	5
	Limitations	5
	Summary	6
Chapter 2.	Review of Literature	7
	Elder Perceptions of Healthcare	7
	Elder Expectations of Healthcare	10
	Summary	13
Chapter 3.	Methodology	15
	Research Design	15
	Setting	16
	Participants	16
	Instruments	18
	Procedure	18
	Interview procedure	18
	Protection of Human Subjects	19
	Analysis	19
	Methodological Rigor	21
	Credibility and Dependability	22
	Transferability	22
	Confirmability	22
	Summary	23
Chapter 4.	Data Analysis	24
	Phenomenological Reflection of Experiential Descriptions	24
	Hope	24
	Della	31
	Alyce	34
	Moe	38
	Sally	42
	Ron	44
	Belle	49
	Mike	50

LIST OF TABLES

Table 1. Participant Demographic Data 25

Table 2. Participant Themes and Subthemes 26

Table 3. Essential Themes and Related Subthemes 56

Table 4. Elders' Expectations of Healthcare 67

CHAPTER 1

Introduction

Americans are living longer now than ever before and with more co-morbidities (The Federal Interagency Forum on Aging-Related Statistics, 2010). With advances in healthcare and technology, people can now survive and even thrive with conditions once considered immense contributors to mortality. The need to investigate elders' interactions with healthcare is especially important as the United States faces the immense task of healthcare reform. Currently, the average life expectancy is 83.5 years; approximately a 22% increase from the 1960 average life expectancy of 79.5 years. The number of interactions between elders and healthcare is rising alongside the longer average life expectancy that includes an increasing number of co-morbidities (The Federal Interagency Forum on Aging-Related Statistics). Therefore, a better understanding of the elder perception and expectations of healthcare is warranted.

13% of the United States population was age 65 and older in the year 2008. Projected growth of the elderly population is estimated to reach 20% of the entire U.S. population by 2030 (The Federal Interagency Forum on Aging-Related Statistics). With the number of older adults expected to double by year 2030, the majority of individuals seeking healthcare will be elders (Zwillich, 2008). In 2009, it was estimated that 37.6% of Americans aged 65 and older made 1-3 visits to healthcare professionals in one year, with only 5.6% making no visits at all (U.S. Census Bureau, 2012). Major changes in

Americans' access and utilization of healthcare are expected in the near future. Investigating the elders' perception of and general expectations of healthcare should be conducted to inform the process. When healthcare professionals have an understanding of how elders perceive healthcare and their expectations, care delivery could be tailored to elderly individuals, thereby, improving satisfaction, feelings of control in decision making, and, in turn, quality of life (Zwillich, 2008).

In order to create better healthcare experiences for elders, an understanding of what is perceived and expected is necessary. It is important to understand the experiences of elders in healthcare to aid in decision making, care delivery, and policy formation on a basis of their needs and expectations (Prato, et al., 2007).

Purpose

The purpose of this study was to explore the experiences of elders in healthcare, including their expectations. The knowledge gained through this study will be especially useful to those who directly provide or participate in the healthcare of elders. It will also benefit those who are responsible for making policies affecting elders and healthcare. With an understanding of the needs and expectations of elders in healthcare settings, improvements can be made to enhance the experience.

Research Questions

The questions that guided the research were:

1. "What is the elder perception of healthcare?"
2. "What is the elder expectation of healthcare?"

Significance

This study was important due to the fact that there is a paucity of research on the topic of elders' experiences in healthcare. As the United States population ages, the body of evidence surrounding the experiences, needs, and expectations of elders will also need to expand. Currently, the United States is facing dramatic healthcare reform. Such a reform is expected to greatly affect how Americans, including elders, utilize and access healthcare services. As there is limited research concerning elder individuals' perceptions and expectations of healthcare, it is likely that without more research, reforms will occur without substantial consideration of those factors. This research will be beneficial not only to those who provide and/or participate in the healthcare of elders, but also to those who are involved in healthcare policy. In order to create a better experience for elders in the healthcare setting, it is imperative to gain an understanding of their experience and expectations.

Phenomenological Approach

This was a qualitative study that utilized a phenomenological method expounded by the hermeneutic phenomenologist Max van Manen. Phenomenological research investigates "the lived experience" of everyday situations and contexts (van Manen, 1990). Analysis of such experiences provides insight and reveals theoretical understandings of what each experience means. Phenomenology allows researchers to experience what individuals' lives are like (van Manen, 1990).

Phenomenological research does not attempt to prove or discover theories. It simply inquires what the meaning of a human experience is. Research conducted in the approach of van Manen (1990) pursues an "insightful description of the way we

experience the world pre-reflectively, without taxonomizing, classifying or abstracting it" (p. 9).

Data sources in the current study's interviews were collected by the researchers to create vivid descriptions the lived-experience. Analysis of the descriptions reveals general themes. Those themes seek to divulge the deeper meanings of the lived-experience. Three methods for analysis to reveal themes are explicated by van Manen (1990): "the wholistic or sententious approach; the selective or highlighting approach; and the detailed or line-by-line approach" (p. 93).

Operational Definitions

The following operational definitions were utilized by the researcher to improve understanding in this study.

1. *Healthcare* is the diagnosis, prevention, and/or treatment of any illness or disease, mental or physical, performed for or sought by elders; this encompasses all settings and/or services, only excluding pharmaceutical encounters.
2. *Urban* is defined as a population greater than 50,000 (U.S. Census Bureau, 2010).
3. *Rural* is defined as a population less than 50,000 (U.S. Census Bureau, 2010).
4. An *elder* is any study participant aged 70 years or older.
5. *Living independently* encompasses the following elements: living alone, with a spouse, or with family in a non-institutional community setting.
6. *Mental competence* is being *oriented x 4*, or to person, place, time, and situation.
7. *Oriented x 4* means that a participant knows who they are, where they are, what time it is, and understands his/her role in the current situation.

Assumptions

The following assumptions were made by the researcher.

1. Individuals who sought healthcare in the past year will have a perception of the experience and will be willing to share the perception.
2. Mental competence can be measured by assessing orientation x 4, as previously defined.
3. If elder participants are oriented x 4, then elders can accurately describe their experiences.

Limitations

This study educed personal descriptions of an experience. The experiences of the elders in this study might not parallel the experiences and/or perceptions of all elders in the healthcare setting; however, since this was a qualitative study, generalization to greater populations was not a goal. Other factors that could have limited the study were the place and timing of interviews, which may have influenced the information that participants disclosed to the researcher. Also, the presence of the tape recorder may have had a reactive effect on the participants. The participants may not have fully understood the questions presented by the researcher. In an attempt to minimize these limitations, interviews occurred in a confidential setting and at a time chosen by the elder participant. The presence of the tape recorder appeared to have a negligible effect on the interviews. The researcher assessed orientation x 4 at the beginning of each interview to ensure that the elder participant had mental competence for the purpose of this study. To further reduce misunderstanding of questions posed by the researcher, questions were re-worded and re-stated when necessary.

Summary

The number of older adults (aged 65 and older) seeking healthcare in America is expected to dramatically rise in the near future (Smeltzer, Bare, Hinkle, & Cheever, 2010). This phenomenon will be due the projected growth of the elder population and the anticipated increase in access to healthcare (The Federal Interagency Forum on Aging-Related Statistics, 2010). With an aging population, it is increasingly important for healthcare professionals and policy makers to have an understanding of the perceptions and expectations of elders. There has been very little published research exploring the elder perception and/or expectation of healthcare. With an understanding of what elders expect of healthcare, improvements can be made by healthcare professionals and policy-makers to improve the experiences and the quality of elder-American life.

CHAPTER 2

Review of Literature

The phenomenon of interest within this study was the perceptions and expectations of elders concerning healthcare. This chapter presents a review of literature relevant to the topic. An extensive review of the literature revealed few studies that focused precisely on the perceptions and expectations of elders within the realm of healthcare. Most studies were conducted in other countries where very different healthcare systems exist. The reports of those elders in those studies may not be relevant or even similar to the reports of American elders. Other studies were quantitative in design and measured elder satisfaction with healthcare with various rating scales. The lack of research on the perceptions and expectations of elders who live within the United States pointed to the importance of a qualitative study to examine the perceptions or expectations of the elder related to healthcare. The review of literature which follows consists of published research related to the phenomenon of interest in this study: elders' perceptions of healthcare and elders' expectations of healthcare.

Elder Perceptions of Healthcare

In a dissertation study conducted by Beigay (2007) elders (median age 75 years) living in subsidized housing were asked about their experiences with healthcare. This study utilized a qualitative approach, consisting of personal interviews with elders. Several themes emerged in analysis. The issue of trust surrounding heath care was a main

focus of the elderly participants. Analysis appeared to reveal a beginning of general mistrust of physicians, while at the same time, a growing trust in nurses among the participant population. Trust was believed to have a significant effect on patient satisfaction and health behavior outcomes. Beigay also reported that it was difficult to define what is meant by the word trust, and that each elder probably had his/her own personal meaning and beliefs surrounding the word. Beigay's study also asked elders about general health concerns and expectations for meeting those concerns. Many elders reported that they worried about the speediness of help to arrive if they were to sustain an injury. Other participants were disgusted with the high costs of healthcare; many not knowing where or how they would obtain healthcare in the future, if costs continued to rise at rapid rates. All other concerns educed from the interviews in this study were related to a specific disease process, aging, or death.

A study conducted in Italy sought to describe the differences in elders' and general practitioners' perception of various disease processes (Prato, et al., 2007). The researchers chose a qualitative approach utilizing telephone interviews for data collection. The elder participants (mean age 76.3 years) expressed that their practitioners did not understand the debilitating nature of their illnesses. The researchers found two polar perspectives between the elders and the practitioners which created a large disagreement surrounding perception and treatment. The elders involved in this study also revealed a greater trust in hospitals than other healthcare arenas. The care they received at hospitals was reported to be more satisfactory than care delivered in other settings; the reasons behind this finding were not investigated within the study. The majority of study participants reported that they were generally satisfied with the care

they received, but also reported the necessity of healthcare to take into account the social aspects and implications of disease in the future. The researchers asserted that the most important factors surrounding the elderly population's development of a perception about healthcare are: degree of loneliness experienced during care, self-care capacity and ability to comply with prescribed treatments, overall health status or presence of disease, level of anxiety, and availability of financial resources.

Frail elders and their perspectives of healthcare were the focus of a study conducted in Sweden (Jakobsson, Kristensson, Hallberg, & Midlov, 2011). A mixed methodology, both quantitative and qualitative in nature, was utilized by the researchers. The focus was the amount of healthcare utilization by frail elders and their resulting perspectives and satisfaction. The participants were age 65 and older. Feelings of loneliness were a main concern of the elder participants; feeling less lonely in a healthcare setting resulted in reports of more satisfaction. The quantitative element of the study focused on the number of visits and/or contacts with healthcare professionals made by the elders. Although the results were not definitive, the elders with more visits were less likely to display characteristics of depression; thus, suggesting that elders who spend more time and have more opportunities to establish communication with a healthcare professional will have more positive perceptions of healthcare and improved quality of life. The researchers concluded that more research is needed in the realm of elders, their satisfaction with healthcare, and the factors that influence satisfaction. (Jakobsson, et al., 2011).

Elder Expectations of Healthcare

Although there have been several published research studies surrounding patient satisfaction and expectations, a thorough review of published research did not reveal any study that focused specifically on elders' expectations of healthcare. Many of the studies that investigated elders' perceptions of healthcare mentioned that further research is necessary to ascertain and delineate the unique needs and expectations of elders in the healthcare setting (Lynn & McMillen, 1999; Kenten, Bowling, Lambert, Howe, & Rowe, 2010; Bowling, et al., 2003; Bleich, Ozaltin, & Murray, 2009).

A study conducted thirteen years ago by Lynn and McMillen (1999) sought to describe the discrepancy in healthcare providers' and patients' expectations of care delivery. It is not mentioned where this study was conducted. Lynn and McMillen stated: "Comparability of patients' and [healthcare providers'] perceptions have been investigated primarily during the last decade in conjunction with the emphasis on patient-centered care and quality improvement in healthcare" (p.66). The participants were not necessarily elders; the requirement was that they be at least 18 years old. A quantitative approach was utilized, asking participants to rate various elements by degree of importance. The research revealed that patients and healthcare providers were generally in disagreement about healthcare and what is important. The researchers reported that many patients felt that healthcare providers underestimated their perceptions and feelings and hoped that stronger communication between patients and healthcare professionals would be established in the future. The authors investigated the specific difference in nurses' and patients' expectations. Their findings revealed that nurses often ranked the significance of various elements of health and patient care lower than their patients did;

suggesting that nurses did not understand what patients expected and valued to be important. In this admittedly dated study, aspects of importance that patients expected when seeking healthcare included: an environment conducive to healing, feeling like the center of attention, providers being talkative and friendly, providers appearing as professionals, and finding mutual understandings of goals. In order for healthcare to improve in the future, it was suggested by the authors that healthcare providers need to make more conscious efforts to determine patient expectations and tailor care delivery to meet the unique needs and wants.

A qualitative study conducted by Kenten, Bowling, Lambert, Howe, and Rowe (2010) investigated patient expectations prior to a healthcare visit and whether or not those expectations were met. This study, conducted in the United Kingdom, utilized patient interviews as a means of describing and understanding what patients expect from healthcare. The participants had a mean age of 51.2 years. The researchers discussed the idea that expectations were a concept that were not well-defined and quite subjective; thus the researchers proposed that arriving at an understanding that can be generalized to a greater population is difficult. Expectations of patients seeking care were reported to be: not feeling embarrassed or stigmatized, not experiencing anxiety related to the unknown, having confidence in their own abilities and in their healthcare providers', avoiding physical discomfort, feeling like the healthcare provider is warm and inviting, expecting the provider to be professional and thorough, being treated in a clean and modern environment, and receiving acceptable lifestyle advice. The researchers suggested that further research was needed to determine if their findings are consistent with the expectations of all patients before implementations to improve satisfaction are instituted.

Another qualitative study employed interview methodology to explore the concept of enhancing quality of life among people age 65 and older. Although this study did not focus on the healthcare aspect of elder expectations, its findings might be useful to healthcare providers seeking to meet elders' expectations and improve quality of life. A sense of having good social relationships was the main factor that elders reported as making a significant positive contribution to quality of life. Poor health was the main factor reported to threaten quality of life. In this study, implications for healthcare professionals to improve social relationships with their elderly patients included: decreasing feelings of loneliness, building trust, improving feelings of safety, keeping in touch, increasing the level of mutual participation in decision making, and having greater tolerance of the aged by younger generations (Bowling, et al., 2003).

Examination of what determines patient satisfaction with healthcare was researched by Bleich, Ozaltin, and Murray (2009). This quantitative study conducted in Europe collected data by means of the 2003 *World Health Survey*. The researchers reported that satisfaction was a complex concept and presented the challenge of reaching a consensual definition. Analysis of the data revealed several elements of patients' experiences with healthcare that significantly shaped perceptions of satisfaction and influenced expectations for the future. Predictors of patient satisfaction were reported to include: degree of autonomy, choices, effective communication, preservation of confidentiality and dignity, receiving prompt attention, and the quality of basic amenities. Participants reported that preservation of dignity, receiving prompt attention, and being treated in a reasonable quality setting as being most important. Another important element of satisfaction was reported as having contact with individuals who displayed

positive or pleasant attitudes. Another interesting finding within this study was patients receiving inpatient care were generally more satisfied than those in outpatient care facilities. The researchers suggested that this finding may have been related to the expectations of the patients. The reports of those individuals receiving outpatient care may have displayed less satisfaction due to the fact that their expectations of outpatient facilities to meet their personal needs may have been higher. The higher degree of patient expectations makes it increasingly difficult to meet or exceed unique needs. The researchers recommended further research on the topic of patient satisfaction and expectations.

Summary

The review of literature revealed that there is a gap in the body of knowledge surrounding the perceptions and expectations of elders in healthcare. In the published research, there were few recent studies that examined the elders' experience with healthcare in the United States. The few qualitative studies rendered understandings of the fact that trust and feelings are important factors in the development of elders' perception of healthcare (Beigay, 2007; Prato, et al., 2007; Jakobsson, Kristensson, Hallberg, & Midlov, 2011). A small number studies focused on the expectations of elders concerning healthcare. Patient expectations were often measured by quantitative means, including surveys and rating scales. Study participants in the perception studies were similar in age to the participants in the current study. Inclusion criteria for study participants in the expectation studies were generally aged 18 and older, therefore not specific to elders. Reported patient expectations in healthcare included desiring better communication, developing mutual understandings, being treated promptly in a clean,

calm environment, and believing that healthcare professionals are truly professional and display appropriate affect (Lynn, & McMillen, 1999; Kenten, Bowling, Lambert, Howe, & Rowe, 2010; Bowling, et al., 2003; Bleich, Ozaltin, & Murray, 2009).

CHAPTER 3

Methodology

The purpose of this study was to explore the perceptions and experiences of elders concerning healthcare. The questions that guided the research were: (1) what is the elder perception of healthcare, and (2) what is the elder expectation of healthcare? The methods that were used in this study provided the most appropriate and thorough understanding of the elders' experience. This chapter describes the study design, setting, participants, instruments, interview procedure for data collection, protection of human subjects, analysis methods, and methodological rigor.

Research Design

This is a qualitative study that utilized a phenomenological method expounded by the hermeneutic phenomenologist Max van Manen. Phenomenological research investigates "the lived experience" of everyday situations and contexts (van Manen, 1990). Analysis of such experiences provides insight and reveals theoretical understandings of what each experience means. Phenomenology allows researchers to experience what individuals' lives are like (van Manen, 1990). The general approach will be descriptive in nature; seeking to provide readers with a rich description of the phenomenon and enabling the development of awareness, both of which are essential elements of genuine understanding.

Phenomenological research can be conducted via several methods, as described by van Manen (1990): "(1) by turning to a phenomenon which seriously interests us and commits us to the world, (2) by investigating experiences as we live them, rather than as we conceptualize them, (3) by reflecting on the essential themes that characterize the phenomenon of interest, and (4) by describing the phenomenon through the art of writing and rewriting" (p 30). Phenomenological research does not necessarily progress in a linear manner; intermittent or simultaneous research methods may be utilized (van Manen, 1990). The data collection, transcription, and analysis may occur at the same time. Analysis may occur after each interview; not only after the entire data collection process.

Setting

Data collection occurred at a time and place chosen by the participants, to ensure acceptability and confidentiality. The chief investigator collected data in the form of face-to-face interviews. It was expected that only one interview, lasting approximately one hour, with each participant would be required to obtain the data. To maintain privacy and reduce the potential that having others present might limit the openness of the participant sharing experiences, the participant, the researcher, and/or the mentor, Dr. Robin Wilkerson, were the only ones present during interviews.

Participants

It was estimated prior to the initiation of the data collection that no more than 20 participants would be required, and that interviews would cease when redundancy in the data occurred. Participants were elders residing within a 100 mile radius of Oxford, Mississippi. Participants were required to meet the following inclusion criteria: (1) male

or female, (2) aged 70 years or older, (3) lives independently (as defined in operational definitions), (4) has mental competence measured by assessing orientation x 4, (5) understands and speaks English (6) can hear (with or without assistive devices) (Per self-report), and (7) has used some form of healthcare in the past year. As long as participants met all of the inclusion criteria, no exclusions were made on a basis of gender, race, spiritual preferences, or disability. The participants did not need to have the ability to read or write for this study.

Demographical information such as: age, gender, ethnicity, urban or rural residence, level of education, number of prescribed medications, how often have been to healthcare provider in last year, how often have been to hospital in last year, and if the participant has ever worked in healthcare, were collected to provide context for the study. The demographic data collection sheet can be found in Appendix A.

A snowball (purposive) sampling method was used in this study. The researcher asked initial participants to refer other study candidates. This type of sampling if often used in qualitative studies and assures that participants included in the study share certain demographics. Purposive sampling is appropriate when specific members of a population are wanted for a study in qualitative research and where the data will not be generalized to a larger population (Brink & Wood, 1998).

The researcher attended a function at a local church that is frequented by elders and presented the opportunity to participate in the study. Initial participants were recruited from this function and the researcher then asked each participant to inform others that he or she believed to be eligible for the study. The investigator provided

participants with an information sheet (Appendix B) and contact information to give to others who might have been eligible.

Instruments

As with all qualitative studies, the researcher was the primary study instrument. An information sheet was given to potential participants. Collection of demographic data utilizing a demographic data sheet occurred prior to starting the interview to ensure that all inclusion criteria was met. The phenomenological research included the collection of data from experiential descriptions derived from personal interviews with participants.

Interview Procedure

Data in the form of personal interviews was recorded on a digital tape recorder. The interview began with validation of the participant being oriented times four. After it was established by the interviewer that the participant was oriented, the demographic information was collected. After the collection of the demographic information and verification that all inclusion criteria were met, the recorder was turned on and the interview began. Demographic information was collected for the sole purpose of providing context for the study. The interviews began with the following statement: "Tell me a story about an experience you had with healthcare in the past year." All other questions arose from the interview and were used to clarify, redirect, or seek more information. The participant was informed orally and in the information sheet (1) that if he/she wished to withdraw from the study during the interview, that the interview would stop and the recording would be destroyed at that point, and (2) if the participant wished to withdraw after the transcription was completed, the participant may do so, however, the data would be retained for the study. No participant requested to withdraw from the

study at any point. Transcriptions of the interviews were used for data analysis and in the study report.

Protection of Human Subjects

Approval for this study was obtained from the University of Mississippi Medical Center (UMMC) Institutional Review Board (IRB) (Appendix C). The researcher was granted a waiver of informed consent as the study did not involve greater than minimal risk, waiving consent did not adversely affect the participants' rights and welfare, and information concerning the study findings could be provided to participants later on. The participants were given an information sheet on the study. Participation in the interview was considered consent to participate in the study and for the data to be used. To preserve confidentiality, the participants chose a fictitious name to be used during the interview, in the transcriptions, and in the researcher's report. The fictitious name was associated with a code on the demographic form. The data belong to the primary investigator and is stored in designated files at the University of Mississippi Medical Center (UMMC) School of Nursing for 7 years. Only the researcher has access to the files during that time. After the 7 year period, the data will be destroyed either by shredding, deleting, or incinerating all information. A permanent copy of the research report will remain in possession of the Sally McDonnell Barksdale Honors College at the University of Mississippi and at the UMMC School of Nursing.

Analysis

Data collection and analysis occurred in a non-linear manner. Interviews, analysis, and transcription occurred simultaneously. While verifying the accuracy of transcriptions, the researcher and/or her mentor, Dr. Robin Wilkerson, began reflection

upon the data. The mentor was the researcher' s professor and thesis advisor. Her role was to educate the researcher about data collection and analysis processes. She also assisted the researcher with any element of the research process, as needed, and with editing this research report.

The researcher identified patterns within the interviews; later developing the patterns into themes. Post-transcription verification, the interviews were analyzed as a whole (the wholistic or sententious approach), by paragraph (the selective or highlighting approach), and line-by-line (the detailed approach) (van Manen, 1990). The overall meaning of the elders' descriptions was investigated via analyzing the transcriptions as a whole; a single phrase that sums up the description was derived. Analysis of paragraphs revealed themes or elements that were unique in describing the phenomenon of interest. Line-by-line analysis allowed the researcher to explore the fine details surrounding the participants' life experiences.

The wholistic approach allowed the researcher to derive a sentence that communicated the overall meaning of the interview. In the highlighting approach the researcher utilized color coding to separate themes. The detailed approach involved underling statements within the transcripts, with the researcher making notes about the possible meaning of the experience. Findings were discussed by the researcher and her mentor until a consensus was found.

A linguistic transformation of the interviews must occur in order for the researcher to convey interpretations of the phenomenon (van Manen, 1990). The interpretations and derived themes were transformed into the researcher's own words within the analysis chapter and are supported by providing interview excerpts. The

writing of the analysis was revised until a meaningful description of elders' perceptions and expectations concerning healthcare were composed.

Methodological Rigor

For qualitative research to be considered high-quality, it must possess methodological rigor (Maggs-Rapport, 2001). There are four essential elements of methodological rigor: "ethical rigor, rigor in documentation, procedural rigor, and auditability" (Burns, 1989, p.48). To ensure ethical rigor, the research was carried out according to the research plan approved by the UMMC IRB. Rigor in documentation was met by including all appropriate elements of the phenomenological research process described by van Manen (1990).To prevent errors in recording interviews by hand, the interviews was recorded and transcribed verbatim. In order to ensure that no manipulation of transformation of data occurred in transcription, the recorded copy was compared to the transcription for accuracy of transcription by the researcher. Procedural rigor was ensured by the researchers having consistency in interviews; the same interview question and procedure was used with each participant. After demographic information was obtained, the initial question was always "tell me a story an experience you had with healthcare in the last year." The research process has been carefully documented and under similar circumstances one would expect to obtain similar findings.

Trustworthiness should also be established when considering the value of qualitative research. Credibility, dependability, transferability, and confirmability are necessary elements to establish trustworthiness in research (Lincoln & Guba, 1985).

Credibility and Dependability

Credibility of this study was established by the researcher and her mentor analyzing the interviews and reaching consensus on meaning interpretations. In order to make sure that the research team derived credible descriptions of the data, the analysis methods were used consistently. In order to allow readers to establish credibility of the research team's interpretations, verbatim quotations from the interviews are provided within this text. It is also expected that the study results are believable and repeatable.

Transferability

Transferability of qualitative studies cannot be explicitly stated. The findings of this study are specific to a certain group of elders residing in very a small region of the United States of America. Although the reports of these elders may not be relevant to the reports of all elders, it is believed that the findings would be similar to those of other studies; however, this would require further research. It is also important to remember that qualitative studies do not seek generalization to a greater population; only a rich description of a lived experience is sought (Polit & Beck, 2010).

Confirmability

In order for confirmability to be established, the findings and inferences of the researcher must be logical (Lincoln & Guba, 1985). The researcher utilized a consistent analysis process to develop a firm basis for interpretation of the participants' experiences. This study could be replicated using the same methodology and derive similar results; thus, contributing to confirmability. Confirmability was also enhanced by the researcher by obtaining a phenomenological nod. She contacted the majority of the participants after the conclusion of the study, informed them of the results, and asked if the results

adequately captured their perceptions and expectations of health care. The participants approved the results of this study as adequate and accurate descriptions of their experience.

Summary

This qualitative phenomenological study, conducted in a manner expounded by van Manen (1990), was intended to provide readers with a description and understanding of the lived experience of elders within healthcare. The researcher collected data through personal interviews. The interviews were transcribed verbatim and analyzed for themes as a whole, by paragraph, and line-by-line. The next chapter presents the researcher's interpretation of themes derived through analysis. The themes are supported by direct quotations from the interviews.

CHAPTER 4

Data Analysis

The researcher's reflections of the experiential descriptions are presented in this chapter. The participant interviews were reflected upon utilizing the phenomenological methods described in Chapter 3. The research questions were: (1) What is the elder perception of healthcare, and (2) What is the elder expectation of healthcare? A description of the participant and the situational context of each interview is presented prior to the researcher's reflections of individual themes, with the focus on providing answers to the questions that guided the research. Themes are elements that emerged within the body of data and provided a description of the meaning behind the lived experience of the participants (van Manen, 1990). The demographical data that provided context for the study are presented in Table 1. The individual themes that emerged for each participant are in Table 2.

Phenomenological Reflection of Experiential Descriptions

Hope

Hope was the first participant. She was a 70 year old Caucasian who resided in a rural area. Hope was a very healthy elder, who reported no major health conditions throughout her life. Per self-report, she had five medications prescribed to her, visited a healthcare provider six times in the past year, and had no hospitalizations in the

Table 1. Participant Demographic Data

Participant	Age in Years	Gender	Ethnicity	Number of Prescribed Medications	# of Healthcare Provider Visits in past year	# of Hospitalizations in past Year	Worked in Healthcare
Hope	70	F	Caucasian	5	6	0	Yes
Della	86	F	Caucasian	6	30+	10	No
Alyce	84	F	Caucasian	8	6	2	No
Moe	87	M	Caucasian	4	4	0	Yes
Sally	77	F	African-American	3	3	0	Yes
Ron	72	M	African-American	5	5	1	No
Belle	77	F	Caucasian	0	3	0	Yes
Mike	71	M	Caucasian	6	20+	3	No

Note: rural = population <50,000, urban = population >50,000. Number of prescribed medications, number of healthcare provider visits, and number of hospitalization are per self-report.

Table 2. Participant Themes

Participant	Themes
Hope	Time Healthcare provider meeting elder's expectations Respect The future Financial concern
Della	Presence and appearance of the healthcare provider matter Involvement/Collaboration Meeting the expectations of the healthcare provider Fear of the unknown
Alyce	Perseverance Trust in the healthcare provider Support Taking the time The future
Moe	Time Trust in the healthcare provider Presence and appearance of the healthcare provider matter The future
Sally	Taking the time Healthcare provider's trust in the elder Healthcare provider's respect for the elder
Ron	Time Trust in the healthcare provider Meeting expectations Presence and appearance of the healthcare provider matter Healthcare provider's respect for the elder
Belle	Trust in the healthcare provider The future I don't want to be a burden
Mike	Taking away time Trust in the healthcare provider Healthcare provider meeting elder expectations The future

past year. Hope previously worked in the healthcare field. The interview occurred in the participant's home; both researcher and participant were seated on her sofa.

Reflection on Hope's description of the experience of being an elder in healthcare revealed five themes.

Themes.

Time. Hope described the aspect of time in her experience in different ways. The first description of time was related to time being taken away. Hope described taking away from her time as having to wait unnecessarily or too long. Waiting not only included waiting to be seen by a healthcare provider, but in some instances, it meant that elders had to wait for someone to take them to and from a visit with a healthcare provider. A loss of independence related to transportation was viewed as a significant event to Hope, as it meant that personal time would be taken away. She also voiced her perception that time is taken away when there is a delay in care that seems unnecessary due to waiting rooms that are not crowded or busy. Hope described how she did not want there to be a delay in administering healthcare because she did not want to expose the people around her to the ailment for which she had come to the healthcare provider's office.

> *I always feel sorry for them. Uh, sometimes their family member will just drop 'em off at the doctor's office, and they take off, and they have to sit out in the waiting room, waiting for someone to come back and pick them up.*
>
> *Healthcare, to me, means that when I am ill or I have a discomfort, sick, and I go to an emergency room or to see a doctor, my expectation is that they're going to not delay in seeing me, and when I get there, that I don't have to sit out in a waiting room, when I'm sick with probably a fever or diarrhea or something and expose the other patients that are sitting in the waiting room. I would expect that they would get me into a room by myself, and that way there would be less contamination among the other people in the room.*

The other aspect of time analyzed from Hope's experiential description was remaining time. Hope knew that elders are nearing the end of their lives. She expressed feelings that elders may not receive the best healthcare in their remaining time due to insufficient resources and the prioritization of care based on age. Her expectation was that elders should be treated as any other age group, throughout life. Hope's description of remaining time may also be related to concern for the future of healthcare.

> *I think that the elderly would be set aside just to die of natural causes because we're not going to be able to take care of everybody. And the elderly have already lived their life, so to speak, and so, they're just making room for the younger generation who have their lives ahead of them. Ours is kind of in the back.*

A fear that Hope expressed was becoming a burden in her older age and remaining time. She perceived that a loss of independence and depending on others to meet her needs would create a burden for her family. She did not discuss how loss of independence could be a personal burden, only a burden to others. Hope perceived that in her remaining time, nursing homes will have high placement rates and will be too full care for the expected growth of the elderly population and due to family members no longer wanting to care for elders for whatever reason. She expressed her belief that her family would "step-up to the plate" and care for her, but she still did not want to burden them.

> *The fear is that, uh, when you get old, and you have to depend on other people to take care of your basic needs. I don't want to be a burden on my family, or anyone like that. And I think that the nursing homes are going to become extremely overcrowded because families no longer want to take care of the sick and the elderly. Yes, that's a concern. And at the same time, I don't want to be a burden on my family.*

Healthcare provider meeting elder expectations. Hope described how doctors and nurses can have misperceptions about elders and their reasons for seeking healthcare.

She expressed her perception that healthcare providers can become angry with elders when they do not fully understand why care has been sought. The lack of mutual understanding can lead to elders being dissatisfied with healthcare. Hope expects healthcare providers to develop a thorough understanding of why an elder seeks care; doing so requires developing a relationship and spending time with elders.

> *Um, my concerns with the elderly as a group of people, more or less, don't get the prime medical care that they need. I think that, and some doctors and some nurses, uh, become more agitated with the elderly people because it seems like, at our age, we usually have something wrong with us, and they think that we're just coming to the doctor's office for, I guess, company, or sympathy, or somebody that shows that they care about them.*

Respect. Reflection upon Hope's experiential description revealed two facets of respect. The "two-way street" of respect includes healthcare providers respecting elders and elders respecting healthcare providers. Hope described how healthcare providers can disrespect elders, almost subconsciously, through their tone of voice. Hope also expressed that disrespect on the part of healthcare providers can arise from their personal beliefs that an elder patient makes too frequent visits, wasting their time and resources. Hope expressed how she felt healthcare providers sometimes spoke in a condescending manner, possibly related to their perceptions of why an elder had sought care. She also talked about the demeanor of elders. She expected elders to respect healthcare providers and behave in a socially acceptable fashion.

> *I think that elderly people should be treated with respect. Uh, now, if they come, if an elderly person goes into a facility and they are acting ugly, no, I don't go along with that at all. But, uh, sometimes I, this has never happened to me, but I have seen where elderly people have been talked down to; their tone of voice, I'm talking about the medical personnel, their tone of voice is more harsh, particularly when you have a patient that comes in more frequently than what they think that they should. And they think that they are abusing the medical field.*

I think that they all should be treated with the same respect. Uh, but I failed to see that, particularly with the elderly people.

The future. Hope described the future of healthcare in a range from concerns to worries to fear. Hope expressed a fear of the unknown related to future availability of healthcare. She also talked about how future decisions about healthcare to be made by the American government contribute to her fear. Her fear of the unknown stemmed from her concern that elders may not receive the best care in the future due to multiple reasons, including: financial worries, availability of care, and possible government dictation.

Well, it's a scary thought, um, not knowing what the future holds for the elderly people, that when we become ill, and we can't get medical treatment, that just seems to accelerate, uh, the illness pursuing and cut your life even shorter. And, that is a concern.

The fear that I expressed earlier is, if we go under this Obama-care umbrella, then yes, I think the elderly will be the first ones that come under the highest risk of declining healthcare.

But, what worries me is the insurance of the future is going to dictate a lot of what doctors and nurses can do.

Financial concern. Hope described her perception that elders who have Medicare as their only form of insurance receive sub-par healthcare. She talked about the fact that many healthcare providers no longer accept Medicare as a method of payment. Elders who only have Medicare are left with the responsibility of paying medical bills out of their personal funds. Hope described elders as frequently having insufficient funds to cover the cost of a healthcare provider visit, much less a major procedure. Decreases in insurance coverage have created a burden for elders. Hope also discussed her perception that the insurance of the future could limit availability of care. She expressed her worry that healthcare providers may not administer care as they previously would have due to

financial constraints; thus, further adding to her concern that elders may not receive the care that they should.

> *And the physicians cannot afford to have a practice that's full of elderly people, if they can't meet their, um, their financial, uh, necessities in having medicines and, uh, things to treat people in the office. So, therefore, I think that the elderly people are really not getting what they should, when they only have Medicare insurance. And a lot of the supplements, they do not, the doctor's office, do not accept some of the other supplemental to Medicare, such as: Humana, and there are two or three others that I cannot recall at the present time; and so therefore, it puts a burden onto the elderly people that are living on a limited income of having to pay for their visits up-front.*

> *But, what worries me is the insurance of the future is going to dictate a lot of what doctors and nurses can do. It's going to tie their hands to a lot of situations that otherwise, if we had free choice of insurance, it would not tie the doctors and nurses down to where, um, they could not administer like they would like to.*

Della

The second participant was Della, an 86 year old Caucasian female. Della's residence was in a rural area. She reported that she took six prescription medications. Della visited a healthcare provider 30 or more times in the past year, as she had broken both of her hips and had difficulties in recovery. She remembers being hospitalized 10 times during her long recovery. Della was the least healthy participant interviewed. Although living independently, she required the services of a home healthcare nurse four days a week. She was alone at the time of the interview. Della did not previously work in the healthcare field. The interview took place in the participant's retirement community apartment; the participant and the researcher were seated in her sunroom.

Della talked quite a bit during her interview, but veered off topic frequently. She did not expand on her perceptions very much. Reflection upon Della's experiential description of being an elder in healthcare revealed four themes.

Themes.

Presence and appearance of the healthcare provider matter. Della talked about a doctor that she had seen visiting other patients. The doctor apparently had a very distinctive style of dress; one that Della was unsure if she felt comfortable with. Della was not even sure if the physician was a man or a woman, and that made her uncomfortable. However, Della did not expand on her expectations for a healthcare provider's appearance.

> *But, they have a doctor here. And she was, she, I don't know, somebody's physician; but, it was a man who wears long hair, and uh, earrings. Oh boy, I don't know if it's a man or a woman...Yeah! And she dresses like a man...Well, I'm afraid to say he or she, but gracious me.*

Involvement/Collaboration. Della expressed how she perceived the healthcare team felt involved in her care. She had broken both of her hips due to falls. She described how the long healing process entailed collaboration of many people. She perceived that all of the healthcare providers and professionals working with her were nice. She described her physical therapy, which required involvement and collaboration between her and the people that cared for her. She was pleased with their level of involvement, and even surprised by the therapy methods. She walked on the toes of healthcare professionals so that they could determine if she was appropriately distributing her body weight. She enjoyed the collaboration of physical therapy. She also described how she felt that her healthcare providers were amazed at her progress. She said that their feeling of involvement with her care and life gave them a thrill. Della expects collaboration and involvement between patients and healthcare providers.

> *And they're just so amazed. They're just thrilled to death with it because they feel involved with it; because everyone knows how sick I was, and all that medication... Yeah, everybody's just happy with it. And, every day or two,*

someone mentions, "oh, I'm so proud of you!" I just say, "yes, thank you! I'm proud of me, too."

Meeting the expectations of the healthcare provider. Another aspect of care that Della voiced as important was to keep a positive attitude and use humor to make situations easier. She talked about how she tried to make jokes with those who cared for her to hopefully make their work enjoyable. She also described how she did not want to "gripe." She wanted her healthcare providers to like her and to make their work easier. Della also talked about patience. She knew that she had to be patient with people working with her to ensure good care. Throughout her recovery, she diligently tried to make the work of her healthcare providers easier by meeting their expectations and behaving in manners that she thought they expected from her.

> *And you ought to see that scar that's on my hip! I'll tell you what, you wouldn't believe. The first time I looked at it I said, "Oh! Oh my goodness. I will never wear a bikini again!" And they [the nurses] all fell out. They thought it was the funniest thing.*
>
> *Uh huh. I wasn't "gripey" about it, either. I wanted to be jolly about it and make their work easier... Yeah. They liked me because we were laughing and talking and all that stuff. So, I tried hard to do that and not be "gripey." Or impatient.*

Fear of the unknown. Della discussed her fear of not knowing the world around her. She expressed that she would much rather have a physical injury than an injury that would disturb her ability to think and process thoughts. She realized some of the elders around her had lost their ability to think and know, possibly due to Alzheimer disease or other processes. She fears having to live without mental ability in the future.

> *And then I say, give me broken hips, break my arm or something, but please don't break my mind. There's so many people down here [points to other apartments] who don't know the end of the world. Oh, and it just makes you feel so bad. I kind of felt like a cheat, because I was taking up a bed that somebody desperately needed, more so than I did.*

Alyce

Alyce was an 84 year old Caucasian female. She, too, lived in a rural area. Alyce took eight prescription medications, per self-report. She visited a healthcare provider six times in the past year and was hospitalized twice. Alyce never worked in the healthcare field. Alyce was recovering from a knee replacement. She was living alone in a retirement apartment complex. She has visits from a home health nurse a few times per week. In recent years, Alyce was in poor health. The interview occurred in the participant's living room. The researcher and participant were seated side-by-side in recliner chairs.

Analysis of Alyce's description of her experience as an elder in healthcare revealed five themes.

Themes.

Perseverance. No matter how bad her knee hurt after surgery, Alyce strove to do her best. She discussed the importance of maintaining a physical therapy regimen and remaining confident in her healthcare provider's abilities and suggestions. Over time, Alyce developed a personal form of perseverance related to her numerous surgeries after a boating accident. She expressed that it is up to the individual to decide if they want to get better. If one does want to get better, her expectation is that they will persevere in treatment endeavors and listen to their healthcare provider, no matter what.

> *The exercise and doing what they said, regardless of how hard it hurt or how bad it hurts, that is the worst part. You might think you can't come through it, but you can make it through it. If you don't stand up with the therapy, it wouldn't ever get better. And, uh, so it's very important, very important to stick with your rehab to get over the surgery.*

> *They told me in '71 that I'd never walk again. I walked until the day I went in the hospital and had my knee surgery. So, it's something you have to stick with; if you want it or not. If you want to get over it, you have to do what they tell you and stick with your rehab and just keep working with it.*

Trust in the healthcare provider. Alyce described the theme of trust as having trust in her healthcare providers. She expressed that she knew her recovery and care would not have been the same if she didn't trust her doctors. She felt confident in her doctors' abilities; thus contributing to her trust in them. Alyce described a trustworthy healthcare provider as one who takes the time to develop a relationship with her, which emerged as a separate theme. Upon reflection of her past experience, Alyce described how she knew she would not have made it without trust. She also described another element of trust. She believed that one must have trust in a spiritual being for a full recovery.

> *With your doctors, if you don't have trust in them, you feel like you can't make it. You also have to rely on the Lord to get you through and what you've been through.*
>
> *And so, if I didn't have trust in him, I wouldn't have ever made it. You've got to have trust in them. Sometimes you wonder, but after you get over everything, you stop and think about them and how you had trust in them, or you wouldn't have made it.*
>
> *I was taken care of good. And, uh, you just have a lot of things to accept, I guess. And, you have to go along with everything; everything don't just go as planned or go right the first time. You just have to have trust in people and know that they are doing right.*

Support. Two forms of personal support in healthcare were described by Alyce. She discussed familial and divine support. Alyce sought comfort in her religion and in her family, particularly her grandchildren, when recovering from her numerous critical surgeries. Between the two, she felt satisfied and strengthened in her efforts. Alyce also described her perception of the importance of supporting healthcare providers. Without support from elders who need so much healthcare, Alyce felt that care would decline. In

order for care to remain at an appropriate level, she stressed the importance of patients and healthcare providers supporting each other in all endeavors.

> *So, it's, uh, all the surgeries I've had have been bad surgeries. So, I know that if I didn't have the Lord with me, that I wouldn't have made it through. Between that and my grandchildren; they've made me get through in life.*
>
> *Only that, uh, we have to let them know how we feel about it because we've got some fine doctors and nurses out there. And, uh, they're going need our help, and we need their help; if we don't stick with them, it's not going to hold our healthcare up as good as it should be. It's an important thing, especially since I've gotten to where I need so much healthcare. It makes you stop and think more about it.*

Taking the time. The element of time that was important to Alyce was taking the time to develop a relationship with her. She described a healthcare provider that she thought highly of. He took the time to make her feel important and develop a relationship with her before and after their visits. Alyce said that her doctor would talk with her about whatever she desired, no matter if it was healthcare related. The time that he spent with her also contributed to her trust in him; she said that if he hadn't spent time with her and made her feel valued, she probably would not have been so open and sociable. Alyce also described how her physician did not make her feel rushed. She perceives that valuing patients' time and answering all questions without a hurried demeanor contributes to the level of trust.

> *Well, he takes time with you. He'll sit and listen to you. And, he'll work with you in any way that he can. But, he's a person that just sits down, and after you get through with the business part, if you want to talk about fishing or hunting or something, we sit down, and we talk about it. And, he rides horses a lot. So, we sit, and we talk about things like that. But, I think that if I didn't have trust in him, I wouldn't be able to sit down and talk about things besides my surgery. So, he's always been very polite, and if it takes thirty minutes to answer your question, he'll take it. He don't try to slide you through, but he'll take that time and listen to you. So, I feel like that's what made me have so much trust in him.*

Another facet of taking time that was described by Alyce was within younger generations. She talked about younger people not having time to fully keep up with the changes in healthcare and the effect on elders. She perceived that younger people have the ability to understand the changes, but simply do not have the time to investigate future effects on the elderly population due to busy schedules, school, and lifestyles.

> *They just don't want to take time, or they think, you know, they can just go to healthcare and it's all over with. But, it's more than that...But, uh, it isn't that they don't understand; they just don't have time. Maybe they think that they'll probably pick that on up later, you know.*

The future. Alyce described her worry for the future. Her worry was related to politics and upcoming changes within the American healthcare system. She hopes that people will work together to reach a common goal and uphold healthcare to high standards. She also talked about the financial aspect of healthcare. She perceives that financial changes and possible decreases in insurance could harm the healthcare system and bring it to an unsatisfactory level. Alyce expressed her appreciation and hope that doctors and nurses will continue to dedicate their interests to their patients and strive to uphold the healthcare of the future.

> *I think we've got a lot of improvement in healthcare to go. And, I worry right now if we're going in the right direction and a lot of things to be voted on. It's going to be a very important thing when it comes election time. And, uh, a lot of things that needs improving; that if people don't stick together, it might not go that good.*
>
> *But, it's, I don't think the healthcare, only the financial part that's going to be affected; it's going to hurt healthcare. I hope it don't. I hope and pray that it don't go that, goes that bad that our healthcare don't stay up to like it is now or get better.*
>
> *You know, if it wasn't for them, we probably wouldn't have any healthcare or any good healthcare. If it wasn't for the nurses that dedicate their lives and the doctors that dedicate their lives, uh, we'd really be hurting in our healthcare. And, it worries me a lot, since I am affected a lot by my healthcare.*

Moe

The fourth participant interviewed was Moe, an 87 year old Caucasian male. He resided in a rural area. Moe took four prescription medications and had contact with a healthcare provider four times in the past year. He had no hospitalizations. Moe previously worked in a healthcare position; he conducted extensive research. Moe was a very healthy elder. He was very active in his community and had numerous hobbies. The participant and researcher were seated at a conference table in a private counseling room at a local hospital during the interview.

Moe's previous work experience made him very knowledgeable of healthcare processes and current changes. Analysis of Moe's experiential description of being an elder in healthcare revealed four themes.

Themes.

Time. Moe discussed two aspects of time. The first element was taking away time. Moe talked about the importance of healthcare procedures being performed on schedule and in a timely manner. He also mentioned that he wanted to be informed of progress, which keeps him enlightened and confident that procedures go as expected. Moe described his perception that his time was taken away whenever there was a delay in care delivery. He perceived that a life or death situation was the only way to increase the current speed of care delivery. He also stressed that the availability of care, more so than the quality of care, was declining; thus, taking away from his time. He further emphasized that his expectations were being met in current healthcare, but he felt disturbed by the possibility of longer waiting times and further delays in the delivery of healthcare if changes are made within the American healthcare system in the years to

come. He compared this concern other countries' healthcare systems and the delays that are experienced there. Excessive paperwork was another factor that Moe contributed to taking away from his time.

> *The efficiency of it; everything went accordingly to what time they said it would and keeping me informed in the process. It was; she was up and around within a few hours.*

> *That's my perception that it has to be a life or death situation to get in touch with them. They are so busy and underpaid, I might add, that the availability, more than the quality, that delivery or fairly rapid delivery of services has deteriorated some.*

> *I think the hospital and the staff reach all of my expectations. I do feel that it is going to be longer and longer and longer waits, and longer lines, and longer and more and more stacks of paper. And one thing that irritates me; signing all those papers that the law and regulations have placed on them and are required to have... But uh, the time delay in healthcare delivery, I perceive is going to be longer and longer. And, that disturbs me, particularly if you've got surgery and you don't want to worry about: "have I got to wait a week or two weeks or a month?" Like in Canada, if you're going to be on the healthcare government system, unless you have a life or death emergency or surgical procedure or whatever, it takes you six months sometimes even for minor surgery, but it takes that long to get.*

The second aspect of time described by Moe was taking the time. He described how it bothered him when healthcare providers did not take the time to get to know him as a person, not just as a patient. He related his experience to his visits with Hospitalist physicians. Hospitalists only see patients in the hospital; their case-load and work schedules change daily. This poses a problem when patients expect healthcare providers to spend time with them. Moe expressed concern that they did not take the time to get know him on a deeper level like his primary physician did. Moe was worried about healthcare providers' level of interest in him and his lifestyle. He expressed his personal difficulty with trusting healthcare providers that had not spent appropriate time with him or developed a relationship, which emerged as a separate theme.

It does bother me, somewhat considerably, the, uh, hospitalists. He doesn't know me; I don't know him. I seem him today; I don't know if I'm going to see him tomorrow. That really concerns me. You go to the hospital now, and you don't see your doctor at all, unless he just happened to drop by.

So, I'm not worried about the professionalism of the person, but uh, their level of interest in me as an individual, since he doesn't know me from Adam. So, it's kind of hard to realize that the person taking care of you is a total stranger.

Trust in the healthcare provider. Moe described trust in his healthcare providers as a reassuring factor. His trust arose from feelings of confidence in his healthcare providers' abilities and knowledge. He discussed his perception that healthcare providers must also be confident in their own abilities to gain the trust of elders. He expects healthcare providers to outwardly display confidence to foster the growth of trust; thus their presence and appearance matter.

Confident, and I felt like everybody knew what they were going to do; they were prepared to do it and do it well. And, uh, after the result, they came out and said everything went according to the procedure, which was reassuring.

It's just that I like the idea that everybody knows their profession and knows when they're going to do it and do it well.

That they feel confident enough in themselves that they don't have to worry about things coming up that they haven't experienced before. It's a self-confidence that is assurance that they are going to do their job; within themselves, they feel that skilled. And, when they give you a talk beforehand, most doctors will come in and see you, they exude an air of confidence that I can detect whether or not they're for real. And, it's uh, reassuring.

Presence and appearance of the healthcare provider matter. Presence and appearance of the healthcare provider was important to Moe. He believed that they should not only outwardly display confidence, but they should also have a reassuring demeanor. Moe said that their actual style of dress did not matter to him, but the way that they presented themselves did. Moe expected to receive truthful information from his healthcare providers and personally feel confident with the way it was presented. His

experience included nonverbal communication; they [his healthcare providers] "exuded an air of confidence."

> *Not their dress, but their demeanor in the interview; telling me what they are going to do and doing it and telling you if they had a problem during the surgery.*

The future. Moe's description of the future of healthcare revealed a range of feelings from concern to worry to fear. He also described several different elements of future care that were concerning to him. The first element of future healthcare Moe discussed was his perception that elders may not receive the care they need and deserve. This discussion included his discouragement related to possible changes in government involvement with healthcare. He perceived that government involvement would harm the American healthcare system and decrease the current level of care delivered to elders.

> *Where we're headed, I'm very discouraged about what I perceive to be headed. Uh, government-run healthcare is just what it sounds like; it's government-run. And already, there is deterioration in the delivery of certain levels of healthcare. It's getting almost impossible to, or appears to be getting more impossible, to see doctor other than for an appointment.*

Moe also described how the future of healthcare may have severe implications when it comes to filling out paperwork. Moe perceived that the amount of paperwork would be increased in the future and could possibly put elders' lives at risk. He described this perception as a fear.

> *Almost like healthcare will be unavailable. At my age, if have a problem, it's usually going to be serious...I have a DNR. But, if I am resuscitatable, so that I can be resuscitated, then I want that done with speed. And, I'm getting more and more fearful that just before they can engage in saving my life, they've got to fill out a bunch of papers. And uh, I think that is going to be an increasing problem.*

The final aspect of the future described by Moe was his concern that there could be a decline in the number or quality of healthcare providers. This concern was related to his perception that financing for healthcare will continue to decrease. A possible decline

in financing for healthcare may mean that elders will not receive the care they need or deserve in the future, except from providers who are truly interested in elders.

> *So, I think right now I have a perception that the healthcare system isn't going to be nearly as good as I know it is now. It's going to deteriorate. Why would a person go into medical school with no real incentive, except for the rare person that really wants to help people, not the money?*

Sally

Sally was 77 years old and African American. She resided in a rural community. Per self-report, she had three medications prescribed to her, saw a healthcare provider three times in the past year, and had no hospitalizations. Sally had previously worked in the healthcare field. She was a healthy elder, with no health complaints. She, too, was very active in her community. Sally was interviewed alone in a private conference room at a local hospital. Both participant and researcher were seated at a table.

Sally was very soft-spoken and answered questions posed by the researcher in few words. Three themes were revealed through reflection upon Sally's description of being an elder in healthcare.

Themes.

Taking the time. Sally described the importance of healthcare providers taking the time to have a genuine conversation with their patients. She also mentioned how she has detected healthcare providers not truly listening to her, making her feel unimportant. To enhance her level of trust, Sally expected healthcare providers to take the time to listen and to be cognizant of nonverbal language. Taking time with an elder involves developing a relationship, displaying care, and finding a thorough understanding of why they sought healthcare.

Uh, sometimes you may go to the doctor or what have you, and they don't seem to listen to you. Uh, they don't have the time to listen to you. They say, "Hi, how are you doing?" And while you're explaining, they stop you. And before you know it, they're gone. So, I think that's not good.

Healthcare providers' trust in the elder. Sally described her experience when healthcare providers did not trust her. In order for good care to occur, trust must exist between both parties involved. Sally described how everyone was nice to her during her recovery from surgery, but the niceness was short-lived. She believed that her surgery had left her physically damaged; however, her doctors and nurses did not. During the course of her care, Sally perceived that her healthcare providers did not trust in her or her opinions. Eventually, she felt like they were trying to convince her that perceived physical damage was only in her mind. She was very dissatisfied with the care she received because she felt that no one trusted her or her thoughts.

Everybody was real nice, but eventually they made me feel like it was in my head. They made me feel like I was losing it, and I wasn't losing it.

Healthcare provider's respect for the elder. Sally's description of respect was related to her healthcare provider's respect for her. She talked about an experience where she had investigated the side effects of a medication prescribed to her. Her healthcare provider was disrespectful to her by telling her that she "reads too much." The healthcare provider blocked therapeutic communication and dissolved an educational opportunity by being disrespectful.

She further emphasized the healthcare provider's disrespectful comment by stating that the medications were going to affect her body. Sally felt that it was important for patients to be active participants in their care because providers are only human and may leave something important out.

I can look up something; they've got the printouts right there. And, sometimes if you ask, they'll tell you about it, but they may miss something. That's why I read the side effects. If you go and read the side effects, they say, "You read too much." But those pills are going in my body.

Sally also described some of her expectations of a healthcare provider, including respect. An element of respect important to Sally was effective and therapeutic communication. Sally expected healthcare providers to be specific when describing a treatment plan, but to also respect her by speaking on her level and ensuring that she understood what was communicated.

I like to be treated fairly. I would like for you to be nice to me and gentle with me. And, when you tell me if you have a plan, be specific. Use terms that I can understand, instead of medical terms that I don't know what you're saying.

Ron

The sixth participant was Ron. Ron was a 72 year old African American male. He had a rural residence. Ron reported that he took five prescription medications and saw a healthcare provider five times in the past year. He had one hospitalization in the past year. Ron had not worked in healthcare. He was a healthy and active elder; teaching local health classes and participating in exercise groups. He was also an active member of the local *Mended Hearts* support group for post-cardiac surgery patients. Ron was interviewed at a local hospital in a private counseling room. The researcher and participant were seated in facing chairs.

Reflection on Ron's experiential description of being an elder in healthcare revealed five themes.

Themes.

Time. Ron described time in two different ways. Time being taken away was the first aspect that Ron discussed. Ron appreciated that his procedures and the healthcare

staff working with him were on time. He perceived long waits as taking away from his time, for they added to his nervousness.

> *Uh, the response from all personnel; from the nursing staff, to the doctor, and the tests that were given. Everyone was, uh, I say punctual... For one, I think it's great because it's a soothing, calming effect. It removes nervousness.*

Ron also described time in the form of health providers taking time with him. He talked about the importance of healthcare providers not rushing through an assessment. He expected them to take the time to develop a thorough understanding of the situation at hand and not rely too much on past experiences. Ron also described his experience with a healthcare provider who took the time to develop a relationship with him. He felt that the encounter fostered his development of trust in the healthcare provider, which emerged as a separate theme.

> *If they come in and seem to be in a hurry; they don't take the time to listen. Uh, each situation is different because he might have had a similar infraction, the solution might be different. I'm saying, don't come in cocky, that "I know the answer and this is the only choice I have." Make an assessment and an evaluation and then discuss it with the patient.*

> *The most reassuring fact was that I had met Dr. Deese about a month earlier. We were just talking in general; never knowing that I'd ever see him as a doctor.*

Trust in the healthcare provider. Ron's trust in his physician was established when he realized that his physician had the same religious beliefs as he did. He described the feeling as reassuring to know that he could trust his doctor. Ron felt confident in his physician's abilities, which further contributed to his trust. The healthcare provider's communication skills and sharing of personal beliefs were effective in securing the trust of the patient in this particular situation.

> *And the things that were most important in that particular conversation was, uh, I believe he was a Christian, and he asked me, "was I?" And, he said that my procedure would be one that he felt comfortable with, but nothing is always the*

same, but he felt comfortable that I would be okay. After realizing who he was, when I had met him, and with him explaining the way he did, I was ready to have the procedure then.

Regardless of your religious beliefs, and I can only speak from a Christian point of view, but if you are a believer, and you're dealing with someone who is a believer, that's a reassuring factor. It's a comforting factor. So, I think religion does, and being Christian, it does have importance. I would hate to see a man in a red suit and a pitchfork enter here; that's for sure.

Meeting expectations. Two sides of meeting expectations were described by Ron. The heath care provider should meet the elder's expectations and vice-versa. Ron talked about a time when his expectations were met by healthcare providers. Fully answering his questions and keeping him enlightened of his plan of care were important factors. He also described how healthcare providers need to understand their patients on a deeper level and develop a relationship with them. Acting appropriately depending on the context and location of care delivery were also elements that Ron expected to see in healthcare providers.

Everyone answered all questions asked. And, I was constantly being reassured by being made aware of what was going on. Uh, I wasn't left in the dark where I didn't know what they were going to do next; that type of situation. I had a good comfort with the staff and personnel.

I think what I'm saying is, the medical profession must be wary of who they are talking with; time, conditions, to make an honest assessment to where you don't put one into a state of fear. On the other hand, I wouldn't expect somebody to come up and see an arm hanging off and say, "Oh, what did you do? You shouldn't have done so and so." Assess the situation and put a calming effect to the situation.

Ron also described how elders can meet the expectations of healthcare providers. He felt that patients should be active participants in their care and learn as much as they could. He perceived that healthcare providers in all forms of practice expect their patients to be able to describe their condition in a relatable manner. In order to meet healthcare

providers' expectations for a patient, Ron felt that people should read as much as possible and develop a partnership.

> *I think, um, just the general public, if they would pay more attention to publications and pamphlets, blurbs, newsletters, uh, handouts, and realize that their care is dependent upon their involvement. If the general public would be more involved, themselves, I think that would be a factor that would help the medical profession greatly.*

> *I think on the front end, the patient should be more involved, and that way they can relate their conditions to, uh, their primary physicians and/or people they will encounter and are involved with later. To be able to express yourself, I can't say in common language, but just be able to express your symptoms in a manner that you can relate to something that I read, I know, or I've heard; something that would be most beneficial.*

Presence and appearance of the healthcare provider matter. Ron talked about his expectations for a healthcare provider's appearance. He appreciated a simple and professional style of dress. Ron described his perception that white coats and stethoscopes were only "power symbols." He preferred a clean and tailored appearance.

> *Their attire, their appearance: clean dress, not hanging off; those are factors that impress me more than somebody just having a white jacket on and a stethoscope hanging down your back. Uh, if you have a business professional appearance, that means a lot to me.*

Ron also described how the presence of a healthcare provider is important, too. Nonverbal communication was viewed as important as the spoken word. Ron liked to see healthcare providers who appeared confident with their abilities and displayed confidence in their demeanor. He also described presence as being able to provide appropriate answers to questions and engaging in truly therapeutic communication.

> *If they don't say it, just their presence is a reassuring factor, which helps to relax and calm a person. Uh, sometimes the unspoken word is just as seeing what somebody said; it's reassuring.*

I like to see and feel that the person that's attending to me is knowledgeable and visible with what they are doing. No matter what questions you ask, they have an answer that you feel comfortable in receiving.

Healthcare provider's respect for the elder. Respect on behalf of the healthcare provider was important to Ron. He described an experience when he felt respected by a healthcare provider. The physician provided Ron with choices and respected his abilities to make decisions for himself. The physician also allowed him time to discuss his options with family, a gesture that Ron perceived to be of utmost respect, as his family was very important to him. Another experience that Ron discussed was when he was encouraged and allowed to progress at his own pace after surgery. In that particular experience, Ron felt respected because of the level of understanding, compassion, and respect for time exhibited by his healthcare providers. He also expressed the importance of not being left alone. Ron liked being checked on by healthcare providers; it reassured him and helped him to feel respected.

But uh, as we talked, he explained to me what the test results were. He gave me a choice. He said that I needed to take the time to make an honest evaluation He pointed out the fact that it was important, but not urgent. He recommended that I do it, but he gave me time to talk with my wife and my family.

Everyone was compassionate. Everyone understood, and everyone let me progress at my level of comfort, but they also pushed me, which is sometimes necessary to make patients realize that you're not an invalid because you had a procedure; you still have to do some things on your own. And, it wasn't a rush, rush, "you've got to do it now." I was allowed to function at my own level; that was good.

Just open communication. Uh, not being just left in a room. Allowing any family or friends that come to visit. Just seeing medical staff come to check on you; they come by a do a reassuring statement. That helps to relax you and put you mind, as well as your body, at ease.

Belle

Belle was 77 years old, Caucasian, and female. She lived in a rural community. Belle was not hospitalized in the past year. Belle reported that she took no prescription medications and had visited a healthcare provider three times in the previous year. She had retired from healthcare as a Registered Nurse in the pediatric field. Belle was a healthy elder, without report of any major illness throughout her life. The participant was interviewed alone in her home. The interview was completed with both participant and researcher seated at the kitchen table.

Belle's nursing experience allowed her to discuss various medical procedures and disease processes in great detail. Because she personally did not have a lot of experience as a patient, she described numerous cases that she had seen. Analysis of Belle's experiential description of being an elder in healthcare revealed three themes.

Themes.

Trust in the healthcare provider. Belle's trust in her healthcare provider was established on a basis of confidence. She felt confident in his abilities. She also sensed empathy in her healthcare provider, enhancing her relationship and trust in him.

> *Well, it was uh, I mean, he had good rapport with people, and he explained stuff very well. And his technique, apparently, was good; he never did hurt. He apparently put a little Xylocaine in before he stuck me. So, it was good.*

The future. Belle's perception of the future of healthcare revealed concern for finances. Not knowing the future of insurance coverage concerned her because several members of her family required a lot of medical care. She did not know how they would afford the medical care they needed without sufficient coverage. Belle expects there to be changes in insurance coverage, especially for those who have previous illness. Since one

of her family members has multiple sclerosis and another has cystic fibrosis, she is very concerned for their welfare in the future.

> *Well, uh, not actually healthcare, but our insurance is really getting to be a problem. And I don't know, we may end up without anything. I mean, who knows? I have a daughter-in-law that has MS, and she has medicine that she takes IV like every three weeks or something. But you know, as long as she doesn't have any symptoms, she'll take it. That's another big cost, and if she ever, or [Wayne] ever goes somewhere else, they may not insure her. Of course, you never know. And, that's back in their mind, as well as everybody that cares for them. It's just like [Ben], you know if he can't...but, if they could just pass that part that says "no previous illness," to where it would cover previous illness. But, it's been that way forever, you know, and that's really nothing new.*

I don't want to be a burden. Belle discussed two ways that she did not want to be a burden. She did not want to bother people with having to take her to and from visits with a healthcare provider. The experience she described was when she received spinal blocks and had to depend on someone else to take her to get them. She perceived that the burden of making arrangements to receive the shots outweighed the actual benefits of the medication.

> *The physician that did them did a great job, but you know, it's going and getting it done and somebody has to take you home because they sedate you a little bit. And, it's not worth it, but I know it does help some people.*

Belle also did not want to burden her family in her older age. She expressed her concern for their busy schedules and lifestyles. Belle's hope is to maintain her independence for as long as possible.

> *And they're all so busy, you know. I don't want to be a burden on them one day. I don't want that.*

Mike

The last participant was Mike. Mike was a 71 year old Caucasian male. He resided in a rural area. Per self-report, Mike took six prescription medications and had

ntact with a healthcare provider 20 or more times in the past year. He was hospitalized ree times in the past year. Although he had some health issues in the previous year, Mike could be considered as quite healthy. He still has a full-time job, works a lot of over-time, and has no plans of retiring. Mike had not previously worked in healthcare. The interview took place in the participant's home. The researcher and participant were seated in the living on the sofa at the time of the interview.

Reflection upon Mike's description of his experience as an elder in healthcare revealed four themes.

Themes.

Taking away time. Mike felt that his time had been taken away from him when he visited the emergency room. The delay in care caused Mike to feel unimportant and like his emergency was trivial. His pain was inadequately controlled. Excessive paperwork and strict regulations further contributed to Mike's perception that his emergency was being treated inappropriately.

> *I had two visits to the hospital, uh, to the emergency room. That experience wasn't the greatest. It appeared to me that there was not enough urgency. Maybe it was just this particular hospital; I'm not sure, but it seems to me that there should be more urgency in an "emergency" room.*
>
> *Well other than the fact that it was, again, the lack of urgency. And, uh, at one point, I was in pretty severe pain. It appeared to me that, uh, there was too much, too many administrative things that had to be done before they could give me something for the pain. They had to go through too many processes, and too many people had to approve it and all of that kind of thing; which, maybe that's a good thing. Maybe there are good reasons behind that, but uh, it appeared to me that something could have been done a little quicker.*

Trust in the healthcare provider. Mike was confident in his doctors' abilities, for he had chosen to visit them based on their credentials and level of expertise. His trust was established after researching the healthcare providers and evaluating their reputations.

Mike's trust was also related to his respect for individuals who devote their lives to the medical field and the pursuit of saving lives.

> *Well, I have been particularly selective. In other words, the doctors that I go to, I have a lot of confidence in because I've asked questions. I try to find doctors that have a good reputation for their particular field.*
>
> *And again, as I mentioned earlier, I try to pick doctors that I have researched a little bit about. And uh, the ones that I've had, I have a lot of respect for because they appear to be dedicated. They have a reputation for, uh, excellence in their field.*
>
> *You know, you feel like you've got people who are really dedicated and educated and care about their patients and care about their profession. So, I feel good about it.*

Mike described an experience he had with a neurosurgeon. He was confident in the doctor because of his reassuring communication skills. His trust in the neurosurgeon further developed when he realized that what he had been told about his surgery was precisely what happened.

> *The more recent doctor I went to is well known. He's a neurosurgeon, and I had a back problem. He told me when I was being examined and prepped for surgery, he said, "Look, I do this all of the time. This is not an operation that I feel uncomfortable. I've done thousands of them. When I do this procedure and get you healed and get your stitches out, you won't be back." He had a lot of confidence, and so far, he was right.*

Healthcare provider meeting elder's expectations. Mike set his expectations for his healthcare providers very high. He wanted the best care he could receive; his insurance allowed him that luxury. Mike expected his healthcare providers to come from prestigious medical schools. Knowing their background enhanced his confidence in their abilities. Mike also expected a healthcare provider to be reputable in their field.

> *And uh, I was impressed that this particular orthopedic surgeon went to school at Vanderbilt; did a fellowship at Harvard. I mean, what better credentials can you ask for than that? And uh, his reputation for what he does is all good.*

The future. Mike described his perception of the future as concerning. He perceived the possibility of a decline in the number or quality of healthcare providers. Mike expressed his strong desire to retain the ability to choose healthcare providers. He attributed the possible decline in the quality of providers to doctors who come from foreign countries to the United States. He did not feel the same confidence in their abilities as he did in American physicians. He perceived that their educational programs were not as rigorous as American course of study. He also perceived that physicians from foreign countries do not have the same level of dedication as American physicians due to their willingness to leave the care of their home population to others in pursuit of money. Mike was concerned that he may not receive the care he needs and deserves in the future.

> *Now, one of the concerns I have is that, uh, as we become more socialist in our country; I'm really concerned about socialized medicine because if we do have socialized medicine, it's going to limit who you can see. I want to be able to pick the doctor I go to. I don't want some government agency telling me who I've got to see. And, furthermore, I think if we become socialized in medicine, we're going to uh, we're going to see lesser quality doctors. I think we are going to have a lot of doctors coming in from other parts of the world and all that. So, I think that's not something that I would want to see.*
>
> *Well, I feel like that, uh, if, in fact, our system becomes like Europe...at least right now, people in Europe and people in Canada who have socialized medicine, if they need a serious operation, and they want to pick their doctor; they come to the United States to get it done. If we become socialist, where are we going to go? There's no place left. And again, we'll be back to having doctors who are not the best and brightest. A lot of doctors will come from foreign countries, and you don't know what you're getting there. And uh, most of us people in this country would prefer not to see doctors from Middle-Eastern countries or India or any of these other places. It's not to say that they are not really bright people. There's a few pretty bright people over there, but I just don't think that they have the same entry. I don't think that they would be as dedicated to healthcare as the people that I would like to see. For example, if they were, why wouldn't they stay in their own country and take care of their own people? They came here to make more money. Now, under socialized medicine, they are not going to make the money, and that's why the best and brightest in country probably won't take up the profession; not as many of them.*

Summary

This goal of this study was to describe the experience of being an elder in healthcare and to reveal elders' perceptions and expectations. Each participant's experiential description was analyzed for themes. The essential themes derived from analysis are presented in Chapter 5.

CHAPTER 5

Findings

The purpose of this study was to explore the perceptions and experiences of elders concerning healthcare. The essential themes, subthemes, and expectations derived from analysis are presented in this chapter. Italicized quotes from participant interviews will be included to exemplify the themes. Upon further reflection and analysis, three essential themes and ten subthemes were identified (Table 3). Elders' expectations of healthcare will also be discussed. The questions that guided the research were: (1) what is the elder perception of healthcare, and (2) what is the elder expectation of healthcare?

Research Question 1
Essential Themes and Subthemes

1. The future

The future emerged as a common essential theme. The elders were cognizant of political changes that could affect their healthcare. They openly voiced their opinions of the political side of healthcare. The elders' descriptions of the future ranged from having concern, to being worried, to experiencing a state of fear. One subtheme of the future was concern for the future care of elders. Some participants were not sure if healthcare for elders would remain at an acceptable level. Concern that they may not receive the care they need or deserve in the future was related to the other subthemes.

I think we've got a lot of improvement in healthcare to go. And, I worry right

Table 3. Essential Themes and Related Subthemes

THEMES	SUBTHEMES
1. The future	Concern for the future care of elders Financial concern Possible decline in the number/quality of healthcare providers Fear of the unknown
2. Time	Taking away time Taking the time Remaining time Perseverance
3. Trust	Respect Meeting expectations

now if we're going in the right direction and a lot of things to be voted on.It's going to be a very important thing when it comes election time. And, uh, a lot of things that needs improving; that if people don't stick together, it might not go that good.

Where we're headed, I'm very discouraged about what I perceive to be headed. Uh, government-run healthcare is just what it sounds like; it's government-run. And already, there is deterioration in the delivery of certain levels of healthcare. It's getting almost impossible to, or appears to be getting more impossible, to see doctor other than for an appointment.

Now, one of the concerns I have is that, uh, as we become more socialist in our country; I'm really concerned about socialized medicine because if we do have socialized medicine, it's going to limit who you can see. I want to be able to pick the doctor I go to. I don't want some government agency telling me who I've got to see. And, furthermore, I think if we become socialized in medicine, we're going to uh, we're going to see lesser quality doctors. I think we are going to have a lot of doctors coming in from other parts of the world and all that. So, I think that's not something that I would want to see.

Financial concern was also quite evident in analysis. They expressed concern for being able to pay for the healthcare they may need in the future. They expressed a perception that elders will require increasing amounts of healthcare as they age and develop more serious illnesses. Not being able to afford necessary care would create a burden for the elders.

> *And the physicians cannot afford to have a practice that's full of elderly people, if they can't meet their, um, their financial, uh, necessities in having medicines and, uh, things to treat people in the office. So, therefore, I think that the elderly people are really not getting what they should, when they only have Medicare insurance. And a lot of the supplements, they do not, the doctor's office, do not accept some of the other supplemental to Medicare, such as: Humana, and there are two or three others that I cannot recall at the present time; and so therefore, it puts a burden onto the elderly people that are living on a limited income of having to pay for their visits up-front.*
>
> *But, what worries me is the insurance of the future is going to dictate a lot of what doctors and nurses can do. It's going to tie their hands to a lot of situations that otherwise, if we had free choice of insurance, it would not tie the doctors and nurses down to where, um, they could not administer like they would like to.*
>
> *But, it's, I don't think the healthcare, only the financial part that's going to be affected; it's going to hurt healthcare. I hope it don't. I hope and pray that it don't go that, goes that bad that our healthcare don't stay up to like it is now or get better.*
>
> *Well, uh, not actually healthcare, but our insurance is really getting to be a problem. And I don't know, we may end up without anything. I mean, who knows?*
>
> *I have a daughter-in-law that has MS, and she has medicine that she takes IV like every three weeks or something. But you know, as long as she doesn't have any symptoms, she'll take it. That's another big cost, and if she ever, or [Wayne] ever goes somewhere else, they may not insure her. Of course, you never know. And, that's back in their mind, as well as everybody that cares for them. It's just like [Ben], you know if he can't...but, if they could just pass that part that says "no previous illness," to where it would cover previous illness. But, it's been that way forever, you know, and that's really nothing new.*

The participants also described a concern for the future quality of healthcare providers. A possible decline in the number or quality of healthcare providers was

attributed to a lack of incentive to go to medical school if the current level of healthcare reimbursement is not changed. Another factor discussed by one participant was the influx of healthcare providers from foreign countries. The participant perceived that healthcare providers trained in other countries were not as highly educated or dedicated as American doctors; thus, a decline in quality would occur if the majority of doctors in the U.S. were from other countries. Both participants discussed the need for better reimbursement to ensure the best healthcare providers will remain in practice.

> *So, I think right now I have a perception that the healthcare system isn't going to be nearly as good as I know it is now. It's going to deteriorate. Why would a person go into medical school with no real incentive, except for the rare person that really wants to help people, not the money?*

> *Well, I feel like that, uh, if, in fact, our system becomes like Europe...at least right now, people in Europe and people in Canada who have socialized medicine, if they need a serious operation, and they want to pick their doctor; they come to the United States to get it done. If we become socialist, where are we going to go? There's no place left. And again, we'll be back to having doctors who are not the best and brightest. A lot of doctors will come from foreign countries, and you don't know what you're getting there. And uh, most of us people in this country would prefer not to see doctors from Middle-Eastern countries or India or any of these other places. It's not to say that they are not really bright people. There's a few pretty bright people over there, but I just don't think that they have the same entry. I don't think that they would be as dedicated to healthcare as the people that I would like to see. For example, if they were, why wouldn't they stay in their own country and take care of their own people? They came here to make more money. Now, under socialized medicine, they are not going to make the money, and that's why the best and brightest in country probably won't take up the profession; not as many of them.*

Fear of the unknown was another subtheme of the future described by the participants. One participant described this fear as losing her ability to think and know. She was afraid of losing her independence. Another participant described her fear of elders not being able to obtain medical care. She perceived that younger individuals would be treated with priority over elders under a new healthcare system. Fear of

experiencing a delay in initiating life saving measures due to excessive regulatory processes and paperwork was expressed by another participant.

> *And then I say, give me broken hips, break my arm or something, but please don't break my mind. There's so many people down here [points to other apartments] who don't know the end of the world. Oh, and it just makes you feel so bad. I kind of felt like a cheat, because I was taking up a bed that somebody desperately needed, more so than I did.*

> *Well, it's a scary thought, um, not knowing what the future holds for the elderly people, that when we become ill, and we can't get medical treatment, that just seems to accelerate, uh, the illness pursuing and cut your life even shorter. And, that is a concern.*

> *The fear that I expressed earlier is, if we go under this Obama-care umbrella, then yes, I think the elderly will be the first ones that come under the highest risk of declining healthcare.*

> *Almost like healthcare will be unavailable. At my age, if have a problem, it's usually going to be serious…I have a DNR. But, if I am resuscitatable (sic), so that I can be resuscitated, then I want that done with speed. And, I'm getting more and more fearful that just before they can engage in saving my life, they've got to fill out a bunch of papers. And uh, I think that is going to be an increasing problem.*

2. Time

The concept of time was very prominent in the participants' experiential descriptions. The common essential theme of time emerged in participant narratives as four subthemes during analysis.

The first subtheme of time identified was taking away time. The participants described how their time was taken away when they experienced a delay in care or long waiting periods. Long waiting times and resulting dissatisfaction were explained by comparison to other countries' healthcare systems. Healthcare providers' punctuality and maintenance of correct schedules were important factors to the participants. They also

perceived that the large amount of paperwork required by the American healthcare system took away from their time.

> *I always feel sorry for them. Uh, sometimes their family member will just drop 'em off at the doctor's office, and they take off, and they have to sit out in the waiting room, waiting for someone to come back and pick them up.*

> *Healthcare, to me, means that when I am ill or I have a discomfort, sick, and I go to an emergency room or to see a doctor, my expectation is that they're going to not delay in seeing me, and when I get there, that I don't have to sit out in a waiting room, when I'm sick with probably a fever or diarrhea or something and expose the other patients that are sitting in the waiting room. I would expect that they would get me into a room by myself, and that way there would be less contamination among the other people in the room.*

> *The efficiency of it; everything went accordingly to what time they said it would and keeping me informed in the process. It was; she was up and around within a few hours.*

> *That's my perception that it has to be a life or death situation to get in touch with them. They are so busy and underpaid, I might add, that the availability, more than the quality, that delivery or fairly rapid delivery of services has deteriorated some.*

> *I think the hospital and the staff reach all of my expectations. I do feel that it is going to be longer and longer and longer waits, and longer lines, and longer and more and more stacks of paper. And one thing that irritates me; signing all those papers that the law and regulations have placed on them and are required to have... But uh, the time delay in healthcare delivery, I perceive is going to be longer and longer. And, that disturbs me, particularly if you've got surgery and you don't want to worry about: "have I got to wait a week or two weeks or a month?" Like in Canada, if you're going to be on the healthcare government system, unless you have a life or death emergency or surgical procedure or whatever, it takes you six months sometimes even for minor surgery, but it takes that long to get.*

> *Uh, the response from all personnel; from the nursing staff, to the doctor, and the tests that were given. Everyone was, uh, I say punctual... For one, I think it's great because it's a soothing, calming effect. It removes nervousness.*

> *I had two visits to the hospital, uh, to the emergency room. That experience wasn't the greatest. It appeared to me that there was not enough urgency. Maybe it was just this particular hospital; I'm not sure, but it seems to me that there should be more urgency in an "emergency" room.*

Well other than the fact that it was, again, the lack of urgency. And, uh, at one point, I was in pretty severe pain. It appeared to me that, uh, there was too much, too many administrative things that had to be done before they could give me something for the pain. They had to go through too many processes, and too many people had to approve it and all of that kind of thing; which, maybe that's a good thing. Maybe there are good reasons behind that, but uh, it appeared to me that something could have been done a little quicker.

Taking the time was the second time related subtheme recognized upon further reflection and analysis. The participants described how they believed healthcare providers should take the time to form a genuine relationship with them. Spending time and getting to know them was perceived as a good way to show compassion and respect; thus enhancing trust. Taking the time to develop a thorough understanding of why a patient sought care was also described as important. Making careful assessments and having genuine conversations were expressed as important for healthcare providers to do when taking time with elders.

Well, he takes time with you. He'll sit and listen to you. And, he'll work with you in any way that he can. But, he's a person that just sits down, and after you get through with the business part, if you want to talk about fishing or hunting or something, we sit down, and we talk about it. And, he rides horses a lot. So, we sit, and we talk about things like that. But, I think that if I didn't have trust in him, I wouldn't be able to sit down and talk about things besides my surgery. So, he's always been very polite, and if it takes thirty minutes to answer your question, he'll take it. He don't try to slide you through, but he'll take that time and listen to you. So, I feel like that's what made me have so much trust in him.

It does bother me, somewhat considerably, the, uh, hospitalists. He doesn't know me; I don't know him. I seem him today; I don't know if I'm going to see him tomorrow. That really concerns me. You go to the hospital now, and you don't see your doctor at all, unless he just happened to drop by.

So, I'm not worried about the professionalism of the person, but uh, their level of interest in me as an individual, since he doesn't know me from Adam. So, it's kind of hard to realize that the person taking care of you is a total stranger.

Uh, sometimes you may go to the doctor or what have you, and they don't seem to listen to you. Uh, they don't have the time to listen to you. They say. "Hi, how are

you doing?" And while you're explaining, they stop you. And before you know it, they're gone. So, I think that's not good.

If they come in and seem to be in a hurry; they don't take the time to listen. Uh, each situation is different because he might have had a similar infraction, the solution might be different. I'm saying, don't come in cocky, that "I know the answer and this is the only choice I have." Make an assessment and an evaluation and then discuss it with the patient.

The most reassuring fact was that I had met Dr. Deese about a month earlier. We were just talking in general; never knowing that I'd ever see him as a doctor

The concept of remaining time was identified as another subtheme of time during analysis. The participants described remaining time in terms of not wanting to be a burden to others with having to care for them. At the same time, they did not want to be forgotten or left out of care. A loss of independence was identified as a fear for the elders' remaining time.

The fear is that, uh, when you get old, and you have to depend on other people to take care of your basic needs. I don't want to be a burden on my family, or anyone like that. And I think that the nursing homes are going to become extremely overcrowded because families no longer want to take care of the sick and the elderly. Yes, that's a concern. And at the same time, I don't want to be a burden on my family.

And they're all so busy, you know. I don't want to be a burden on them one day. I don't want that.

Perseverance was the final subtheme of time. Sticking with a treatment plan and working with healthcare providers over time was emphasized by one participant. She expressed the importance of keeping a positive and determined attitude over time, too.

The exercise and doing what they said, regardless of how hard it hurt or how bad it hurts, that is the worst part. You might think you can't come through it, but you can make it through it. If you don't stand up with the therapy, it wouldn't ever get better. And, uh, so it's very important, very important to stick with your rehab to get over the surgery.

They told me in '71 that I'd never walk again. I walked until the day I went in the hospital and had my knee surgery. So, it's something you have to stick with; if you

want it or not. If you want to get over it, you have to do what they tell you and stick with your rehab and just keep working with it.

3. Trust

Elements of trust were described by every participant. The most obvious form of trust was the elders' trust in their healthcare providers. Trust in the healthcare provider was associated with complete recovery, both mentally and physically. Before an elder can develop trust in their provider, a relationship must be developed. When a relationship is formed, usually after spending adequate amounts of time communicating, elders believe that the best treatments for them will be executed, even if they do not go as initially planned. Identifying with the healthcare provider's spirituality was an important factor to one participant. Confidence in the healthcare providers' abilities was another necessary element of trust described by the elders; one participant described how he selected his doctors on a basis of confidence and trust. Therapeutic communication and spending adequate time with patients were the two most important indicators of trust identified by the participants.

> *And so, if I didn't have trust in him, I wouldn't have ever made it. You've got to have trust in them. Sometimes you wonder, but after you get over everything, you stop and think about them and how you had trust in them, or you wouldn't have made it.*

> *I was taken care of good. And, uh, you just have a lot of things to accept, I guess. And, you have to go along with everything; everything don't just go as planned or go right the first time. You just have to have trust in people and know that they are doing right.*

> *That they feel confident enough in themselves that they don't have to worry about things coming up that they haven't experienced before. It's a self-confidence that is assurance that they are going to do their job; within themselves, they feel that skilled. And, when they give you a talk beforehand, most doctors will come in and see you, they exude an air of confidence that I can detect whether or not they're for real. And, it's uh, reassuring.*

And the things that were most important in that particular conversation was, uh, I believe he was a Christian, and he asked me, "was I?" And, he said that my procedure would be one that he felt comfortable with, but nothing is always the same, but he felt comfortable that I would be okay. After realizing who he was, when I had met him, and with him explaining the way he did, I was ready to have the procedure then.

Well, it was uh, I mean, he had good rapport with people, and he explained stuff very well. And his technique, apparently, was good; he never did hurt. He apparently put a little Xylocaine in before he stuck me. So, it was good.

Well, I have been particularly selective. In other words, the doctors that I go to, I have a lot of confidence in because I've asked questions. I try to find doctors that have a good reputation for their particular field... And again, as I mentioned earlier, I try to pick doctors that I have researched a little bit about. And uh, the ones that I've had, I have a lot of respect for because they appear to be dedicated. They have a reputation for, uh, excellence in their field.

The healthcare provider was also expected to have trust in the elder. One participant described her experience of not being heard or understood. She wanted her healthcare provider to believe what she had to say and trust in her judgment.

Everybody was real nice, but eventually they made me feel like it was in my head. They made me feel like I was losing it, and I wasn't losing it.

Respect was a subtheme of trust identified through further reflection. The participants discussed how respect should be reciprocal between patients and healthcare providers. Respect was described as using appropriate communication techniques and tone, not making assumptions, having genuine interest, providing time and options when critical decisions are to be made, and behaving in a socially acceptable manner. One participant described a lack of respect on the part of the healthcare provider through an inappropriate and insensitive comment made to her.

I think that elderly people should be treated with respect. Uh, now, if they come, if an elderly person goes into a facility and they are acting ugly, no, I don't go along with that at all. But, uh, sometimes I, this has never happened to me, but I have seen where elderly people have been talked down to; their tone of voice, I'm talking about the medical personnel, their tone of voice is more harsh,

particularly when you have a patient that comes in more frequently than what they think that they should. And they think that they are abusing the medical field.

But uh, as we talked, he explained to me what the test results were. He gave me a choice. He said that I needed to take the time to make an honest evaluation He pointed out the fact that it was important, but not urgent. He recommended that I do it, but he gave me time to talk with my wife and my family

I can look up something; they've got the printouts right there. And, sometimes if you ask, they'll tell you about it, but they may miss something. That's why I read the side effects. If you go and read the side effects, they say, "You read too much." But those pills are going in my body.

Meeting expectations was another aspect of trust identified in analysis. In order for the participants to develop trust in their healthcare providers, their expectations had to be met. Misperceptions and misunderstandings were the main identified reasons for the elders not having their expectations met. The elders expected to be kept informed of all care plans and progress. Effective communication was also identified as important in meeting the expectations of elders. One participant described how his expectations were met through healthcare providers having desirable credentials.

Um, my concerns with the elderly as a group of people, more or less, don't get the prime medical care that they need. I think that, and some doctors and some nurses, uh, become more agitated with the elderly people because it seems like, at our age, we usually have something wrong with us, and they think that we're just coming to the doctor's office for, I guess, company, or sympathy, or somebody that shows that they care about them.

Everyone answered all questions asked. And, I was constantly being reassured by being made aware of what was going on. Uh, I wasn't left in the dark where I didn't know what they were going to do next; that type of situation. I had a good comfort with the staff and personnel.

I think what I'm saying is, the medical profession must be wary of who they are talking with; time, conditions, to make an honest assessment to where you don't put one into a state of fear. On the other hand, I wouldn't expect somebody to come up and see an arm hanging off and say, "Oh, what did you do? You shouldn't have done so and so." Assess the situation and put a calming effect to the situation.

And uh, I was impressed that this particular orthopedic surgeon went to school at Vanderbilt; did a fellowship at Harvard. I mean, what better credentials can you ask for than that? And uh, his reputation for what he does is all good.

Some participants also described how elders should seek to meet their healthcare providers' expectations. They perceived that healthcare providers' expectations could be met through behaving in specific ways and by mutual participation in care. One participant believed that she should bring humor into her interactions with healthcare providers; she perceived it made their jobs easier and more enjoyable. Mutual participation was described as keeping informed and learning about diagnoses so that the healthcare provider could better deliver care.

And you ought to see that scar that's on my hip! I'll tell you what, you wouldn't believe. The first time I looked at it I said, "Oh! Oh my goodness. I will never wear a bikini again!" And they [the nurses] all fell out. They thought it was the funniest thing.

Uh huh. I wasn't "gripey" about it, either. I wanted to be jolly about it and make their work easier... Yeah. They liked me because we were laughing and talking and all that stuff. So, I tried hard to do that and not be "gripey." Or impatient.

I think, um, just the general public, if they would pay more attention to publications and pamphlets, blurbs, newsletters, uh, handouts, and realize that their care is dependent upon their involvement. If the general public would be more involved, themselves, I think that would be a factor that would help the medical profession greatly.

I think on the front end, the patient should be more involved, and that way they can relate their conditions to, uh, their primary physicians and/or people they will encounter and are involved with later. To be able to express yourself, I can't say in common language, but just be able to express your symptoms in a manner that you can relate to something that I read, I know, or I've heard; something that would be most beneficial.

Research Question 2

Reflection on the participants' experiential descriptions of being an elder in healthcare revealed numerous expectations to ensure good care (Table 4). The expectations mostly involved the actual healthcare provider, not the healthcare system.

Table 4. Elders' Expectations of Healthcare

Expectations	Presence and/or appearance of the healthcare provider Excellence in the healthcare provider Involvement/Partnership Having a relationship Caring and nice Listening Fairness

Healthcare provider characteristics were some of the most important factors influencing the participants' perception of receiving "good" healthcare.

The presence and/or appearance of the healthcare provider were reoccurring themes in analysis. Some participants expected their healthcare providers to look a certain way, while others did not particularly care what they wore. The participants expressed the expectation of appearing as a professional; both in dress and demeanor. One participant expressed how a white coat meant nothing to him; it was the overall presence that mattered most.

> *But, they have a doctor here. And she was, she, I don't know, somebody's physician; but, it was a man who wears long hair, and uh, earrings. Oh boy, I don't know if it's a man or a woman... Yeah! And she dresses like a man... Well, I'm afraid to say he or she, but gracious me.*

Not their dress, but their demeanor in the interview; telling me what they are going to do and doing it and telling you if they had a problem during the surgery.

Their attire, their appearance: clean dress, not hanging off; those are factors that impress me more than somebody just having a white jacket on and a stethoscope hanging down your back. Uh, if you have a business professional appearance, that means a lot to me.

If they don't say it, just their presence is a reassuring factor, which helps to relax and calm a person. Uh, sometimes the unspoken word is just as seeing what somebody said; it's reassuring.

The participants wanted to see excellence in their healthcare providers. Excellence was described as having impressive credentials and as having dedication to people instead of money. It was also described as knowing the profession of medicine well. One participant chose his healthcare providers strictly based on his expectation for excellence.

You know, if it wasn't for them, we probably wouldn't have any healthcare or any good healthcare. If it wasn't for the nurses that dedicate their lives and the doctors that dedicate their lives, uh, we'd really be hurting in our healthcare. And, it worries me a lot, since I am affected a lot by my healthcare.

It's just that I like the idea that everybody knows their profession and knows when they're going to do it and do it well.

So, I think right now I have a perception that the healthcare system isn't going to be nearly as good as I know it is now. It's going to deteriorate. Why would a person go into medical school with no real incentive, except for the rare person that really wants to help people, not the money?

I like to see and feel that the person that's attending to me is knowledgeable and visible with what they are doing. No matter what questions you ask, they have an answer that you feel comfortable in receiving.

Well, I have been particularly selective. In other words, the doctors that I go to, I have a lot of confidence in because I've asked questions. I try to find doctors that have a good reputation for their particular field.

And again, as I mentioned earlier, I try to pick doctors that I have researched a little bit about. And uh, the ones that I've had, I have a lot of respect for because

they appear to be dedicated. They have a reputation for, uh, excellence in their field.

You know, you feel like you've got people who are really dedicated and educated and care about their patients and care about their profession. So, I feel good about it.

And uh, I was impressed that this particular orthopedic surgeon went to school at Vanderbilt; did a fellowship at Harvard. I mean, what better credentials can you ask for than that? And uh, his reputation for what he does is all good.

Involvement and partnership with healthcare providers was expected by the participants. Playing an active role in treatment plans was described as beneficial to both parties in terms of satisfaction, happiness, pride, and attaining good care. The sharing of insight and beliefs between healthcare providers and patients was also expected by one participant.

And they're just so amazed. They're just thrilled to death with it because they feel involved with it; because everyone knows how sick I was, and all that medication… Yeah, everybody's just happy with it. And, every day or two, someone mentions, "oh, I'm so proud of you!" I just say, "yes, thank you! I'm proud of me, too."

Only that, uh, we have to let them know how we feel about it because we've got some fine doctors and nurses out there. And, uh, they're going need our help, and we need their help; if we don't stick with them, it's not going to hold our healthcare up as good as it should be. It's an important thing, especially since I've gotten to where I need so much healthcare. It makes you stop and think more about it.

I think on the front end, the patient should be more involved, and that way they can relate their conditions to, uh, their primary physicians and/or people they will encounter and are involved with later. To be able to express yourself, I can't say in common language, but just be able to express your symptoms in a manner that you can relate to something that I read, I know, or I've heard; something that would be most beneficial.

The participants expected their healthcare providers to develop a relationship with them. As previously discussed, developing a relationship takes time. The expected relationship was one that was supportive, understanding, and truly interested.

> *The most reassuring fact was that I had met Dr. Deese about a month earlier. We were just talking in general; never knowing that I'd ever see him as a doctor.*

> *So, I'm not worried about the professionalism of the person, but uh, their level of interest in me as an individual, since he doesn't know me from Adam. So, it's kind of hard to realize that the person taking care of you is a total stranger.*

Being caring and nice was also expected of healthcare providers. Dedication was one element that a participant expected. He perceived dedication to the profession as a form of caring. Another participant viewed her healthcare providers as nice because they were so involved with her care and spent time to provide her with a unique treatment plan. She expressed her desire for all care of her care to be that way. Another participant perceived caring as having a having a genuine interest in medicine. He expected his healthcare providers to care about more than money.

> *But oh gosh, everybody's been so nice. There was one thing that, uh, they told me to do: 25 percent of my weight on the left. And, I had to walk on their toes. [Laughter]. See, you're standing on top of their foot, when I first started walking. And, they would tell me if I was putting too much weight on them. That's how good they were to me down there in therapy, and the nurses and the aides. And I walked on their toes!*

> *You know, you feel like you've got people who are really dedicated and educated and care about their patients and care about their profession. So, I feel good about it.*

> *So, I think right now I have a perception that the healthcare system isn't going to be nearly as good as I know it is now. It's going to deteriorate. Why would a person go into medical school with no real incentive, except for the rare person that really wants to help people, not the money?*

The participants also expected their healthcare providers to listen to them. However, listening requires more than just hearing. The participants expected to be

understood, not just heard. Thoroughly answering questions was another expectation related to listening.

> *Uh, sometimes you may go to the doctor or what have you, and they don't seem to listen to you. Uh, they don't have the time to listen to you. They say, "Hi, how are you doing?" And while you're explaining, they stop you. And before you know it, they're gone. So, I think that's not good.*

> *I like to see and feel that the person that's attending to me is knowledgeable and visible with what they are doing. No matter what questions you ask, they have an answer that you feel comfortable in receiving.*

Fair and respectful treatment was also expected from healthcare providers. The participants expected to be treated as any other generation. The participants perceived that some healthcare providers did not fully believe or respect them. Another expectation of healthcare providers related to fair treatment is the utilization of comprehendible terminology. One participant felt disrespected and treated unfairly when her doctors used words that she could not understand.

> *I like to be treated fairly. I would like for you to be nice to me and gentle with me. And, when you tell me if you have a plan, be specific. Use terms that I can understand, instead of medical terms that I don't know what you're saying.*

> *I think that they all should be treated with the same respect. Uh, but I failed to see that, particularly with the elderly people.*

> *Everybody was real nice, but eventually they made me feel like it was in my head. They made me feel like I was losing it, and I wasn't losing it.*

Summary

In summary, three essential themes were revealed through analysis of participant interviews. Ten subthemes related to the four essential themes were identified. Participants expectations of healthcare were also presented. The following chapter contains a discussion of the findings. The implications for practice, education, and research are also included.

CHAPTER 6

Discussion of Findings

The purpose of this study was to explore elders' perceptions and expectations of healthcare. Analysis of the participants' experiential descriptions revealed three essential themes. Further reflection revealed ten subthemes. Seven expectations emerged from analysis of the narratives. Chapter 5 contains a detailed description of the themes, subthemes, and expectations. A comparison of this research to other studies related to elder perceptions and expectations of healthcare is presented in this chapter. Additionally, the implications for practice, education, and research are discussed.

The participants in the study openly shared their experiences in healthcare. They also discussed their numerous expectations of healthcare providers and healthcare in general.

One common essential theme which emerged from the analysis of participant interviews was thoughts and perceptions of the future. There was a general concern that elders may not receive the care they need and deserve in the future. Financial concerns related to possible changes or decreases in insurance coverage were also discussed. Perceptions of a possible decline in the quality or number of healthcare providers in the future were articulated by some. Participants also expressed a fear of the unknown.

A second common essential theme was time. A general perception of time being taken away was described in terms of experiencing long waits, delays in receiving

treatment, or feeling rushed by healthcare providers. A positive aspect of time described by the participants was healthcare providers taking time with them. Spending time to develop a relationship, fully answering questions, and providing support were common expectations of a healthcare provider. The participants also discussed the concept of remaining time. They expressed a desire of not burdening others in their remaining time. Perseverance and remaining strong over time were described as important elements of their experience.

The third common essential theme which emerged in the analysis was trust. The participants expected to have reciprocal trusting relationships with their healthcare providers. Respect was described in several different ways and was analyzed to be a necessary element of trust. The participants' trust in the healthcare provider was described as being enhanced through fulfilled expectations.

The participants provided descriptions of good healthcare experiences when they perceived their expectations had been met. In particular, the elders were concerned with characteristics of individual healthcare providers. They described their expectations of healthcare providers, including: being caring and/or nice, having a relationship with them, giving fair treatment, listening, dressing appropriately, having presence, and developing a partnership or sustaining involvement.

Discussion

Few studies have been published relating to elders' perceptions or expectations of healthcare. An extensive review of the literature revealed no previous qualitative study that explored both the perceptions and expectations described by elders concerning healthcare. The majority of published literature on the topic of interest was quantitative in

nature; thus a need for further qualitative research was justified. This study provided a rich description of the experiences of elders in healthcare. A comparison of the themes identified in this study to previous studies will be explicated in the following discussion.

Chapter 2 included a complete literature review and described the focus of previous studies. The participants of previous studies ranged in age from young adults to elders. The selected literature was included to provide focus for the current study. Descriptions of individual themes identified by previous studies can found in Chapter 2.

Themes and Expectations Related to Previous Research

All of the essential themes within the current study were identified in previously published research. The relationship between themes revealed by this study and themes identified in existing research are discussed in the following sections.

The future. The elders in the current study described a range of feelings about the future of healthcare. They discussed concern for the future care of elders, financial concern, the possibility of a decline in the quality or numbers of health providers, and fear of the unknown. The subtheme of financial concern identified in this study was consistent with findings of the Beigay and Prato, et al. studies conducted in 2007.

Time. The participants in this study described time as four subthemes: taking away time, taking the time, remaining time, and perseverance. The elders did not like to experience long waits or delays in care. Beigay (2007) reported that many elders worried about the speediness of help to arrive if they were to sustain an injury. The elders in this study expected healthcare providers to spend adequate time with them. Remaining time was described in terms of burdening others in the event of loss of independence.

The focus of another study was the amount of healthcare utilization by frail elders and their resulting perspectives and satisfaction (Jakobsson, Kristensson, Hallberg, & Midlov, 2011). Although the results were not definitive, the elders with more visits to a healthcare provider were less likely to display characteristics of depression; thus , suggesting that elders who spend more time and have more opportunities to establish communication with a healthcare professional will have more positive perceptions of healthcare and improved quality of life. This is similar to the subtheme of taking the time, which was identified in the current study.

Trust. This study identified the development of mutual trust between healthcare providers and elders to include respect and meeting expectations. A few previously published qualitative studies rendered understandings of the fact that trust and feelings are important factors in the development of elders' perception of healthcare (Beigay, 2007; Prato, et al., 2007; Jakobsson, Kristensson, Hallberg, & Midlov, 2011).

The participants in the current study described an essential element of trust as knowing the healthcare provider and believing in their abilities. Knowing the healthcare provider required spending time with them. Frail elders and their perspectives of healthcare were the focus of a study conducted by Jakobsson, Kristensson, Hallberg, & Midlov (2011). They reported that elders who spend more time and have more opportunities to establish communication with a healthcare professional will have more positive perceptions of healthcare and improved quality of life. These findings could be related to developing trust.

Expectations. The participants in the current study identified the following expectations of healthcare providers to ensure good care: presence and/or appearance of

the healthcare provider, involvement partnership, having a relationship, caring and nice, listening, and fairness.

A qualitative study conducted by Kenten, et al. (2010) investigated patient expectations prior to a healthcare visit and whether or not those expectations were met. Some expectations of patients seeking healthcare in the Kenten et al. study were similar to the current study: having confidence in their own abilities and in their healthcare providers', feeling like the healthcare provider is warm and inviting, expecting the provider to be professional and thorough, and being treated in a clean and modern environment.

Lynn and McMillen (1999) reported aspects of importance that patients expect when seeking healthcare. Similar to the current study, expectations included: an environment conducive to healing, feeling like the center of attention, providers being talkative and friendly, providers appearing as professionals, and finding mutual understandings of goals.

Predictors of patient satisfaction may also be closely related to expectations. Bleich, et al. (2009) reported the following predictors, which are similar to the expectations which emerged in this study: degree of autonomy, choices, effective communication, preservation of confidentiality and dignity, receiving prompt attention, and having contact with individuals who displayed positive or pleasant attitudes.

Themes Not Related to Previous Research

All of the essential themes identified through analysis in this study were discussed in previously published research; however, several subthemes were not identified in the previous studies. The current research identified a subtheme of remaining time. The

participants discussed their remaining time in life in terms of not wanting to be a burden on other people. A fear of losing independence was associated with this subtheme. The participants expressed that they did not want to be left behind or excluded from necessary care, but at the same time, did not want to become a hindrance to family or others caring for them.

The second subtheme identified in the current study that was not found in the literature review was the concept of elders meeting the expectations of healthcare providers. Participants in this study described how they tailored their behaviors to make the jobs of healthcare providers easier and more enjoyable. Such behaviors included: utilizing humor, staying informed of current research, and researching one's own diagnosis or symptoms. The elders believed that mutual participation in care was necessary to meet the expectations of a healthcare provider.

Limitations to Transferability

This study educed personal descriptions of an experience. The experiences of the elders in this study might not parallel the experiences and/or perceptions of all elders in the healthcare setting; however, since this is a qualitative study, generalization to greater populations is not a goal. Selected exemplars from participant interviews were included in Chapters 4 and 5 to assist readers with developing judgments of transferability. The participants were recruited via snowball sampling, as described in Chapter 3. This method of sampling may have resulted in the recruitment of participants who were similar in lifestyle or background. Elders residing in urban areas or other regions of the United States may have differing experiences and perceptions.

Implications

This study is important due to the fact that more research on the topic of elders' experiences in healthcare is needed for improvements to be made. As the United States population will gain more elders than ever before in the years to come, the body of evidence surrounding the experiences, needs, and expectations of elders will also need to expand. Currently, the United States is facing dramatic healthcare reform. Such a reform will greatly affect how Americans, including elders, utilize and access healthcare services. As there is limited research concerning elders' perceptions and expectations of healthcare, it is likely that reforms might occur without substantial consideration of those factors. This research will be beneficial not only to those who provide and/or participate in the healthcare of elders, but also to those who are involved in healthcare policy. In order to create a better experience for elders in the healthcare setting, it is imperative to gain an understanding of their expectations, so that care can be tailored to meet them.

Practice. As a qualitative study, this research was not intended to develop interventions for practice; however, healthcare providers in all settings could potentially benefit from the information presented in this study. Before a perception that "good" healthcare was attained can be developed, elders must have several expectations met. If healthcare providers understood the exact needs and wants of elder clients, they could tailor their care to better meet expectations. Satisfaction with care also has the potential to improve elders' perceived quality of life. The themes identified in this research suggest that healthcare providers should be more cognizant of elders' concern for future care, developing trust, perception of time, and individualized expectations. Spending the time to develop a genuine relationship with elders was identified as one of the best ways to

meet expectations and foster the development of trust; thus, leading to more meaningful and lasting interactions. This research expands the body of knowledge for all who interact with elders, directly or indirectly.

Education. This study contributes to the existing body of knowledge concerning elders' perceptions and expectations of healthcare. Courses of study for all healthcare providers, including doctors, nurses, therapists, technicians, and etcetera, could be enhanced by including discussion and lecture of elders' perceptions and expectations of healthcare. Individuals who are active in making healthcare policy need to be aware of elders' healthcare concerns, as their decisions directly affect elders' level of satisfaction with care. The elderly population could also use this study to expand their body of knowledge and possibly advocate for better healthcare experiences based on their own needs and expectations.

Family members or other caregivers of elders could potentially benefit from this study by expanding their understanding of the perceptions and expectations of other elders. The findings from this research would be a good starting point for initiating discussions with elder family members regarding how to make the healthcare experience better. One potential benefit of families discussing healthcare with elders is learning about their individual wishes and expectations for care in the event they could not make their own decisions.

Research. As this study was completed in a small region of the southern United States, it should be replicated in other areas of the country. Inclusion of participants from a larger variety of ethnicities and localities is suggested to provide a more inclusive understanding of elders' perceptions and expectations of healthcare.

This research was conducted during a presidential election year. The participants were very cognizant of possible changes to many elements of the American healthcare system due to massive media representation. The participants may have been hyper-aware of supposed political agendas. The theme of the future was a common essential theme of the participant narratives in this study, however, it is recommended that this study should be repeated in a non-election year to see if theme remains important to elders in non-election years.

It would also be possible to continue this research in a longitudinal design. If the American healthcare system is subject to major changes in years to come, the elder perception and expectations of healthcare are likely to be different. Investigating their perceptions over time would allow for researchers to evaluate the effectiveness or satisfactoriness of any changes in healthcare. Even if no changes to the American healthcare system are made, the elder perception and expectations of care could transform. In order to most effectively evaluate progress and success in improving healthcare for elders, it is imperative that research be continued.

Summary

This study educed rich descriptions of the experiences of elders in healthcare. Through analysis of experiential descriptions, the researcher sought to identify the elder participants' perceptions and expectations of healthcare. The participants willingly shared their experiences. It is important that their voices be heard. If healthcare professionals had a better understanding of how elders perceive healthcare and their expectations, care delivery could be tailored to elderly individuals; thereby, improving satisfaction, feelings of control in decision making, and, in turn, quality of life.

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APPENDICES

APPENDIX A

Through the Eyes of the Elder

Demographic Data Form

Participant #____________

1. Age in years: ________________

2. Gender: Male ____ Female_____

3. Ethnicity ___________________________

4. Rural or Urban Residence
   Rural = <50,000 Urban= >50,000

5. Number of prescribed medications? ____________________
   (Self-report)

6. Number of visits to a healthcare provider in last year? _____________
   (Self-report)

7. Number of hospitalizations in last year? _________
   (Self-report)

8. Have you ever worked in the healthcare field? YES NO

APPENDIX B

Through the Eyes of the Elder
Research Study
Information Sheet

I am a professor in the School of Nursing at the University of Mississippi Medical Center. I am conducting a research study to learn more about elders' experiences in healthcare by talking to elders. It is important for doctors and nurses to know how you view healthcare so that your healthcare can be given in a way that meets your needs and makes your experiences better and maybe improve quality of life.

You are being invited to participate in this study because you are over the age of 70. If you agree to participate, you will complete an interview and you will be asked to give some basic information like your age. . The interview will be recorded so we don't lose any important information that is shared. You will choose the time and place for the interview. The interview will last about one hour.

Being in the research study is voluntary. If you do the interview you are saying that you want to be in the study. If you want to quit the study during the interview, the interview will stop and the recording will not be kept. If you want to stop after the interview is done, you may do so but the interview will be used in the study.

The results of the research study may be published, but your name will not be used. You may find out what we learned from the interviews by either coming to a presentation (the researcher's thesis defense) and/or by asking for a copy of the results.

If you have any questions or wish to participate in the study, please contact:

Micaela DeLashmit
Researcher
662-801-8113
mdelashmit@umc.edu
or
Robin Wilkerson, PhD, RN
Researcher
601-540-7059
rwilkerson@umc.edu

APPENDIX C

UNIVERSITY OF MISSISSIPPI MEDICAL CENTER

2500 North State Street
Jackson, Mississippi 39216-4505

Institutional Review Board
Telephone (601) 984-2815
Facsimile (601) 984-2961

DHHS FWA #00003630
IORG #0000043
IRB 1 Registration #00000061
IRB 2 Registration #00005033

Approval Notice
Initial Application

02/21/2012

Robin Wilkerson, PhD, RN
School of Nursing
University Of Mississippi Medical Center
2500 North State Street
Jackson, MS 39216

RE: IRB File #2012-0021
Through the Eyes of the Elder: Perceptions and Expectations of Health Care

Your Initial Application was reviewed and approved by the Expedited Review process on 02/21/2012. You may begin this research.

Please note the following information about your approved research protocol:

Protocol Approval Period: 02/21/2012 - 02/19/2013
Approved Enrollment #: 20
Participant Population: Adults - Healthy Controls
Performance Sites: School of Nursing ? Oxford
Expedited Review Category(ies): (6) Collection of data from voice, video, digital, or image recordings made for research purposes.;
(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.);

Documents / Materials:

Type	Description	Version #	Date
Research Protocol	IRB Submission 2.2.12.docx	1	02/02/2012

Other Material	Information Sheet	1	02/17/2012

Review History:

Date	Type	Decision
02/13/2012	Administrative Review	Revisions Required
02/17/2012	Administrative Review	Revisions Required
02/21/2012	Expedited Review	Approved

Please remember to:

- Use the IRB file number (2012-0021) on all documents or correspondence with the IRB concerning your research protocol.

- Review and comply with all requirements on the enclosure, UMMC Investigator Responsibilities, Protection of Human Research Participants.

The IRB has the prerogative and authority to ask additional questions, request further information, require additional revisions, and monitor the conduct of your research and the consent process.

Please note, if this study involves an intervention (whether or not it involves a drug or device) you (or the "responsible party") must register the study before enrollment begins and report results within 12 months of study closure through Clinicaltrials.gov http://www.clinicaltrials.gov . Penalties for responsible parties who fail to register applicable clinical studies are significant and include civil monetary penalties and, for federally-funded studies, withholding or recovery of grant funds. For additional information please go to http://irb.umc.edu/GuidanceInfo/ClinTrialRegistry.htm.

We wish you the best as you conduct your research. If you have questions or need additional information, please contact the Human Research Office at (601) 984-2815.

IRB 1

Enclosure(s): (1) Investigator Responsibilities, Protection of Human Research Participants

cc: Sharon Lobert, Ph.D.

Office of Integrity and Compliance

UMMC Investigator Responsibilities
Protection of Human Research Participants

The IRB reviews research to ensure that the federal regulations for protecting human research participants outlined in UMMC policy, the Department of Health and Human Services (DHHS) regulations (45 CFR 46) and the Food and Drug Administration (FDA) regulations (21 CFR Parts 50 & 56), as well as other requirements, are met. The University of Mississippi Medical Center's Federalwide Assurance (FWA), FWA# 00003630, awarded by the Office for Human Research Protections (OHRP) at DHHS, is a written pledge to follow federal guidelines for protecting human research participants in accordance with the principles of the Belmont Report. **All investigators must read both the Belmont Report and the UMMC FWA to understand their responsibilities in conducting research involving human participants.** Both documents are available on the Human Research Office webpage, http://irb.umc.edu, and in hard copy by request from the Human Research Office. Some of the responsibilities investigators have when conducting research involving human participants are listed below.

1. Conducting the Research: You are responsible for making sure that the research is conducted according to the IRB approved research protocol. **You are also responsible for the actions of the study's co-investigators and research staff.**

2. Participant Enrollment: You may not recruit or enroll participants prior to the IRB approval date or after the expiration date of IRB approval. All recruitment materials for any form of distribution or media use must be approved by the IRB prior to their use. If you need to recruit more participants than was noted in your IRB approval letter, you must submit an amendment requesting an increase in the number of participants.

3. Informed Consent: Informed consent is a process that begins with the initial contact and ends at some point after the study is complete. You are responsible for the conduct of the consent process, ensuring that effective informed consent is obtained and documented using **only** the IRB-approved and stamped consent document(s), and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Whoever is presenting the consent document to the potential participant and conducting the consent discussion must have all pertinent information at hand, be knowledgeable about the study and the disease or condition involved, if any, and have the ability and experience to answer questions regarding the study and any treatment involved. Please give all participants a signed copy of each consent or assent document they sign, and keep the originals in your secured research files for at least six (6) years. When appropriate, you should place a copy of the consent document in the participant's medical record.

4. Continuing Review: The IRB must review and approve all IRB-approved research protocols at

intervals appropriate to the degree of risk, but not less than once per year. **There is no grace period.** Prior to the date on which IRB approval of the research expires, the IRB will send you three reminders to submit a Continuing Review, *90, 60 and 30 days prior to expiration.* Although reminders are sent, **it is ultimately your responsibility to submit the renewal in a timely fashion to ensure that a lapse in IRB approval does not occur.** If IRB approval of your research lapses, you must stop new participant enrollment, and contact the IRB immediately.

5. Amendments and Revisions: If you wish to amend or change any aspect of your research, including research design, interventions or procedures, number of participants, participant population, consent document, instruments, surveys or recruitment and retention material, you must submit the amendment or revisions to the IRB for review with a Request for Change. You **may not initiate** any amendments or changes to your research without first obtaining IRB review and written approval. The **only exception** is when the change is necessary to eliminate apparent immediate hazard to participants. In that case the IRB should be immediately informed of this necessity, but the change may be implemented before obtaining IRB approval.

6. Unanticipated Events: All adverse events that are unanticipated **(unanticipated means that the event is serious,unexpected, related or possibly related to participation in the study and places participants at greater risk of harm than previously recognized)** and serious protocol deviations, must be reported to the IRB **within ten (10) business days** of discovery. The only exception to this policy is death - **the death of a UMMC research participant must be reported within 48 hours of discovery.** Reportable events should be submitted to the IRB with the Adverse Event/Unanticipated Problem Report form.

   Events that do not meet the definition of an unanticipated problem involving risk to participants or others, including research related injury occurring at a UMMC performance site or to a UMMC study participant, participant complaints, problems, minor protocol deviations and non-compliance with the IRB's requirements for protecting human research participants should be reported as follows: Minor deviations and problems should be submitted at the time of continuing review, as instructed on the form. All other events should be reported in writing via letter or email to the IRB with sufficient detail to allow the reviewer to understand the problem and any actions taken to prevent it from happening again.

7. Research Record Keeping: At a minimum, you must keep the following research related records in a secure location for at least six years: the IRB approved research protocol and all amendments; all versions of the investigator's brochure; all informed consent documents; all recruiting materials; all renewal applications; all adverse or unanticipated event reports; all correspondence to and from the IRB; and all raw data.

8. Reports to FDA and Sponsor: When you submit the required annual report to the FDA or you

submit required reports to your sponsor, you **must** provide a copy of that report to the IRB. You may submit the report with your IRB continuing review application.

9. Provision of Emergency Medical Care: When a physician provides emergency medical care to a participant without prior IRB review and approval, to the extent permitted by law, such activities will not be recognized as research and the data cannot be used in support of the research.

10. Final Reports: When you have completed the study, (no further participant enrollment, interactions, interventions or data analysis) or stopped work on it, you must submit a Final Report to the IRB using the Final Report form.

11. On-Site Evaluations, FDA Inspections, or Audits: If you are notified that your research will be reviewed or audited by the FDA, OHRP, the sponsor, any other external agency, or any internal group, you **must** inform the IRB immediately and submit all audit reports received as a result of the audit to the IRB.

If you have questions or need assistance, please contact the Human Research Office at 601 984-2815.