Anticipated Response of African Americans to Stroke Symptoms

by

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Abstract

This study explored what African Americans aged 55 and older believed they would do in response to stroke symptoms.   The study focused on individual factors related to stroke risk, extending beyond concerns in the African American community of limited health care access and genetic predisposition to stroke. The study examined whether an individual's illness representation of stroke, stroke risk factor knowledge, time perspective, or spirituality influenced that person's anticipated response to stroke symptoms. Specific aims include a) enhancing present understanding of how African Americans respond to stroke, b) distinguishing the biological, societal, and behavioral factors related to stroke in the African American community, and c) providing insight and data to serve as a foundation for targeted stroke prevention interventions in the African American community. A qualitative dominant mixed methods approach was used to collect data from African Americans, either after a diagnosed stroke (n=6) or without a stroke history (n=14). Face-to-face interviews with participants explored their knowledge about strokes. Participants also completed questionnaires regarding factual knowledge, as well as illness representation, spirituality, and time perspective.   Participants in the study were found to be highly spiritual. Participants in both groups were found to be future oriented. Participants each had understanding of stroke as emergency and could recall symptoms of acute stroke. Participants routinely stated they would "call 9-1-1" if they thought they were having a stroke. When asked about their anticipated response to specific stroke symptoms, the participants reported they would call emergency medical services approximately 40% of the time. There continues to be a gap between stroke knowledge and action in the African American population. Stroke is regarded as emergency, yet specific symptoms of stroke may not always be viewed as warranting immediate attention. These results support a continued need for stroke

education in this community. Stroke education should consider an individual's culture and how culture may influence an individual's health behavior. This education should also emphasize how seemingly benign symptoms may be indicative of a more serious condition.   Approaching health education by integrating an individual's spiritual preferences, time orientation, and illness representation may help build more effective individualized health education and promote an improved adherence to health recommendations.

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Dedication

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Introduction and Organization of the Dissertation

As part of the comprehensive review process three separate literature reviews were conducted that led to the formation of the question for the current study. The literature reviews were focused on three topics 1) caregiver burden, 2) understanding health information, and 3) acquiring health information. The first review examined caregiver burden in the context of neurological health conditions to understand caregivers' needs and how they perceive their caregiving roles. The second review focused on health literacy in an effort discuss how people understand, and ultimately use, health information presented to them. The third review provided a general discussion of how health information is disseminated to the lay public. These three literature reviews lay the foundation for the current study and are included as appendices A-C.

Chapter 1 of the dissertation will briefly define and discuss personal and cultural factors that are thought to have influence over anticipated response to stroke as well as the general outline of the study design. Chapter 3 and Chapter 4 of the dissertation will present the methods and results for the quantitative and qualitative aspects of the study respectively. Chapter 5 will provide the discussion and conclusions that draw information from both chapters 3 and 4.

Prologue
Problem Statement

The purpose of this exploratory study was to examine African American's anticipated response to stroke symptoms. The study examined if an individual's knowledge about stroke, stroke risk factor knowledge, time perspective, and spirituality have influence over their anticipated response to stroke symptoms. Limited access to health information and to health care may explain part of the race/ethnic disparity, but do not provide a complete answer. This study attempted to fill a gap in the current literature by going beyond the frequently discussed health

care access and genetic predisposition concerns regarding stroke in the African American community and instead focused on individual factors related to stroke risk.

Study Aims

1) Gain a better understanding of how African Americans respond to stroke symptoms.

2) Use this research as a starting point for the investigator's research agenda and ultimately use the findings from this research to begin developing targeted stroke prevention interventions in the African American community.

One additional hope for this research, and future studies, is that findings from the study can extend to multiple communities and thereby help shape stroke interventions for all persons.

Theoretical Orientation

The theoretical orientation for this study is based on two theories used in health promotion research. The first theory is Everet Rogers Diffusion of Innovation Theory (DIT) (2003). This theory suggests that individuals (and groups) adopt or make behavioral changes based on the characteristics of an innovation or behavior in question and that these individuals and groups do so at different rates. DIT is discussed in detail in the literature review provided in Appendix C. The second theory is Leventhal, Meyer, and Nernez (2008) Common Sense Model of Illness Representation (CSMIR) which suggests that people conceptualize illnesses in their minds and that individuals behave and respond when confronted with an illness based on their representations. CSMIR will be further discussed in Chapter 1.

People are constantly getting messages about health from multiple sources (e.g., medical professionals, media, web based sources, family and friends, etc.) and as these messages are diffused and disseminated into the community, people must choose what to do with them. It is reasonable to assume that an individual's choices are often driven by how he or she perceives the

message to fit with their lives and current understanding of their conditions. If a person has a less than adequate understanding of his or her condition then the healthful messages they receive may not fit well with their established thoughts about the illness thus they may not act in a healthful manner.

Guiding Questions

This research was guided by four questions. These questions were

1. What are illness representations of stroke within the African American community?

2. What is the knowledge of stroke and stroke symptoms within the African American community?

3. Do time perspective, spirituality, and/or current health status have any influence over illness representation of stroke?

4. Does illness representation of stroke influence African American's anticipated response to stroke symptoms?

Significance

Researchers and clinicians search for the best methods through which to disseminate health information to healthcare consumers that is accurate, accessible, and appealing to use. There are numerous stroke education programs targeted toward African Americans and while this stroke education is appropriate and valuable from an information standpoint, stroke continues to be one of the numerous health disparities affecting the African American community. Thus, a better understanding of African American's perception of stroke and objective knowledge about stroke is one-step toward improving dissemination of stroke information to this community with the goal of increasing preventative health behaviors and response to stroke symptoms should they occur. Gaining this insight may lead to reducing or

eliminating stroke-related health disparities, providing more focused stroke education, and

building interventions targeted toward this community.

Chapter 1: Introduction and Study Design

A Review of Personal and Cultural Factors Influencing Anticipated Responses to Health Concerns

The concern for health issues in the African American community has long been discussed in the literature (see Kleindorfer, 2008; Stansbury, Jia, Williams, Vogel, & Duncan, 2005 for example studies). There continues to be a widening of the gap in regards to health status between African Americans and European Americans (Williams, 1997).   Health promotion researchers state the need for research that examines racial group and health because of interest in how race health intersect (Williams, 1997). Williams (1997) suggests that as a social category, race is important in the study and promotion of health because it encompasses an individual's or group's identity, societal rewards, and resources. Williams (1997) concludes that race is important in understanding the differences in mortality and morbidity among groups. The current study examines stroke in African Americans because this group is twice as likely as White Americans to have a stroke and sustain significant disability or die because of stroke (National Stroke Association [NSA], 2013).

African Americans, or Black Americans, are a culturally diverse, racial group of individuals living in the United States (US Census Bureau, 2011).   The United States Office of Management and Budget defines African American as "a person having origins in any of the Black racial groups of Africa" (US Census Bureau, 2011, p. 2). African Americans make up approximately 13.6% of the total population with approximately 55% of African Americans residing in the southern states (i.e., Alabama, Mississippi, Georgia, etc.). The Administration on Aging (AoA) estimates that between the year 2010 and 2030 the number of African American older adults will increase by 114% (Administration on Aging [AoA], 2012). Age is a primary factor in stroke incidence as the risk of sustaining a stroke doubles each year after the age of 65

(National Stroke Association [NSA], 2013).   African Americans are at increased risk of stroke

and other chronic health conditions having long term implications for level of function,

independence, and overall quality of life (Centers for Disease Control [CDC], 2013). Health

conditions such as hypertension, diabetes, sickle cell anemia, cigarette smoking, and obesity all

are conditions common in the African American community, and all increase the risk of stroke

(NSA, 2013).   Factors outside of health conditions such as environment and access to care also

increase the risk of stroke, and other chronic health conditions in the African American

community (Medline Plus, 2013).

Health Disparities

Linda Raskin, an African American woman, wrote a letter to the editor of *Neurology*

Today in response to the article Black, White, and Grey (Collier, 2009) which examined African

Americans and stroke risk. In her letter, she expressed concern that African Americans may not

be getting information about stroke that is important for both preventative and rehabilitative

health (Raskin, 2009). Raskin (2009) stated "I really don't think that African Americans are

getting the message, including myself […]. Many of us don't know the big picture, and when we

do, it's too late" (October 2009, p. 6). Raskin's statement reflects a concern about the health in

the African American community. The health of the African American population as a whole is

declining in part due to health disparities (Williams, 1997). Health disparities can be viewed as

arising from either 'avoidable' or 'unavoidable' factors that increase risk of certain health

outcomes (e.g., stroke) (Trimble & Morgenstern, 2008). Health disparities are widely researched

and are known to have an effect on individuals living in lower socioeconomic status, having

lower levels of education, and holding minority status (Beacom & Newman, 2010). Getting

appropriate health information to those individuals that are affected by health disparities is

important because it may help to improve overall health outcomes.

African Americans are disproportionately affected by 'health disparities' (Brandon & Proctor, 2010). Several, interconnected factors contribute to, and sustain, health disparities in the African American community (Williams & Braboy-Jackson, 2005). Factors such as holding lower socioeconomic status, decreased access to quality education, racial segregation in housing, and lack of access to medical care contribute to disproportionate chronic health conditions in the African America community (Williams & Braboy-Jackson, 2005).   Historically, older African Americans have had less educational opportunities than younger African Americans and White Americans (Taylor & Lockery, n.d.). This is in part due to these older adults experiencing the effects of discriminatory practices that limited their participation in employment, housing, employment, health, and education (e.g., Jim Crow Laws) (Taylor & Lockery, n.d.). Taylor and Lockery (n.d.) found that African Americans who were of school age in the 1930s and 1940s, especially in the south and including Missouri, were either not legally allowed to attend junior and senior high school, or were severely limited in access to these levels of education. Because of lack of access to education these individuals were at risk of poor literacy skills and subsequently at risk of lower levels of health literacy (U.S. Department of Health and Human Services, n.d.). Health literacy is known to have role in health promoting behaviors (AAFP, 2008; Nielsen-Bohlman, et. al, 2004; Baker, 1998).

Trahan and Williamson (2009) found that 58% of African Americans have at or below basic literacy skills, thus placing these individuals at risk of low health literacy. The World Health Organization (2007) defines health literacy as the following:

> The cognitive and social skills, which determine the motivation and ability of individuals to gain access to, understand and use information in ways, which promote and maintain good health… [it is] more than being able to read pamphlets and successfully make

appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment (WHO, 2007, n.p.).

In a survey by the National Center for Education Statistics, African Americans were found to have lower rates of basic health literacy than their White or Asian/Pacific Islander peers (NCES, 2003). The study also found that adults 65 years old or older were have lower rates of basic health literacy than younger adults do. For a complete review of health literacy see Appendix B.   Taylor and Lockery (n.d.) suggest that older African Americans have had to live with the outcomes of these experiences and yet have survived because of family bonds, spirituality, and participation in voting.

 Racial discrimination in health care interactions also contributes to health disparities in the African community (LaVeist, 2005, p. 212).   It is important to note, however, there are additional factors related to the "intrinsic structure of the health care system" that may obstruct an individual's ability to find and access health care successfully (Kleindorfer, 2009, p.75). Although a detailed examination of limitations of health care systems is beyond the scope of this literature review and study, the need for a more complete understanding is noted here to suggest that research in this area may be worthwhile.

Cultural and Personal Factors

It may not be possible to address some unavoidable causes of health disparities such as biological and genetic differences or aging (Cruz-Flores, et. al, 2011). However, some causes may be addressed in such a manner as to close the gap. Research suggests that examining the psychosocial factors that contribute to health disparities in the African American community may offer clinicians and practitioners a way to structure individual educational programs that help reduce these health disparities (Farmer, Reddick, D'Agostino, & Jackson, 2007).

Cultural and personal factors shaping perceptions of health and health care may contribute to health disparities in the African American community (Kleindorfer, 2009). For example, African Americans expectations of health care professionals, general mistrust of the health care system, fear, denial, and fatalism may influence this community's interactions with health care systems. Spirituality is another important aspect of African American culture that may influence health (Franklin, Schlundt, & Wallston, 2008). Cultural and personal factors under review in the current study will include spirituality and time perspective.

Spirituality. Religion and spirituality have similar underpinnings including belief in the divine; however, spirituality has come to be differentiated from religion in that spirituality is an individual set of beliefs and religion involves a collection of ideas and institutions (Hill & Pargament, 2003). Holt, Clark, Kreuter, and Rubio (2003) suggest that there may be an association between spirituality and health and that this association may be positive or negative. Spirituality and its influence on African American health behavior is of interest because of prominence and significant influence of the Black Church and spirituality in the African American community (Franklin, Schlundt, & Wallston, 2008).

Taylor, Chatters, and Jackson (2009) found that African Americans were more likely to describe spirituality as being an important factor in their lives than did their non-Hispanic White peers. Older African Americans in general report attending more church services, engaging in private spiritual and religious exercises, and receiving social support from their church families than do their White peers (Taylor & Lockery, n.d.). Blank, Mahmood, Fox, and Guterbock (2002) found that the Black Church provides a diverse mix of support programs to its members. They suggest that the amount of services provided in the church may be in part due to the lack of

services available in the communities in which they serve (Blank, Mahmood, Fox, & Guterbock, 2003).

While spirituality, and religion, are important in the African American community, it is noted that research shows that African Americans are less likely than their Asian Pacific Islander, American Indian/Alaska Native, and Latino peers to use alternative medicines and treatments based on spiritual and religious beliefs (LaVeist, 2005). However, Figueroa, Davis, Baker, and Bunch (2006) found there to be an influence of spiritualty on African American health behavior. The researchers found that participants in the study had a "Lord will fix it approach" and believed health care providers to be people used by God to help them recover (p. 87). The researchers suggest that encouraging patient's use of "healthy spiritual practices" in the management health conditions will help to improve health behaviors (p. 87).

Some research with regard to African Americans, spirituality, and health has focused on the idea of fatalism (Franklin, Schlundt, & Wallston, 2008). Franklin, et. al, (2008) define fatalism as "belief in an inevitable outcome and/or predetermined course of events beyond human control" (p. 324). Spirituality, religion, and fatalism have been associated because of the belief that a higher power is what is in control of a person's health, or other, outcome (Franklin, Sclundt, McClellan, Kinebrew, Sheats, Belue, Brown, Smikes, Patel, & Hargreaves, 2007).

Morgenstern, Sanchez, Skolarus, Garcia, Risser, Wing, Smith, Zahuranec, and Lisabeth (2012) found that stroke survivors who had more depressive symptoms and increased fatalism prior to having their first stroke were at an increased risk of stroke reoccurrence. While the same was not true for individuals expressing optimism and spirituality (Morgenstern, Sanchez, Skolarus, Garcia, Risser, Wing, Smith, Zahuranec, & Lisabeth, 2012). This research might suggest that spirituality may be a health asset with regard to stroke. Examining spirituality with

regard to stroke may provide insight into how African Americans view stroke as well as if and how spirituality influences anticipated reaction to stroke symptoms.

Time Perspective. Researchers have studied the role of time perspective in health behavior (Henson, Carey, Carey, & Maisto, 2006). Zimbardo (1999) suggests that time perspective is a "non-conscious process whereby the continual flows of personal and social experiences are assigned to temporal categories, or time frames, that help give order, coherence, and meaning, to those events" (p.1271). Zimbardo (1999) further states that time perspective is used for several reasons including "encoding, storing, and recalling experienced events, as well as in forming expectations, goals, contingencies, and imaginative scenarios" (p. 1272).

There are several categories of time perspective including past, present, future, and transcendental (Zimbardo, 1999). Zimbardo (1999) subdivides present and past orientations into present-hedonistic, present-fatalistic, past-positive, and past-negative. He found that people who exhibit an orientation to past-negative view the past through a negative lens, whereas individuals with a past-positive view have a more positive view of past events. Zimbardo (1999) suggested that people who were oriented to present-hedonistic tend to want gratification within the moment whereas people who were present-fatalistic generally held the belief that the future was out of their control. Henson, Carey, Carey, and Maisto (2006) found individuals who were more present oriented typically had increased risk taking behaviors and exhibited less protective behaviors. While individuals who had a more future time perspective tended to orient themselves towards future goals and achievements (Zimbardo, 1999). Zimbardo (1999) suggests that an individual's time orientation exists on a continuum rather than as finite categories into which a person fits. Utsey, Hook, Fischer, and Belvet (2008) found that African Americans are typically more present oriented. Examining the time orientation of African Americans in relation

to health may provide more insight into the patient level causes of health disparities in this community.

Response to stroke symptoms

Several researchers report that in general, people have relatively good knowledge about stroke (Skolarus, Murphy, Zimmerman, Bailey, Fowlkes, Brown, Lisabeth, Greenberg, and Morgenstern, 2013; Fussman, Rafferty, Lyon-Callo, Morgenstern, & Reeves, 2010). Individuals who seek medical care immediately upon the onset of stroke like symptoms are more likely to survive the incident as well as have fewer residual effects post stroke (NSA, 2013). Underscoring this fact is that both the American Heart Association (AHA) (2013) and American Stroke Association (ASA) (2013) emphasize the first and best response to stroke symptoms should be to call Emergency Medical Services (EMS), which typically in the United States means call 9-1-1. Yet, people delay seeking treatment in the presence of these stroke symptoms (Jurkowski, , Maniccia, Dennison, Samuels, & Spicer, 2008) even though the general population's overall knowledge of the risk factors and symptoms of stroke have increased (Reeves, Rafferty, Arana, & Theisen, 2008). A study conducted by Fussman, et. al, (2010) found that only 14% of respondents would call EMS when presented with three different stroke scenarios. Thus, the lack of intent to call EMS is a major concern given the relationship between time between onset of stroke symptoms and administration of therapies for stroke.

Importance of Seeking Treatment Early

Individuals experiencing ischemic stroke may eligible to receive Tissue Plasminogen Activator (tPA) a thrombolytic drug that aides in the dissolution of clots and restores blood flow to the area of the brain impeded by the stroke (NSA, 2013). TPA must be administered within three hours after onset of stroke to be effective, thereby making prompt attention to stroke symptoms necessary if tPA is to be an effective treatment (The National Institute of Neurological

Disorders and Stroke [NINDS], 1995). The NINDS (1995) study suggested that people who received tPA within the given time frame, as compared to individuals receiving a placebo, were approximately 30% more likely to have minimal or no disability at three months post stroke. It is worth mentioning, however, that tPA does carry with it certain risks as well. The NINDS (1995) found that use of tPA increased the risk of intracranial hemorrhage when not used as suggested by the NINDS. Other stroke treatments are currently being researched and most also require the individual seek treatment as quickly as possible after onset of symptoms (Zerwic, Hwang, & Tucco, 2005).

Delay in Seeking Treatment and Common Sense Model of Illness Representations

Cognitive representations are sets of beliefs and ideas regarding a specific topic (Zerwic, et. al, 2005). The work discussing how individuals form these cognitive representations is the Common Sense Model of Illness (CSM) representation based largely on the works by Leventhal in the 1970s. This model has been used in discussion of various chronic health conditions including breast cancer, hypertension, cardiac conditions, and asthma (for review see Hekler, Lambert, Leventhal, Leventhal, Jahn, & Contrada (2008), Figueiras & Alves, (2007), Astin & Jones (2006), and Anagnostopoulos & Spanea, (2005)). CSM is useful in examining how people behave when confronted with health issues (Hagger & Orbell, 2003).

The model suggests the existence of a parallel processing framework (Diefenbach, n.d.), having two separate processing arms. One arm is responsible for the processing of an internal or external stimulus, while the other arm processes the emotional aspects related to the stimulus. An individual's health behaviors may arise through both cognitive and emotional processes (Leventhal, Diefenbach, & Leventhal, 1992). There are six proposed components to illness representation in the CSM theory, including a) identity, b) timeline, c) consequences, d) causes,

e) control/cure, and e) illness coherence (Defenbach, n.d.). CSM theory suggests lay people develop accurate, or flawed, representations of illnesses that form how they understand the illness and ultimately shape their health behaviors towards the illness (Astin & Jones, 2006).

Zerwic, Hwang, and Tucco (2005) specifically examined African Americans and delay in seeking EMS for stroke. Zerwic, Hwang, and Tucco (2005) used the cognitive representation of stroke to understand causes of delay in seeking treatment among individuals that have had stroke. Zerwic, Hwang, and Tucco (2005) found that many individuals have a limited cognitive representation of stroke thus influencing decisions to seek medical care quickly. The study participants included people of multiple races and ethnicities, including African Americans, and found minorities were less likely than non-Hispanic Whites to seek care within two hours after onset of symptoms because of limited cognitive representation of stroke. The researchers did not find minority status to be a significant independent predictor in the logistic regression; however, the researchers attributed this to a relatively small sample size and cautioned that with a larger sample race may be more of a factor (p. 32). Zerwic, et. al (2005) did not find a significant relationship between knowledge of stroke symptoms and length of delay in seeking treatment. This suggests that factors other than stroke knowledge influence a person's treatment seeking.

Leventhal, Meyer, and Nerenz (1980) suggest that individual's reactions to illness may be based on their cognitive representation of the illness (Zerwic, et. al, 2005; Leventhal, Meyer, & Nerenz, 1980). Identity, cause, time (e.g., chronic or acute), consequences, and cures are all factors related to the cognitive representation of illness. There are several studies examining the Common Sense Model of Illness Representation with regard to specific health concerns. Meyer, Leventhal, and Gutman (1985) studied the model in relation to hypertension. The researchers found study participants constructed common sense models of illness representation of

hypertension. Furthermore, the researchers found that the participants tended to base these models on prior illness experiences. An individual's psychosocial characteristics and popular media may also inform their perception of an illness (Anagnostopoulos & Spanea, 2004). Anagnostopoulos & Spanea (2004) examined perception of breast cancer and found that although the lay individual may not have personally experienced an illness, they formed a perception of the disease.

Study Design & Methodology

This exploratory study used a qualitative dominant mixed methods approach. The aim of this research was to determine how African American older adults anticipated they would react if they personally experienced stroke symptoms or if someone they knew was experiencing stroke symptoms. This project received approval from both the University of Kansas Medical Center Human Subjects Committee (HSC) and the Rockhurst University Institutional Review Board.

Study Assumptions

Since a majority of this research is qualitative in nature it is important to expose the primary assumptions of the study. There are three primary assumptions assumed in this study. The first assumption is that all participants answered each question based on his or her personal beliefs and knowledge. This assumption is based on the fact that participants voluntarily agreed to participate in the study at a location and time that was convenient for them. Each participant was also assured confidentiality and anonymity prior to taking part of the study.

The second study assumption is that there are in fact cultural and personal factors that influence health behaviors and health decisions related to stroke of African Americans. This assumption is made based on the research conducted on the cultural and personal factors under

investigation in the current study. The research over the cultural and personal factors is discussed in the literature review.

The third assumption is that the participants are representative of the population of interest. While the current study has a relatively small sample size, the participants chosen reflect the group of people who are thought to be at an increased risk of stroke based on age, race, and lifestyle as identified by National Institute of Neurological Disease and Stroke (NINDS), National Stroke Association (NSA), and Centers for Disease Control (CDC).

Procedures & Participants

Procedures

This exploratory mixed methods study involved three components (i.e., two qualitative components and one quantitative component). All three components were conducted during the same visit with the participant, thereby, limiting the possibility of the participant not completing the study because of time or other constraints.

Population of interest

The population of interest for this study was African American men and women aged 55 and older. Fifty-five years is the age after which stroke risk begins to double with each passing decade of life (NSA, 2013), thus was the rational for targeting this age group. The age group 55 and older was such a broad age group that the researcher used the age categories suggested by Transgenerational (2014) to aid in deeper exploration of the participants responses. The ages of older adults were divided into three categories (Transgenerational, 2014). These categories were *'young-old'* (ages 55-74), *'old'* (ages 75-84), and *'oldest-old'* (ages 85+).

Study Sample

A convenience sample of six (6) participants with stroke and 14 participants without stroke were included in this study. The participants with stroke included individuals who self-

reported as having stroke of varying severity and type. Participants were recruited from the investigator's personal contacts, Palestine Senior Citizens Activity Center, American Stroke Foundation, and the Rehabilitation Institute of Kansas City. The recruitment sites shared common features including providing services to African American adults aged 55 and older, many of whom live in the urban core, which provided the investigator with good access to potential study participants.   Each of these sites expressed enthusiastic support for this project and provided the investigator with a letter of approval to initiate data collection activities. *Twenty out of 21 individuals screened for inclusion in the study agreed to participate. The one individual who declined to participate did so because of concerns with signing the consent form.

Study recruitment sites

Palestine Senior Citizens Activity Center (PSAC) is an urban, community-based, senior activity center serving people aged 55 and older. At PSAC, individuals have opportunities to participate in varied activities such as exercises, nutrition classes, and other recreational activities. PSAC was chosen because the majority of participants are African American, and many appeared to fit the inclusion criteria. The researcher spent a total of 24 hours, across four weeks at PSAC collecting data. A total of 15 participants (three (3) with history of stroke and 12 without history of stroke) were interviewed at PSAC. The administrator for PSAC allowed the researcher to have a private room within which to interview the study participants. While at PSAC, the researcher worked to get to know the participants at the center outside of the research. As such, the center participants became invested in the research and many served as referral sources for additional research participants. At the conclusion of data collection at PSAC, the researcher maintained a presence at the center through visits and another research project. One of the center's members also invited the researcher to provide stroke education to a senior

ministry at a local urban core church with a primarily African American congregation. The researcher provided this education and has been invited to other churches/organizations.

The *American Stroke Foundation (ASF)* is a community based organization currently providing the Next Steps Program in Kansas City, MO, Blue Springs, MO and Mission, KS. The primary site for recruitment was the Next Steps Program in Kansas City because of the investigator's familiarity with the site and clients. The researcher worked with the program manager to identify potential participants for the study. A total of two (2) participants were identified for inclusion in the study. While the researcher had a relationship with ASF prior to the initiation of the study, the researcher has continued her relationship with the program providing pro bono speech language pathology services and stroke education to the program participants on an almost weekly basis.

The remaining three (3) participants in the study were recruited from investigator personal contacts. Participants gained through personal contacts were individuals who fit the inclusion criteria and who were referred to the investigator by community and work associates. The researcher also attempted to recruit participants from the Rehabilitation Institute of Kansas City; however, was unable to secure any participants that fit the inclusion criteria from this site primarily due to the severity of the clients' deficits post stroke and ability to participate in the research.

The participants were each given a unique identifier. The identifier designated the site (e.g., 1=PSAC, 2=ASF, 3=R!KC, 4=Personal Contact) and the number interviewee (i.e., first interview of the day will be assigned a 1). For example, the participant who was the first interview at PSAC was coded as '101' and the first interview at ASF will was coded as '201'.

Recruitment

Participants were recruited via study fliers and word of mouth at each site. Contact with each participant was made face-to-face. The investigator explained the study to each participant. Participants agreeing to participate in the study were given written informed consent. The investigator reviewed the consent form with each participant prior to obtaining signatures. Recruiting was continued at each site until the investigator could not find any additional individuals, meeting inclusion criteria, who were willing to participate in the study.

Participants were offered bottled water and snacks (i.e., granola bars) during the study and written handouts about stroke after the study. The written handouts were created by the investigator and based on the American Heart Association/ American Stroke Association Know Stroke facts. The investigator has used these handouts in community health education events in which she has participated in the past. The investigator self-funded printed materials, snacks, and bottled water.

Inclusion and Exclusion Criteria

Inclusion criteria were: (a) participant self-identified as African American, (b) aged 55 years or older, (c) provided his or her own responses to questionnaires and interview via either verbal or written means, (d) was a fluent speaker of English, (e) was born and raised in the United States, and (f) was able to give consent to participate in the study.

Exclusion criteria for the study were as follows: (a) participant was unable to provide responses to questionnaires due to significant language or cognitive linguistic impairment, (b) had acute illness at the time of the study (e.g., flu, cold, etc.), (c) had a chronic neurological health condition other than stroke (e.g., Parkinsonism, Alzheimer's Disease, Multiple Sclerosis, or other condition), (d) was the primary caregiver to a person that has had a stroke, and (e) had previously participated in this study.

Language impairment and cognitive linguistic impairment were not formally screened by the investigator. The investigator has over 10 years' experience as a speech language pathologist and therefore, informally screened participants' language and cognitive linguistic abilities via informal observation and interaction. The investigator engaged participants in informal conversation prior to initiating the research protocol. Had any potential participant been found to have difficulty with receptive or expressive communication in informal observation interaction, they would have been excluded from the study.

Study Pitfalls and Solutions
Use of the IPQ-R or IPQ-Brief in Multicultural Populations

One of the criticisms of use of the illness perceptions questionnaires is that they have been developed from a culturally neutral, or, etic approach (Rudell, Bhui, & Priebe, 2009). This may limit their applicability to culturally diverse groups as the questionnaires may not capture the cultural variations that may drive health decisions. Rudell, Bhui, & Priebe (2009) suggests that use of a mixed methods methodology is preferable as it may "allow a greater understanding of cross-cultural variations in the content and communication of illness perceptions" (p. 344). Hekler, Lambert, Leventhal, Leventhal, Jahn, & Contrada (2008) successfully used questions based on the Illness Perception Questionnaire-Revised (IPQ-R) in their research discussing African American's, hypertension, and illness representation. To address the use of this measure in the African American population the investigator used questions from the IPQ-R as stated and scored via a five-point scale. Participant's illness representation of stroke were further investigated via the semi-structured interview.

Use of the IPQ-R in Healthy Populations

The use of the IPQ-R in healthy populations is a point of consideration. The IPQ-R is designed to examine the illness representations of individuals currently experiencing the disease

in question. Figueiras and Alves (2007) conducted a factor analysis on IPQ-R questions with revised wording for healthy individuals. The re-worded questions were determined to have similar factorial structure to the original IPQ-R (Figueiras & Alves, 2007). The IPQ-R questions used in the current research were determined to be appropriate to use with healthy individuals (Anagostopoulos and Spanea, 2007).

Purposeful Sampling

Another potential pitfall of this study is that the qualitative data was collected via purposeful sampling and therefore is not generalizable to the African American population as a whole (healthy and not healthy). A solution to this potential pitfall is in how the purposeful sample is interpreted. Purposeful sampling is not meant to generate information that will generalize to the population, but rather, this study is meant to highlight "information rich cases" that answers the proposed research questions (Patton, 1990, p. 169). The information gathered will be used to guide interventions, understand some of the needs of the specific population, and select more targeted education programs for this community (p. 169).

Bias in Qualitative Analysis

Multiple coding was used to buffer against introducing bias into coding procedures (Barbour, 2001). Another, trained, researcher, not connected with this research, analyzed a subset of data (three transcripts) to check for reliability, particularly with respect to discrepancies in the codes (Barbour, 2001). The second coder was an associate of the investigator who has conducted qualitative research in the past. This double check of the data allowed for findings that were more robust as the second coder was more objective since he or she was not directly connected to the research.

Qualifications of the Primary Investigator

The primary investigator has worked with stroke survivors and their families for over 10 years providing stroke education and speech language pathology services as both a clinician and community volunteer. She is an embedded member of the African American community. Her community membership and participation with community groups and organizations have allowed her to form and maintain relationships with members of the community. It is in part through these relationships that she was able to recruit participants and gather the data in the community.

Generalization of Findings

Historically, there has been criticism of qualitative research that its findings are not generalizable to the population at large due to the small sample sizes and the difficulty with exact replication of the study (Meyers, 2000). However, as noted by Meyers (2000), when the qualitative researcher keeps in mind the aims of the study, the generalizability in the traditional sense of the word may become less important. The current study aimed to provide in depth understanding of people's experiences from a cultural perspective. This study sought to understand how the participants' own personal factors and experiences influenced the way that they may respond to stroke. The current study does not suggest that all African Americans in Kansas City would have similar responses; however, the study examined the topic from multiple perspectives to gain further insight (Meyers, 2000).

Chapter 2: Demographic Features and Quantitative Assessments

The goal of quantitative analysis in this exploratory study was to describe the participants in terms of their (a) factual stroke knowledge, (b) anticipated response to stroke, (c) time orientation and (d) spirituality. This information was considered secondary to the qualitative data as it offered additional insights into the participant's statements. To accomplish this, descriptive statistics were calculated using Microsoft Excel 2013 and SPSS Version 22. These two programs were used because they offered the flexibility needed to analyze and visually display the results.

Assessment Instruments

One investigator administered all assessments to each participant. Questions from the assessments were read aloud with repetitions and clarifications as necessary. The rating scales (i.e., Likert or yes/no) were presented visually to participants as to ensure comprehension of what was being asked. Participants were asked to verbalize their responses as well as point to the scale to ensure participant responses were accurately represented.

Participants completed a demographic questionnaire followed by five separate assessments.   These assessments were used to obtain descriptive information about the participants' time orientation, spirituality, illness representation, current health conditions, knowledge of stroke, and anticipated action to stroke symptoms.

The investigator used assessments in Table 3.1 to obtain information about the participants' current health, spirituality, time orientation, and health related quality of life, stroke knowledge, anticipated reaction to stroke like symptoms, and illness representation.   Table 3.1 provides summary information regarding each assessment. The assessments were obtained

through the PsycTests® database which grants use of these assessments for educational and

research purpose. Each of the assessments proposed for use in the current study have been

previously tested for reliability and validity and all were determined to be acceptable for the

current study.

Table 3.1 Study Assessments

Name of Assessment	Author(s) of Test	Dependent Variable(s)	Scoring Used in Dissertation
Zimbardo Time Perspective	Zimbardo, Keough, & Boyd, 1997	Present or future time orientation	Five point Likert Scale. Sum items to yield a Future Time Perspective score, Present Time Perspective score, and total score.
Spirituality Measure	Taylor, Chatters, & Jackson, 2009	Importance of spirituality Self-rating of spirituality	Four point scale. Sum items to yield a total score.
Illness Perception Questionnaire	Moss-Morris, n.d. Anagnostopoulos & Spanea, 2005*	Individual representation of stroke	Five point scale. Sum scores to yield a score for each item category (i.e., Identity, Cause, Control/Cure, Timeline, and Consequence). Sum items to yield a total score.
Health Conditions Index	Schieman, McMullen, & Swan, 2007	Number of health conditions	Yes (1) No (0). Sum items to yield a total score.
Stroke Action Test	Billings-Gagliardi and Mazor, 2004	Response to stroke symptoms	Dichotomous score (1= call 9-1-1, 0= any other response). Sum items to yield a total score.
Know Stroke	National Institute of Neurological Disease and Stroke, 2013	Factual stroke knowledge	Dichotomous score (1= correct, 0= incorrect). Sum items to yield a total score.

While the original authors of the IPQ-R are listed as reference, the procedures for administration and scoring are more closely aligned with that of Anagnostopoulos & Spanea (2005).

The *Health Conditions Index* is a 12-item assessment providing information about an individual's current chronic health conditions (Schieman, McMullen, & Swan, 2007).   The assessment items were scored 1-(yes) or 0-(no) to indicate whether a person has the particular condition. Each item was summed to create a total score.

The *Spirituality Measure* is a two-item assessment normed on African Americans (Taylor, Chatters, & Jackson, 2009). There are two dependent variables measured by this assessment. The first item is the "overall importance of spirituality in the respondent's life" and the second item is the "overall self-rating of spirituality" (Taylor, Chatters, & Jackson, 2009, p. 7). The assessment is scored using a four-point scale with a score of one indicating "not very important or not very spiritual" and a score of four indicating "very important or very spiritual" (p. 7). The items were summed to yield a total score.

The *Zimbardo Time Perspective Inventory-Short Version (ZPTI-short)* (Zimbardo, Keough, & Boyd, 1997) is a four-item inventory examining an individual's orientation to time. The inventory examines specifically future time and present time orientations. The short form of this assessment was chosen because of its functional utility (i.e., number of questions and time needed for administration) and ability to capture information about time orientation similar to that of the prevailing literature, which focuses on present and future time orientations (Henson, et. al, 2006). For example, Brown and Segal (1996) examined present and future orientation with regard to hypertension management. In the study, African American respondents were found to be more present-oriented than their White American peers. This difference in orientation had implications for how the respondents managed their hypertension. The assessment is scored on a five-point Likert scale with a score of one reflecting 'not characteristic

of the participant' and a score of five reflecting 'very characteristic of the participant'. The items were summed and yield a total score.

The *Stroke Action Test (STAT)* is a 28-item assessment examining a person's response to stroke scenarios (Billings-Gagliardi and Mazor, 2004). The dependent variable is response to stroke symptoms. For the purposes of this research, five questions from the assessment will be administered due to the length of the assessment and potential fatiguing of the participant. The five questions chosen for inclusion reflect symptoms of stroke identified by the NSA (2013). Table 3.2 reflects the symptoms and questions included in the current study.

Table 3.2 Questions Used from STAT

Symptom	Question Modification
Face, arm, and/or leg weakness or numbness	Question Number 20: "Suddenly, I couldn't reach for my purse [wallet or other object as appropriate] because I couldn't make my right arm move" (This question has been shortened to reflect only arm weakness. The original question also discussed language deficit.)
Difficulty speaking and/or confusion	Question Number 10: "I answered the phone and realized I sounded drunk. I couldn't speak clearly no matter how hard I tried. I hadn't had any alcohol"
Difficulty with vision in one or both eyes	Question Number 4: "While I was watching TV I started seeing double. I felt like the room was spinning and I felt sick. I grabbed hold to an arm chair and held on tight. I was not drunk"
Difficulty with walking, balance, or coordination	Question Number 28: "While I was walking around my living room, I began to lose my balance for no reason at all" (Modified to be presented as a real-life situation).
Severe headache with no known cause	Question Number 21: "I was having dinner and suddenly felt like I had the worst

headache I have ever had in my life and I don't know why" (Modified to be presented as a real-life situation).

Source (Billings-Gagliardi and Mazor, 2004)

The original wording on the STAT switches from case study type questions about the person themselves, case study questions about family and friends, and factual statements. Case study type questions were used to present a more real-life scenario. Questions discussing what the participant would do if a friend or relative had the symptoms were modified to reflect if the participant had the symptoms. No specific scoring criteria were given for this particular assessment. However, per the NSA (2013), the only response to stroke-like symptoms should be to 'call 9-1-1' which is one of the options given on the assessment. Therefore, the investigator gave a dichotomous score to the assessment with a score of 1 representing the individual's intent to call 9-1-1 and any other response receiving a score of 0. The scores were summed to yield a total score.

The *Know Stroke: Test Your Stroke Knowledge* is a seven-item assessment examining a person's basic knowledge about stroke (NINDS, 2013). The dependent variable is degree of factual knowledge about stroke. This test was created by the NINDS as a part of the 'Know Stroke' campaign. No specific scoring criteria are given for this assessment by the NINDS. In this research, each correct response was scored as "1" and each incorrect response as "0". The scores were summed to calculate a total score for that individual. In addition to the questions on the Know Stroke assessment, participants were asked to do a free recall of stroke symptoms (i.e., list as many stroke symptoms as they could without cues). This information was used in addition to the Know Stroke assessment questions to gather information on how much stroke symptom knowledge the participants have.

The *Illness Perception Questionnaire-Revised (IPQ-R)* is 73-item assessment examining

illness representation (Moss-Morris, n.d.). Not all 73 items were administered, recognizing that

the number of items on this assessment is large and that participants may have had difficulty

completing this assessment along with the other assessments. Instead, the work by

Anagnostopoulos and Spanea (2005) served as a guide in the selection of the most appropriate

questions. Two items from each component of illness representation demonstrating the highest

factor loadings were used in the study. Wording for each statement was changed from "my

illness" to "a stroke". Scoring for this was on a five-point scale with a score of one

representing 'strongly disagree' and a score of five representing 'strongly agree'. A total score

for each category reflecting illness representation was calculated (see Table 3.3). To maintain

consistency with other assessments in the study the scores were reverse scored as above.

Table 3.3 Categorization of IPQ-R Individual Questions for Scoring

Modified IPQ-R Item (Anagostopoulos & Spanea (2005))
Perceived Consequence
1) Stroke leads to social isolation
2) Stroke negatively affects the way a person is viewed
Chance Beliefs
1) It is a matter of God if someone has a stroke
2) Stroke will improve only with God's help
Environmental Causes
1) Stroke is caused by pollution of the environment
Internal Cause Attributions
1) Some aspects of someone's personality are responsible for causing stroke
2) Anxiety or stress is a major factor in causing stroke
Cure/Control Beliefs
1) Stroke will improve in time
2) Stroke can be completely cured

Participant Demographics

Participant demographics were collected prior to the interview. Descriptive statistics

were computed for the non-stroke and stroke groups individually to describe demographics of

the groups (Astin & Jones, 2005, p. 296). Scatterplots and histograms were used to visually

inspect the data and revealed demographic data not to be normally distributed. Therefore,

averages are reported by medians rather than means to reflect skewedness of the data and to limit

outlier influence on the calculation (Portney & Watkins, 2000).   Table 3.4 summarizes

participant demographics of both groups.

Table 3.4 Participant Demographics

		No History of Stroke (n=14)	**History of Stroke (n=6)**
Age (in years)	Median	65.6	70
	Range	55-84	55-91
Age categories	<74 years	11	4
	74-84 years	3	1
	>85 years	0	1
Gender	Female	12	4
	Male	2	2
Education Status	Grades K-11	0	2
	High School	2	2
	Technical	1	0
	School	11	2
	Post-Secondary		
Marital Status	Single	2	1
	Married	4	1
	Divorced	2	2
	Widowed	6	2
Living Situation	Alone	6	4
	With someone	8	2
Outside Activities	Working Full Time	4	0
		3	0

	Working Part Time	7	5
	Retired	0	1
	Unemployed (Disability)		
	Range	0-8	3-8
Median chronic health conditions other than stroke	Median	4	6.5
	Variance	4.7	4.4
Risk factors for stroke	Diabetes	2	6
	Heart Disease	2	2
	Hypertension	8	6
	High Cholesterol	7	5

Analysis of Study Variables

The range, median, and median absolute deviation (MAD) were calculated for all study variables to describe each group. The maximum score achievable on each measure is also reported. Tables 3.5 provides a summary of the study variables.

Table 3.5 Summary of Study Variables

		No History of Stroke (n=14)	History of Stroke (n=6)
Stroke Action Total	Max Score Possible	5	5
	Range	0-5	0-5
	Median	2	2.5
	Median Average Deviation	1	1
	25%tile	0.8	1.5
	75%tile	3.5	4.3
NINDS Know Stroke Total	Max Score Possible	10	10
	Range	6-10	4-9
	Median	9	6
	Median Average Deviation	1	1.5
	25%tile	8	4.8
	75%tile	10	9
Future Time	Max Score Possible	10	10
	Range	2-9	4-10
	Median	7.5	8.5

	Median Average Deviation	2.5	1
	25%tile	6.8	5.5
	75%tile	8.3	9.3
Present Time	Max Score Possible	10	10
	Range	2-8	2-9
	Median	4.5	6.5
	Median Average Deviation	1.5	1.5
	25%tile	3.8	4.3
	75%tile	7	8.3
Spirituality	Max Score Possible	8	8
	Range	7-8	7-8
	Median	8	8
	Median Average Deviation	0	0
	25%tile	7.8	7
	75%tile	8	8
Perceived Consequence	Max Score Possible	10	10
	Range	4-9	5-8
	Median	6	7
	Median Average Deviation	2	1
	25%tile	4	5
	75%tile	8	8
Chance Beliefs	Max Score Possible	10	5
	Range	2-9	0-8
	Median	2	5
	Median Average Deviation	2	2
	25%tile	4	3
	75%tile	8	8
Environmental Causes	Max Score Possible	5	5
	Range	1-4	0-2
	Median	2	2
	Median Average Deviation	0	0
	25%tile	2	.8
	75%tile	3	2
Internal Causal Attributions	Max Score Possible	10	10
	Range	5-10	0-9
	Median	7	8
	Median Average Deviation	1	1
	25%tile	6	4.5
	75%tile	8.3	9
Cure/control beliefs	Max Score Possible	10	10
	Range	4-10	0-8
	Median	6	6
	Median Average Deviation	1	0
	25%tile	4.8	4.5
	75%tile	7	6.5

Intent to call 9-1-1. Participants' total score for the STAT and NINDS Know Stroke are reported in Table 3.5 above. Figures 1 and 2 show a visual representation of the STAT and NINDS Know Stroke data via box plots to visually compare the medians for each participant group. Blue boxes represent participants with stroke history and yellow boxes represent participants without stroke history.
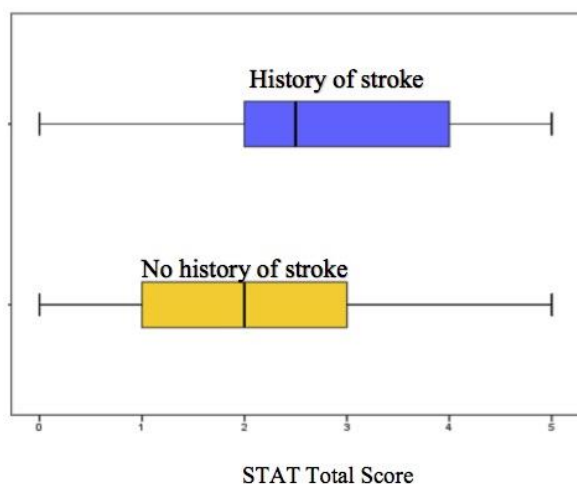

STAT Total Score

Figure 1. Box plot representing distribution of scores on STAT for participants with and without history of stroke. These findings suggest that both participant groups had similar median scores for Call *9-1-1* response to stroke symptoms.
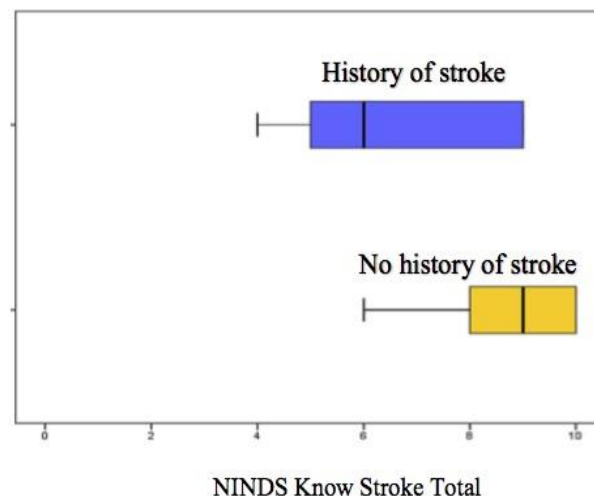

NINDS Know Stroke Total

Figure 2. Box plot representing distribution of scores on NINDS Know Stroke for participants with and without history of stroke. These findings suggest that participants without stroke correctly answered more questions about stroke than participants with stroke history.

Participants' responses to individual items on the STAT were also examined to compare if any particular symptom type would prompt a specific response. The proportion of the sample calling 9-1-1 in response to a specific symptom is reported to get a sense of how the groups as a whole would respond to different symptoms related to stroke (Table 3.6).

Table 3.6 Calling 9-1-1 in Response to Specific Symptoms

Symptom	No History of Stroke Call 9-1-1 (n=14)	History of Stroke Call 9-1-1 (n=6)
Decreased mobility of the upper extremity	6	5
Slurred speech	9	4
Dizziness	7	3

Loss of balance	4	2

Question 6 from the NINDS was analyzed as part of the total NINDS score, but also as a separate question. The rational for this was to get a sense of what individuals would do in response to stroke, not necessarily independent symptoms related to stroke as is the case in the STAT. The proportion of each group who indicated that they would call 9-1-1, or other action, when asked about what they would do if they thought someone were having a stroke was calculated. Participant responses for this question are presented in Table 3.7. Note that in the stroke history group one participant stated none of the options were appealing and that '*having the person lay down and rest'* was the best response to the question. This response is indicated in the *other* category in the table.

Table 3.7 NINDS Response to Stroke Symptoms

Response Choice (from NINDS)	No Stroke History (n=14)	Stroke History (n=6)
Call 9-1-1	12	5
Drive to emergency room	1	0
Drive to doctor's office	1	0
Other response given (not offered as response choice)	0	1

Time Orientation. The majority of the participants with no stroke history believed the statements related to future orientation to be somewhat *characteristic of themselves* to *strongly characteristics of themselves* on these items. These same participants believed the statements related to present orientation to be *not characteristic* of themselves to *somewhat characteristic* of themselves.   The majority of the participants with stroke believed the statements related to future orientation to be somewhat *characteristic of themselves* to *strongly characteristics of themselves* on these items. Participants with stroke history found these statements to be *not*

characteristic of themselves to *very characteristic* of themselves. Figures 3 and 4 provide a

visual representation of Time Orientation for both groups of participants.
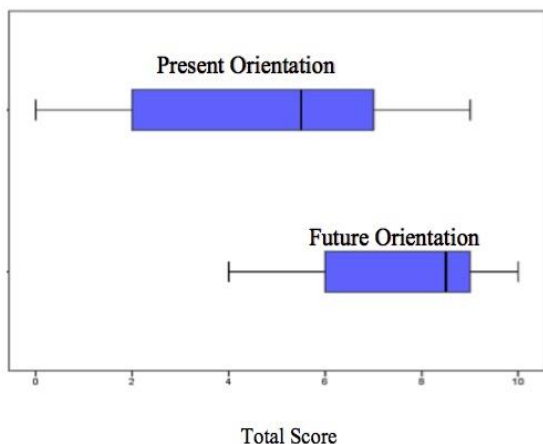

Figure 3. Box plot representing distribution of scores for present and future time orientations for participants with a history of stroke. This finding suggests participants with stroke history have a stronger orientation toward the future.
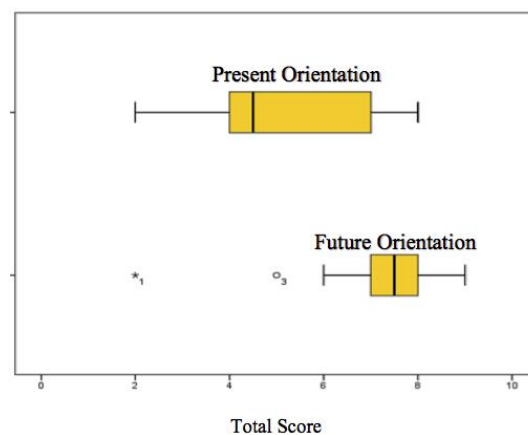
Figure 4. Box plots representing distribution of scores for present and future time orientations for participants without history of stroke. This finding suggests that participants without stroke history have a stronger orientation toward the future.

Association of Study Variables

A Pearson's Correlation was conducted to explore the data for possible associations.

Because the data is not normally distributed, any correlations found must be interpreted with

caution. The analysis revealed correlations between Present Time Perspective and Spirituality

and Internal Causal Attributions (ICA) and Cure/Control Beliefs (CCB). Table 3.8 provides the

correlation matrix of the study variables. Correlations significant at $p<0.05$ are indicated with

one asterisk (*) and correlations significant at $p<0.01$ are indicated with two asterisks (**)

Table 3.8 Correlation Matrix of Study Variables

Variable	1	2	3	4	5	6	7	8	9	10
1. STAT	1									
2. NINDS	.396	1								
3. FTP	-.052	.131	1							
4. PTP	-.371	-.408	.104	1						
5. Spirit	-.135	.047	.395	**-.528***	1					
6. PC	-.166	-.010	.401	.054	.068	1				
7. CB	-.290	-.172	.318	.200	.084	.254	1			
8. EC	-.087	.404	-.271	-.189	-.251	-.154	.251	1		
9. ICA	-.268	.028	-.107	-.019	-.176	-.053	.190	.439	1	
10. CCB	-.021	.106	-.252	-.096	-.059	-.319	.015	.354	**.785***	1

**Correlation significant at <0.05*   *******Correlation significant at <0.01*
Stroke Action Test (STAT), National Institutes of Neurologic Disease and Stroke Know Stroke (NINDS), Future Time Perspective (FTP), Present Time Perspective (PTP), Spirituality (Spirit), Perceived Consequence (PC), Chance Beliefs (CB), Environmental Causes (EC), Internal Causal Attributions (ICA), and Cure/Control Beliefs (CCB

Outcomes of Quantitative Analyses

The purpose of the quantitative portion of this research was to describe participants in the study and variables that may have influence on African Americans' anticipated response to stroke symptoms. The study variables included time orientation, spirituality, illness representation, and factual stroke knowledge.

A total of 21 individuals were recruited for participation in the study with 20 individuals ultimately enrolled in study. One individual was excluded for failing to meet the inclusion criteria as this individual had a previously diagnosed neurologic condition (unrelated to stroke). The majority of participants in both participant groups were female (86% female in the no history of stroke group and 67% female in the stroke survivor group). The US Department of Health and Human Service Administration for Community Living (n.d.) suggests that for every 129 African American females aged 65 and older there are 100 African American males of the same age. The breakdown of participants by sex in the current study is not a surprising finding given that there are more African American females than males of this age group.

Age and activities. The participants with no history of stroke had an average age of 65.6 years with a minimum age of 55 and a maximum age of 84. The participants with history of stroke had an average age of 70 with a minimum age of 55 and a maximum age of 71. The adults in the group with stroke on average are approximately five years older than individuals in the no history of stroke group.

The majority of the participants in both groups fell within the *young-old* age category (aged 74 and younger) (Transgenerational, 2014) with 11 of 14 of the participants with no stroke and 4 of 6 participants with stroke history falling within this category. The age of the participants is an important consideration because individuals falling within the young-old age category may have different life demands than their older counterparts (Transgenerational, 2014). For example, young old adults may be actively parenting children or adolescents and many of these adults may also maintain some degree of employment (Fetsch & Jacobson, 2011). In the current study, half of the participants (n=7) in the group with no history of stroke reported that they worked full or part time. None of the individuals in the history of stroke group reported working full or part time. This may be in part due to their stroke status as the majority of the stroke survivors reported being retired because of age or unemployed due to disability (n=4).

Education. The participants in the no history of stroke group had proportionately more years of education relative to the group size (11 out 14 participants in the group indicated one or more years of post-secondary education) than did participants who have had strokes (2 out of 6 participants in the group indicated one or more years of post-secondary education). The Administration of Community Living (n.d.) reported that in 2008 approximately 60% of older African Americans had completed high school, whereas in 1970 approximately 9% had completed high school.

Chronic health conditions. On average, the participants with no stroke history had four chronic health conditions whereas the participants with stroke history had approximately seven chronic health conditions. The health conditions included diseases such asthma, osteoporosis, and arthritis. The participants were also asked about health conditions known to be risk factors for stroke (i.e., diabetes, heart disease/heart attack, hypertension, and high cholesterol) (NSA, 2014). Eight out of fourteen of the participants without stroke history reported having hypertension. Half of the participants with no stroke history reported having high cholesterol. All participants in history of stroke group reported having both diabetes and hypertension and five out of six individuals reported having high cholesterol.

Assessment Outcomes

Stroke action and stroke knowledge. The results of the analysis revealed participants in the no history of stroke and stroke survivor group to have relatively low scores on the Stroke Action Test indicating that for many of the participants, calling for emergency medical services when confronted with specific symptoms related to stoke was not their first response. Upon further inspection of the results from the Stroke Action Test, the group with no history of stroke were most likely to call 9-1-1 when confronted with speech deficits (n=9) while the stroke survivor group was most likely to call 9-1-1 when confronted with decreased use of the upper extremities (n=5). For both groups, loss of balance was least likely to prompt them to call 9-1-1. The range of scores suggests that there was a high degree of variability within each group with regard to individual scores on the STAT.

Participants in both groups demonstrated stroke knowledge with the group without stroke history scoring an average of 9 out of 10 on the NINDS and the group with history of stroke scoring 6 out of 10. Stroke survivors answered fewer items correctly with regard to

general stroke knowledge; however, this finding is consistent with the literature. Ellis, Barley, and Grubaugh (2013) found that stroke survivors often do not have complete knowledge about stroke especially about risk factors for stroke, even though they may understand the cause(s) of their own stroke. This may lead to difficulty in recognizing stroke symptoms and seeking immediate care (Ellis, Barley, & Grubaugh, 2013). Inspection of the spread of scores via box plots for individuals without stroke showed that overall the scores were clustered around median indicating that these participants' scores overall were similar. Although the median score for the stroke survivor group was lower than that of the group with no stroke history, it is worth noting that these individuals did have an overall more positive agreement of scores (i.e., they tended to answer very similarly).

Question 6 from the NINDS asked participants *what would you do if someone you knew was having a stroke?* This questions offers participants the chance to respond to stroke as a condition, rather than it specific symptoms. The majority of both groups of respondents indicated that calling 9-1-1 would be their first choice (no history of stroke=12 (86%); history of stroke=5 (83%)). Of note, participants in the no history of stroke who responded with something other than call 9-1-1 indicated that the person having the stroke would need help; however, they preferred to *drive the to the doctor's office or emergency rooms in a private car*. The one participant in the stoke survivor group indicating something other than calling 9-1-1 suggested *having the person lay down and rest* was the best response to stroke.

The findings from the STAT, NINDS total, and Question 6 of the NINDS suggest that there may be a gap in stroke knowledge between the overarching concept of stroke as emergency versus specifics about stroke and its symptoms. This finding adds to the current literature suggesting African Americans do not always call emergency medical services when faced with

stroke (Fussman, et. al, 2009) as it offers an alternative explanation that these individuals may know that stroke is emergency, but may not always associate symptom with disease/condition name and therefore, may not act in a healthful manner.

Correlational analysis revealed that stroke action (STAT) and stroke knowledge (NINDS) were not correlated. The non-correlation of the STAT and NINDS scores is not surprising as the finding is consistent with the literature suggesting having stroke knowledge does not always translate into healthful action when confronted with stroke symptoms (Gordon, 2009). Educating people about chronic health conditions is known to be an important part of intervention for individuals with chronic health conditions (Coalition of Nation Health Education Organization [CNHEO], n.d.); however, once an individual no longer requires active care and has less contact with the health care professionals there may be a decrease in persistence of effect (i.e., once the intervention is withdrawn, there is no additional follow through or carry over) (Gordon, 2009).

Time Orientation. On average the participants without stroke history scored higher on the subscales for future orientation (median=7.5) than on the present orientation subscale (median=4.5). This suggests the group with no stroke history was more future oriented which is not consistent with the literature that finds African Americans are more present oriented (Brown & Segal, 1996). The stroke survivor group scored slightly higher on the future orientation subscale (median=8.5) than they did on the present orientation subscale (median=6.5). Participants consistently were more future oriented; these scores should be interpreted cautiously because although the ZPTI-S is useful in gauging present or future orientation Time Perspective is a much more complicated construct than a present or future orientation. The literature on time orientation suggests time orientation is not either present or future oriented (Zimbardo, 1999).

Zimbardo (1999) argues there is a continuum of time orientation which includes past, present, future, and on some scales transcendental orientations (and all of the associated subscales). Time orientation also may be dependent on multiple factors including where the person is (e.g., psychological, emotionally, etc.) when they are being measured (Zimbardo, 1999). The current study shows that the group with no history of stroke and the group with history of stroke are similar in their simplified time orientation. Note significant overlap of scores when the two groups were compared (See Figures 3 and 4).

Spirituality. Both participant groups scored median score of 8 out of 8 on the spirituality questionnaire with both groups being tightly clustered around the median. This indicates individuals in both groups to perceive themselves as highly spiritual and to regard spirituality as an important factor in their lives. This finding is consistent with the literature suggesting that for a large number of African Americans, spirituality is an important part of their daily lives (Hendricks, Bore, & Waller, 2012).

Illness representation. Participants with no history of stroke scored a median score of six out of ten on perceived consequence items suggesting that these individuals believe that having a stroke will have a significant influence on a person's life. The same participants scored an average of five out of ten on chance beliefs, suggesting a moderate belief that God has a role in causing a person to have a stroke or allowing a person to get better. These participants scored an average of seven out of ten on internal causal attributes which suggests that these participants have a high degree of association between stress and/or personality traits as being a primary cause of stroke. This group also scored six of ten on cure/control beliefs meaning that the group does believe that strokes can be managed.

Participants with history of stroke scored similarly to participants with no stroke history on the illness perception scale. The participants without history of stroke scored an average of seven out of ten on perceived consequence which suggests that this group believes that stroke will have an effect on a person's life. They scored an average of five out of ten on chance beliefs suggesting a moderate belief that God has a role in causing stroke and/or curing stroke. The participants scored an average of eight out of ten on internal causal attributions suggesting a moderately high belief that stress and/or personality traits may be a primary cause of stroke. They also scored an average of six out of ten on cure/control beliefs suggesting that these individuals believe that strokes can be managed.

Associations Among Study Variables

The correlational analysis of study variables suggest two variable associations of interest. While the small sample size in the study precludes making any gross generalizations regarding significance, the correlations are discussed to highlight possible connections between variables that may warrant additional investigation in the future. Spirituality was found to be moderately inversely correlated with having a present time orientation ($p<0.05$ significance level). This suggests that the more the participant perceived themselves to be spiritual the lower they would score on present orientation items. A possible explanation for this may be that some types of spirituality, and religions, require individuals to participate in activities such as prayer, church services, and service that ultimately may not have an immediate reward but may help them achieve the individual's future spiritual goals. There have been questions about how far future orientation actually extends (McInerny, 2004). McInerny (2004) suggests that future orientation for adults may extend far past the future orientation of children and adolescents. It is possible that the participants in this study viewed the items on future orientation with a much more long range lens which may explain why they were more future oriented.

The second significant correlation was with regards to Illness Perception. Internal Causal Attribution (i.e., stress and anxiety cause stroke) was strongly positively correlated with Cure/Control Beliefs. A possible explanation for this correlation is that when people view their conditions through a stress belief model they may perceive the condition as more controllable (Phillips, Tuhrim, Kronish, & Horowitz, 2014). The median scores for both groups of participants on Internal Causal Attribution suggests a moderately agree to strongly agree perception that there are stress, personality, and/or anxiety factors at work in the development of stroke. Perhaps because these survivors perceive personal stress and anxiety as something as controllable they may feel as though by reducing stress and worry, they may reduce their chances of having a stroke. This idea will be explored further in Chapter 5.

Summary

Participant results on assessments reveal consistency with the literature regarding African Americans and spirituality, stroke knowledge, and response to stroke. Participants in the current study were found to be oriented to future time whereas the literature suggests African Americans in general are more oriented to the present time. The results from this chapter will be revisited in Chapter 5 along with the findings from the qualitative portion of the study (Chapter 3).

Chapter 3: Analysis and Results of Semi-Structured Interviews

The qualitative portion of the study used a qualitative descriptive approach. Qualitative description allows for an eclectic approach to data collection, which is useful to investigators who want "straight descriptions of phenomenon" of interest (Sandleowski, 2000, p. 334). The participants completed semi-structured interviews consisting of two primary questions (see Table 4.1). Each participant, with stroke and without stroke, were asked same two questions. The qualitative questions were asked first as a means to collect data on the participants' knowledge and representation of stroke before they were asked questions on the assessments. The goal was that by administering the qualitative questions first, the participants' uninfluenced view of stroke was uncovered. Questions in the semi-structured interview were intentionally vague to avoid leading the participants' responses and to promote an environment that was focused more on the participant and less on the investigator. However, the investigator had a pre-determined list of probe questions prepared for instances when participants provided vague or incomplete responses. Probes and requests for expansion and clarification were used throughout the interviews to ensure that participants were given the opportunity to fully express their experiences and opinions.

Question 1 elicited information related to the participant's illness representation of stroke. The questions used to probe for additional information were based on those proposed by Anagnostopoulos and Spanea (2005). Questions 2 and 3, elicited information regarding the participant's proposed plan of action to stroke symptoms for family/friend (question 2) and for self (question 3). These questions were asked separately because caregiver literature suggests that people may react differently to someone else having symptoms of an illness than if it is themselves who are experiencing symptoms (RCI, 2010).

Table 4.1 Semi-Structured Interview Questions

	Specific Questions
Question 1	Part 1: Tell me what you know about stroke.
	Possible probe questions based on Anagnostopoulos and Spanea (2005) *What do you think causes stroke?* *How long do you believe this illness lasts?* *Does stroke get better?* *Can you describe the treatments for stroke?* *How do you think a stroke effects a person's life?*
	Part 2: Tell me what it would look like if someone were beginning to have a stroke.
	Possible alternate question wording: *What are the warning signs of stroke?* *How would you know if someone was having a stroke?* *What are the symptoms of stroke?*
Question 2	If your friend or family member looked like they were having a stroke, what would you do?
Question 3	If you thought you were having a stroke, what would you do? (Follow up with 'why would you <insert participants response>)

Clarification and Expansion

All participants had an opportunity to provide additional narrative information during the third component of the study. The question to elicit this information was as follows: *Is there anything else that you would like to tell me about stroke?* Participants engaging in tangential conversation were redirected, as appropriate, to the topic. Participants were given written information regarding stroke at the conclusion of the study.

Validation of qualitative data

Creswell and Miller (2000) suggest using at least two of eight proposed methods of validation in qualitative research. This study used rich/thick description, peer review, and

clarifying, to validate the findings. Procedures for how these validation techniques were used are presented in the following paragraphs.

Rich description. Rich, thick description was accomplished by providing a detailed explanation of the participants and the information that they discussed in the interview (Creswell & Miller, 2000). The investigator made sure that the participants fully expressed their thoughts and ideas by allowing the interview to take as long as needed as well as using open-ended questions and probing for additional information as needed. The investigator also took field notes and made sure to follow up for clarification and/or deeper exploration into the participants statements. The investigator also gathered demographic information to describe who the participants in this study were.

Peer review. Peer review involves seeking out a peer who is not connected to the research to provide feedback regarding the methods, analysis, and findings. The investigator had a peer reviewer, who verbally agreed to review the codes, categories, themes, and nature of the study, provide the investigator with unbiased feedback about the study. The reviewer examined the data after first cycle coding, again after second cycle coding, and finally after themes were generated.

Clarifying. Creswell and Miller (2000) suggest that clarifying is the process by which the investigator exposes any potential personal biases and experiences that may inform or shape the interpretation of the data. These biases may shape the way data is coded, categorized, and themed (Saldana, 2008). To limit any potential bias, the investigator included information about her background with working with individuals who have had strokes and their families for over ten years, having family members who have had strokes, and being a member of the targeted community.

Procedures

Participants' interview responses were audio recorded and transcribed by the investigator. Participant interviews are included as Appendix D. All codes, categories, and themes were completed by hand. Coding procedures were initiated with careful attention paid to the coding pitfalls identified by Saldana (2008). Both First Cycle and Second Cycle coding procedures were used (Saldana, 2008). The First Cycle Coding procedure used was descriptive coding which allowed for the data to be summarized based on its content (Saldana, 2008, p. 48 & p. 70). Descriptive coding was used because it was most in line with the ideological framework of the study (i.e., qualitative description) as well as the methodological framework of the study (i.e., qualitative dominant mixed methods). Saldana (2008) also suggested that descriptive coding allowed for content analysis of the data and was a good choice for many types of qualitative research. The investigator first examined each transcript individually and generated a list of codes. The transcripts were searched for data that helped explain the research question under investigation. Coding continued for each individual transcript until no further codes could be generated (Braun & Clark, 2006). Transcripts were then cross-coded (i.e., codes in each transcript compared against each other for commonalities) (Braun & Clark, 2006). In instances were codes were the same for individual participants, rather than generate a new code, the previously established code was marked as having multiple occurrences across transcripts.

The Second Cycle coding procedure used was Patterned Coding (Saldana, 2008). In the second cycle of coding, the investigator examined the initial set of codes and determined if any of the codes seemed to cluster together. Codes that clustered together had shared connections. Those that clustered together were reorganized together as a specific category. Note, that none of the original codes generated in the first cycle were abandoned, instead, these codes were written

down individually, only now divided into their specific categories. Qualitative content analysis

procedures suggested by Sandelowski (2000) were used to analyze the data.

A directed content analysis of the codes was completed in both the first and second cycle

coding. A directed content analysis allowed the investigator to use existing theory (e.g., illness

representation) as well as established understanding of stroke (e.g., Face Arm Speech Time, or

FAST) to predetermine the codes needed to analyze the date (Hseih & Shannon, 2005).

Themes

Saldana (2008) suggests that codes, categories, and themes are all distinct from each

other. This current study generates codes, categories and themes according to Saldana (2008).

Saldana (2008) best describes coding process (i.e., descriptive coding) as using nouns to

illustrate and consolidate what participants are saying. He then suggests that categories are

broader groupings of the data. Finally, Saldana (2008) suggests that themes give rise to the

meaning of the data and look different from codes.   Themes are typically short phrases and

sentences that use verbs to describe what is happening. In the current study, themes were

generated based on the categories found in the second cycle of coding.   For example, when

searching for data related to identity of stroke (i.e., participant's ability to identify symptoms of

stroke) codes that clustered included physical aspects of acute stroke, mental aspects of acute

stroke, and emotional aspects of acute stroke. The investigator searched for patterns that existed

in these codes and ultimately used these patterns to generate categories. Categories were then

used to generate a list of themes. Figure 5 provides a visual representation of the qualitative
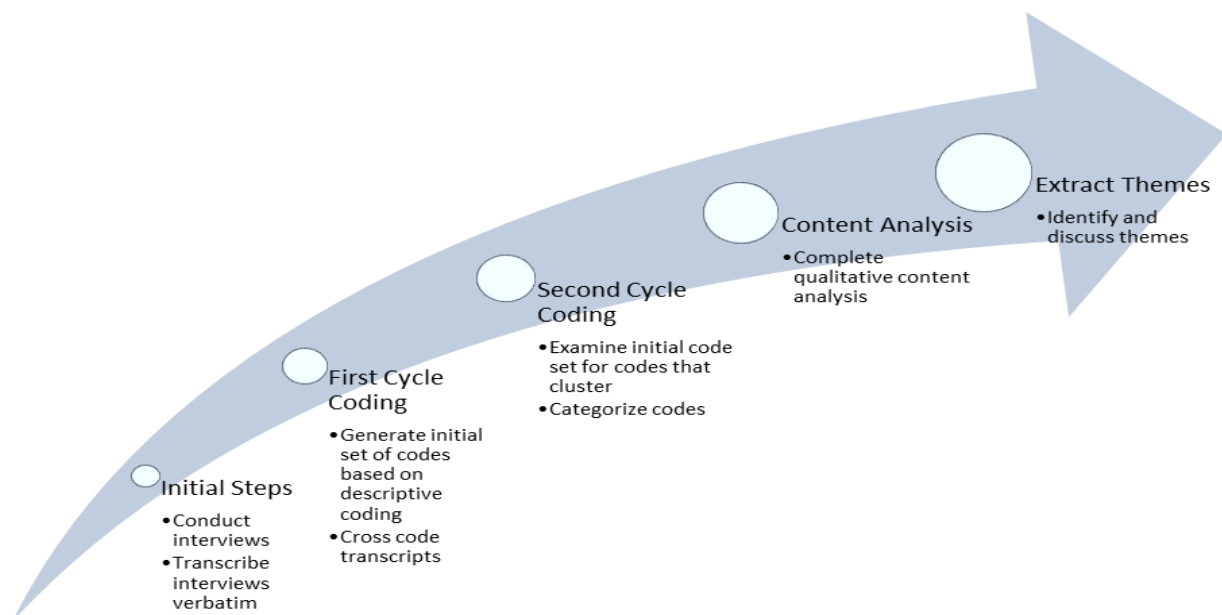
coding procedure.

Figure 5. Visual representation of qualitative coding procedure used in this study.

Analysis

Factual knowledge about stroke. Factual stroke knowledge was analyzed by using

participants' response to the free recall of stroke symptom. The recall of symptoms were

transcribed verbatim by the investigator. Pre-determined codes were used. The pre-determined

codes were in line with the commonly referenced F.A.S.T. (face, arm, speech, time) (NSA,

2013). Although, the 't' in F.A.S.T. was omitted as a code because the 't' in F.A.S.T. does not

describe a symptom, but rather a response to symptoms. Symptoms not falling into face, arm, or

speech categories were also coded. Table 8 provides a list of the themes emerging from the

interview data. Appendix E contains a list of all symptoms recalled for both groups.

Table 4.2 Themes Related to Perceived Symptoms of Stroke

	No History of Stroke Group (n=14)	Stroke Survivor Group (n=6) Symptoms
Perceived Symptoms of Stroke	a) Speech problems may be a symptom of stroke b) Vision problems may be a symptom of stroke c) Difficulty with walking/balance may be a symptom of stroke	a) Speech problems may be a symptom of stroke b) Sudden disorientation and/or forgetfulness may be a symptom of stroke c) Facial twisting may be a symptom of stroke

Illness representation.   Participants were asked the open ended question 'Tell me what you know about stroke' to illicit information about illness representation of stroke. Participants were given the opportunity to discuss stroke without any prompts; however, after describing their ideas about stroke, several prompts were given to encourage participants to provide additional information to establish their illness representation. Interview transcripts were coded individually for factors related to illness representations. The pre-determined codes identity, cause, consequence, timeline, and cure/control were used in accordance to existing literature about the factors that make up illness representations (Leventhal, Meyer, & Nernez, 2008). Cross-coding of transcripts occurred within groups (i.e., individual transcripts from participants without stroke were compared against each other). Codes that had similar underpinnings were then categorized.   Themes emerged in all categories which provided insight into an individual's representation of an illness (i.e., identity, cause, consequence, timeline, and cure-control). Table 9 displays the major themes and selected supporting data for each participant group.

Table 4.3 Illness Representations of Stroke Themes and Supporting Participant Data

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Identity

Theme: Visible symptoms are present in stroke

Participants with No Stroke History (n=42)

      Subthemes: Facial and Mouth Problems, Extremity Deficits, and Cognitive Deficits

      Participant quote: *"I know that the signs are numbness, disorientation, blurred speech, and sometimes there is numbness in your hands or your feet."*

Participants with History of Stroke (n=23)

      Subthemes: Facial and Mouth Problems, Extremity Deficits, and Cognitive Deficits

      Participant quote: *"So pretty much vision problems and started having a slight headache and their hands felt numb, twisting in their mouth and face, and tingling sensation."*

Cause

Theme 1: Stroke is caused by existing medical conditions

Participants with No Stroke History (n=12)

      Subthemes: High blood pressure and stress

      Participant quote: *"It [stroke] can be cause from a surge of blood pressure going through the brain causing it not to react in the normal way thus inhibiting bodily functions and movement."*

Participants with Stroke History (n=19)

      Subthemes: High blood pressure

      Participant quote: "Um, the blood pressure being out of control can cause a stroke."

Theme 2: Stroke is caused perceived unhealthy lifestyle choices

Participants with No Stroke History (n=17)

      Subthemes: Stress, poor nutrition, and lack of exercise

      Participant quote: "Poor diet and not really taking care of yourself cause stroke"

Participants with Stroke History (n=19)

      Subthemes: Stress

      Participant quote: *"Well that I don't know. Maybe stress? Worry might cause them to have a stroke."*

Consequence

Theme: Stroke causes changes to a person's lifestyle

Participants with No Stroke History (n=30)

      Subthemes: Incapacity, lack of independence, and death

      Participant quote: *"A lot of times if you have a stroke you can be incapacitated and you won't be able to take care of yourself."*

Participants with Stroke History (n=14)

      Subthemes: Physical symptoms, cognitive linguistic problems, and effects variable from person to person

Participant quote: *"[Stroke] can change life dramatically just in an instant, you are feeling well and living your life and it stops you from being able to do your job and taking care of yourself , your thought process."*

Timeline
Theme: People deal with stroke for the rest of their lives
Participants with No Stroke History (n=18)
    Subthemes: Effects are lifelong and over time may be able to recover some
    Participant quote: *"I don't think it ever gets back to where it was."*

Participants with Stroke History (n=6)
    Subthemes: none
    Participant quote: *"You may have symptoms that last a life time."*

Cure Control
Theme: Health changes and modifications will lead to improvements after stroke
Participants with No Stroke History (n=27)
    Subthemes: Change lifestyle and monitor health
    Participant quote: *"Watch your blood pressure and I know that I think exercises keep you from having a stroke."*

Participants with Stroke History (n=14)
    Subthemes: Change lifestyle, monitor health, and uncertainty of exactly steps to take
    Participant quote: *"Lose weight, cut down on salt, take blood pressure and all other mediations, keep up with doctor's appointments."*

n=total number of separate statements related to this theme

Anticipated response. Interview transcripts were coded for anticipated response to stroke symptoms based on responses to Question 3 and Question 4 of the research protocol.   In this instance, the investigator did not use pre-determined codes, although it is understood that there are a set of typical responses person could have with regard to responding to stroke symptoms (e.g., call 9-1-1 or do nothing). However, because a main goal of the current study is to understand what people do, the investigator wanted to let this particular data set generate its own codes. A conventional content analysis was used (i.e., codes generated emerge from the data) (Hsieh & Shannon, 2009). The codes were then categorized and major themes were

extracted from the categories. Major themes that emerged for both the no stroke history and

history of stroke groups are presented in Table 10.

Table 4.4 Themes Related to Anticipated Response to Stroke Symptoms and Supporting Data

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Anticipated response to family or friend with stroke symptoms

Theme: Get help immediately
Participants with No Stroke History (n=13)
      Subthemes: Call 9-1-1 and get them to the hospital
      Participant quote: *"Have them lie down and call an ambulance or take them to the hospital immediately so they can be given that medicine within the certain time."*
Participants with Stroke History (n=9)
- Subthemes: Call 9-1-1 and get them to the hospital
- Participant quote: *"Call 9-1-1 because there is nothing that I can physically do and I know now there is medication."*

Anticipated response to experiencing stroke symptoms
Theme 1: Get help immediately
Participants with No Stroke History (n=11)
      Subtheme: Call 9-1-1 and call friend/family member
      Participant quote: *"I know I should call 9-1-1 but I would call my daughter. I know that is probably wrong of me to do, but I would. I don't want to deal with the police, firemen, and all that."*

Participants with Stroke History (n=5)
      Subtheme: Call 9-1-1
      Participant quote: *"If I am able to I would call 9-1-1 and try to get an ambulance."*

Theme 2: Wait and see
(Note: this theme only occurred in the group with stroke history)
Participants with Stroke History (n=3)
      Subthemes: Uncertainty of symptoms leads to no response and refusal of treatment
      Participant quote (uncertainty of symptoms): *"Like when I was in [names a state] and didn't realize what a stroke was…so I didn't call 9-1-1."*
      Participant quote (Refusal of treatment): *"I didn't go to the doctor for three days. I refused, but they [family] took me anyway."*

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n=total number of statements related to this theme

Qualitative Insights from Semi-Structured Interviews

Knowledge and Illness Representation of Stroke

    Stroke symptom knowledge. Participants in both groups identified all of the symptoms commonly associated with stroke including face weakness and asymmetry, weakness/numbness of extremities, speech difficulties, and problems with mobility (NSA, 2014). Eldow and Selim (2011) suggest that stroke may have an atypical presentation, but still warrants the same response as common stroke symptoms. Each participant group identified symptoms they believed could be signs of stroke, such as dizziness, disorientation, and blurred vision. The participants in both groups also listed symptoms that were not necessarily associated with stroke. One participant in the stroke survivor group stated "people may feel strange, like out of body experience" (Participant quote).

    Identity. The overarching theme for both participant groups regarding stroke identity is that stroke has visible symptoms. Subthemes that emerged for both groups regarding stroke include 1) face and mouth symptoms, 2) physical deficits, and 3) cognitive changes. This finding suggests that individuals in both groups were able to accurately identify stroke as separate from any other health conditions (i.e., the participants did not list symptoms of heart attack or other chronic health condition).

    Cause. The main theme that emerged as cause of stroke for both groups was stroke is caused by existing medical conditions. The most commonly mentioned cause of stroke by both participant groups was hypertension with there being a total of 25 mentions of hypertension across both groups. Both participant groups also mentioned other chronic health conditions that they believed could contribute to stroke. These conditions included heart attack, diabetes, and cancer.

A second theme that emerged for both groups was that stroke is also caused by perceived unhealthy lifestyle choices. Participants in the no history of stroke group identified lack of exercise and perceived unhealthful dietary choices as a cause of stroke. Both participant groups firmly believed that stress was a major cause of stroke. Participants in the stroke survivor group were particularly interested in sharing stories about why they thought they had a stroke. For example, one participant stated that the stroke had been caused by the stress of marital infidelity and another participant spoke of facing jail time as the cause of her stroke.

A subtheme that emerged only for the stroke survivor group was the uncertainty of the cause of stroke. Three participants out of six in the stroke survivor group stated that they did not know what caused their stroke. However, these same participants were able to label some causes of stroke when taken out of the context of themselves. This finding suggests there to be a disconnect between symptoms experienced and the person's knowledge. This finding is interesting especially when taken in context of why people do not call 9-1-1. For these participants their own symptom awareness is separate from their stroke knowledge. This suggests that there exists a gap between experience (prior or current), knowledge, and action.

Consequence. The major theme that emerged for both participant groups with regard to the consequence of stroke was that that stroke would have significant effects on a person's lifestyle. Participants in both groups identified decreased mobility, cognition, and numerous health care visits as having significant effects on a person's ability to "go and do as they used to before the stroke" (Participant quote). Stroke survivors also discussed how their lives were no longer the same. One survivor stated stroke "can change life dramatically, just in an instant" (Participant quote). The spirit of this sentiment was reflected in five of six participant transcripts.

The statements supporting this theme for both groups clustered around the negative effects of stroke. However, one participant in the stroke survivor group stated that "surviving" was also an effect of stroke. This more positive consequence of stroke may be of interest in future studies.

Timeline. The timeline of stroke was investigated through the after effects of stroke. The theme that emerged for both groups is that the effects of stroke are life-long. Different subthemes emerged for participants without stroke history and participants with history of stroke. The subthemes that emerged for the no history of stroke group were that 1) stroke is life long and 2) that people have to take medications for the rest of their lives. The subtheme emerging for the stroke survivor group was that each person would have different experiences with stroke across their lives.

Cure/control. Both participant groups regarded stroke as manageable as long as individuals who had strokes were willing to make lifestyle changes and other health modifications. Participants in both groups identified changing diet, taking medications, losing weight, and keeping up with medical appointments as important to help a person improve once he or she has a stroke. An additional theme that emerged only for the stroke survivor group was uncertainty about what helps to improve stroke. There were five statements that related to this theme. When asked what a person could do to get better if they have had a stroke, one stroke survivor simply stated "I don't know, I have not gotten better".

Anticipated Response to Stroke
Response to stroke for friends or family. The overarching theme that emerged for both groups with regard to anticipated response to stroke symptoms was that if a person has stroke symptoms, they need to get help as quickly as possible. Subthemes that emerged in this category

were 1) call 9-1-1 and 2) drive the individual to the hospital. Respondents were asked why they

would call 9-1-1. Each participant indicating they would call 9-1-1 stated they would do so

because the person should get to the hospital quickly. Participants also indicated not knowing

what to do when confronted with stroke and relying on professional assistance.   One survivor

stated "Dial 9-1-1. That would be the first thing I would do because I figure I wouldn't really

know what to do, so if I dial 9-1-1 they could talk me through what I needed to do" (Participant

quote).

Respondents stating they would prefer to drive the individual to the hospital were probed

as to why they chose this over call 9-1-1. Similar to why they would call 9-1-1, participants

indicated the need to "get there quickly" (Participant quote) as rational for their choice. Most

respondents choosing to drive the person to the hospital indicated that they felt as though they

would be able to get the person to the hospital quicker than if they went by ambulance. One

respondent stated "I knew how long it would take them [EMS] to get there it's the urgency of the

situation. I can drive, I can put on my flasher, and I have had the police follow me before, to the

emergency room without any consequences" (Participant quote).

Response to stroke symptoms (self). The major theme that emerged for participants

regarding their own symptoms was again that their symptoms would require immediate attention.

The subthemes that emerged for the group with no history of stroke were 1) call 9-1-1 and 2) call

a friend, family member or neighbor for help. The participants acknowledged the need to call for

help. Participants choosing to call a friend or family member first were asked to discuss why

they would choose this option over calling 9-1-1. Participants expressed feelings of

embarrassment and symptom uncertainty as the primary cause of calling a friend or family

member. One participant stated, "I know I should call 9-1-1, but I would call my daughter. I

know that is probably wrong of me to do, but I would. I don't want to deal with the police, firemen, and all that" (Participant quote).

The subthemes that emerged for the stroke survivor participants were to 1) call 9-1-1 and 2) wait and see. Participants who responded with wait and see reported doing so because of embarrassment, symptom uncertainty, and refusal. One participant stated, "I didn't go to the doctor for three days. I refused, but they [family] took me anyway" (Participant quote). This participant was asked to discuss why he refused and the participant indicated that he or she "did not want to be bothered with doctors" (Participant quote). Another participant in this group stated "like when I was in [state in the United States] and didn't realize what a stroke was…so I didn't call 9-1-1" (Participant quote).

Summary

The findings from the semi-structure interviews revealed that participants generally regard stroke as an emergency and as such participants felt that getting help as soon as possible would be beneficial. However, half of the participants in the stroke survivor group demonstrated a wait and see approach. This is consistent with the finding by Ellis, Barley, and Grubaugh (2013) who suggested that CVA survivors were generally aware of the causes of their strokes but could not always identify stroke symptoms associated with stroke. This in turn influenced stroke survivors' response to stroke symptoms (Ellis, Barley, & Grubaugh, 2013). Chapter 5 will draw upon Chapters 3 and 4 to discuss African American response to stroke symptoms.

Chapter 4: General Discussion, Conclusions, and Implications for Practice

The purpose of this exploratory study was to examine older African American adult's anticipated response to stroke symptoms. Participants included stroke survivors and individuals with no stroke history.   The study examined if individual factors such as stroke knowledge, spirituality, and time orientation have any influence over a person's anticipated response to stroke symptoms. This study attempted to add to the current literature on stroke response by going beyond the frequently discussed health care access, financial considerations, and genetic predisposition in the African American community and focused on each individual's understanding of stroke and in turn the individual's plan for dealing with stroke symptoms.

Findings from the study suggest African Americans in this study understand stroke to be an emergency and plan to 'get help' if they are faced with stroke symptoms. The findings are also consistent with the literature, suggesting that possessing stroke knowledge does frequently does not equate to following through with appropriate actions (i.e., calling emergency medical services) when confronted with stroke symptoms (Fussman, et. al, 2010). Stroke knowledge is multifaceted in that a person has to recognize stroke as an emergency condition (even before being confronted with symptoms) and then link this emergent situation to acutely emerging symptoms. The individual must then be willing to take these symptoms as serious and respond by calling emergency medical services in a timely manner.

Discussion

Representation and Knowledge of Stroke

All 6 stroke survivor participants and 13 of 14 participants without stroke history were able to talk about what they perceived stroke to be (i.e., illness representation). Participants in both groups perceived stroke to be a life and quality of life threatening condition that presented

with visible symptoms. The most common themes regarding symptoms of acute stroke were

facial and mouth problems, extremity deficits (including gait), and cognitive linguistic

impairments (e.g., memory) which is consistent with the findings from the NINDS. Participants

in both groups had a moderate level of agreement the after effects of stroke could be managed.

The themes that emerged reflected ideas of stroke being improved with changes to the person's

health and lifestyle modifications. Participants comments generally centered around controlling

diet and exercise when discussing how to manage the after effects of stroke.

The theme that emerged as cause of stroke for both participant groups was pre-existing

medical conditions. Both groups perceived high blood pressure to be the main culprit in causing

stroke. The second theme that emerged as cause of stroke was perceived unhealthy lifestyle

choices. Included in this theme were lack of exercise and proper nutrition, as well as the idea that

perceived psychological stress is a direct cause of stroke. Median scores for participants without

stroke (Md=7) and with stroke history (Md=8) (minimum score=2 and maximum score=10) on

questions related to Internal Causal Attributions on the Illness Perception questionnaire showed

that participants in both group generally had a strong agreement with statements related to

perceived personal psychological stress as a direct cause of stroke. Generally speaking perceived

psychological stress is not thought to directly cause stroke, but rather influence and exacerbate

other health conditions (Baum & Poluszny, 1999). However, some research, such as that by

Jood, Redfords, Rosengren, Blomstrand, and Jern (2009), has found that there may be a link

between perceived psychological stress and ischemic stroke. Others have reported stressful life

events may be a factor in developing stroke (House, Dennis, Mogridge, Hawton, and Warlow,

1990). It is worth noting that a study by Phillips, Tuhrim, Kronish, and Horowitz (2014)

suggested that stroke survivors who had a stress belief model of stroke were more likely to have

more control over stroke risk factors like cholesterol and hypertension than did individuals with a medication belief model. In the present study, one participant without stroke history commented that "laughter and yoga" (Participant Quote) could also help the after effects of stroke, as she believed stress was a major cause of having a stroke. As there is evidence that perceived stress may have a role in stroke, it may be worth acknowledging and exploring the effects of perceived stress during stroke education.

While stroke is generally regarded as emergency in the African American community, individual symptoms of stroke may not be seen as emergent enough to warrant a call for help. These findings are consistent with the literature regarding the perceived emergent nature of stroke in the African American community (Skolarus, et. al, 2013) and the lack of understanding that individual stroke symptoms warrant immediate attention (Williams, Bruno, Rouch, and Marriott, 1997). Several stoke survivor participants discussed their own symptoms and subsequent action during their acute stroke. One participant who was a multiple stroke survivor stated "*I was sitting in a meeting and it was like this sheet came over my eyes and um it wouldn't go away. Now I know that it is a symptom. Both times I just kept going because it passed after a while*" (Participant Quote). Another survivor remarked "*Man, my arm felt funny and I nearly passed out*" (Participant Quote). Education surrounding stroke often talks about the symptoms happening simultaneously (i.e. facial droop, speech difficulties, upper extremity deficit, dizziness, and gait disturbance) yet, many of the stroke survivors discussed having one or two symptoms or an atypical stroke presentation when interviewed. Stroke education should both focus on the classic presentation of stroke symptoms and focus on getting help immediately for atypical symptoms a person cannot attribute to any other known cause.

Response to Stroke Symptoms

Participants without history of stroke all stated that if they were having a stroke or if someone they knew was having a stroke the response should be to get help immediately. However, for these participants getting help immediately did not always translate to calling 9-1-1. Twelve out of 14 participants without stroke history and 5 out of 6 with stroke history chose 'call 9-1-1' when asked what they would do if they thought someone was having a stroke (question 6 on the NINDS). During the interview portion of the study, both participants without stroke history and participants with stroke history stated calling 9-1-1 if they thought someone was having a stroke. However, when the question was changed to reflect what they would do for themselves, the participants without stroke history also added having a family member or friend transport them to a hospital or doctor's office as a viable option. One stroke survivor stated "*I know I should call 9-1-1, but I would call my daughter. I know that is probably wrong of me to do, but I would. I don't want to deal with police, firemen, and all that*" (Participant Quote). When asked to elaborate on this the participant cited embarrassment and uncertainty of nature and severity of symptoms as primary reason for not calling 9-1-1. Other participants felt they could transport the person having the stroke more quickly than waiting for an ambulance. One participant was asked why she would chose to drive a person to the hospital rather than call 9-1-1 and she stated "*I knew how long the hospital was and I knew how long it would take to get them to there and it's called the urgency of the situation. I can drive, I can put on my flashers, and I have had the police to follow me before to the emergency room without any consequences*" (Participant Quote). Individuals may wait to call 9-1-1 for many reasons. Kleindorfer, et. al (2009) and the National Stroke Association (NSA) (2014) Explaining Stroke 101 tool suggests that people may wait to call 9-1-1 because of concern with cost, embarrassment, and fear.

Others individuals may feel as though they are saving time by self-transporting to the hospital; however, in reality calling 9-1-1 results in initiation of treatment as soon as EMS arrives, which includes calling ahead to the emergency department to prepare the staff for the individual's arrival (Lin, 2012). Fussman, et. al (2010) suggests that although individuals may view stroke as an emergency there continues to be a lack of understanding on the importance of calling 9-1-1 rather than attempting to transport the individual by private car. More community level education on the benefits of EMS when there is suspected stroke, such as calling the emergency room physician and begin administration of treatments, could help improve individual use of EMS for stroke symptoms (Fussman, et. al, 2010).

None of the stroke survivors in the study indicated that they would have someone else drive them to the doctor's office or hospital. However, there were three statements made during the interviews that suggest that some of these stroke survivors had a wait and see response to their stroke symptoms. These responses were mostly centered on being unaware that their symptoms were in fact related to stroke. Another participant simply refused to go to the hospital when symptoms of his first stroke arose. He cited not wanting to endure the cost of a hospital visit for symptoms that may or may not be severe. Ellis, Barley, and Grubaugh (2013) found stroke survivors to be aware of what caused their strokes but to generally lack symptom specific knowledge that would prompt them to call 9-1-1. The current study's findings are consistent with prior reports stating stroke survivors did not demonstrate consistent intent to call 9-1-1 when presented with stroke specific symptoms (Ellis, Barley, and Grubaugh, 2013)

Personal and Cultural Factors

Internal causal attribution and cure/control beliefs. Examination of the study correlational analysis revealed a correlation between Internal Causal Attribution and Cure

Control beliefs. The work mentioned earlier by Phillips, Tuhrim, Kronish, and Horowitz (2014) which suggests that stroke survivors holding a stress-belief model rather than medical-belief model may have better control over their risk factors for stroke. In the stress belief model individuals perceive their health condition to be both caused by perceived stress and controlled by perceived stress reduction whereas individuals holding the medical-belief model believe their health condition to be both caused by medical conditions and controlled by medication (Phillips, et al., 2014). In a similar study by Hekler, Lambert, Leventhal, Leventhal, Jahn, and Contrada (2008) African Americans beliefs about hypertension were found to be most associated with a stress belief model. The authors suggested that a stress belief model led to poorer adherence to medications in favor of engaging in stress reducing behaviors. This finding is somewhat in conflict with the Phillips, et. al work that found stress belief to be helpful in managing stroke. However, since the two studies are comparing two related, yet distinct conditions (i.e., hypertension and stroke) this may suggest that stress-belief is helpful in some conditions while potentially harmful for others. Hekler, et.al (2008) suggests that it is probably most important to understand a person's illness beliefs especially the cause and controllability. Understanding what people believe about stroke coupled with facts may improve healthful responses to stroke.

Time orientation. Future orientation "is characterized by planning for and achievement of future goals" (Zimbardo & Boyd, 1999, p. 1278). Zimbardo and Boyd (1999) found that future orientation was correlated with sensation and novelty seeking (p. 1278). An orientation to the future is thought to be more positive in terms of well-being (Holman & Cohen-Silver, 1998). However, Holman and Cohen-Silver (1998) also suggest that it is not productive to be solely oriented to one time (past, present or future). Study participants tended to be more oriented toward future than present; however, this finding is not consistent with the literature.

Having a present orientation is a consistent finding across multiple studies examining temporal orientation and health in the African American community (Lukwago, Kreuter, Bucholtz, Clark, & Sanders-Thompson, 2002; Brown & Segal, 1996). African Americans on average tend to be more presently oriented and therefore, when faced with health conditions may make decisions based on this orientation. Zimbardo and Boyd (1999) suggests that there are two types of present orientation (*Present-Hedonistic* and *Present-Fatalistic*). Individuals who are present-hedonistic tend to look for things to address immediate needs rather than make sacrifices for future goals (Zimbardo & Boyd, 1999). Individuals with a present-fatalistic orientation believe that the future is predetermined and that individuals will not have influence over its outcome (Zimbardo & Boyd, 1999). The short form of the assessment solely examines orientation from a present or future perspective without consideration of hedonistic and/or fatalistic orientations. Also of note is the inverse correlation of present orientation and spirituality found in the current study. This correlation may be explained by participants perceiving themselves as a whole to be highly spiritual. Because of this, these participants may spend more time engaging in activities (such as church services, Bible studies, and other religious activities) that will lead to certain outcomes after death.

An anecdotal finding, based on investigator observation, was conflict with regard to spirituality and cause of stroke. When simply asked how spiritual they are, all participants rated themselves as "spiritual" or "very spiritual." Participants were also asked questions about God's influence on development and improvement of stroke. Participants generally appeared uneasy when answering this question. When asked why, they were uneasy and most participants simply stated the question was difficult to answer without further explanation. However, one participant commented "*I believe that it is a matter of God and that stroke will improve with God's help, but*

not only. God has given man wisdom and knowledge to use whatever is necessary for man"

(Participant Quote). This anecdote suggests the need to understand the variability of individual

spiritual and religious beliefs when interpreting actions.

Additional insights. There were two additional statements emerging from individual

participants that, while unable to be considered themes due to lack of reoccurrence in other

transcripts, are worth noting for future exploration. During the study, one individual commented

she *"might go home and think a whole lot of things about that"* (Participant Quote) after

participating, suggesting that having this interaction may have prompted her to reflect on her

own stroke status. It may be of interest to investigate further how one-on-one conversations with

individuals at risk of stroke influence their subsequent perceptions and responses to stroke.

Another participant stated "I think we as a people, Afro Americans, need to get more

information about stroke, we need to be more proactive versus reactive" (Participant Quote).

This statement is similar to Linda Raskin's editorial statement (Raskin, 2009) discussed in the

literature review of the current study (see page 65). The idea of *need more information* may

represent a good starting point to understand more specifically the informational needs of the

African American community, and to develop a strategy for how best to disseminate the

information that is needed and wanted by this community.

<div align="center">

Implications for Practice

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Professionals working in stroke care are charged with not only caring for persons after

stroke but also for promoting healthful behaviors among individuals at risk of stroke. The

findings of this research study support a need for continued consideration of an individual's

culture and consideration of how culture may influence an individual's health behavior. While

the literature gives professionals a place to start with regard to cultural consideration, this general

insight cannot replace the importance of a face-to-face interview and the gathering of cultural information specific to each individual. Related research suggests there is greater variability within a cultural group than between cultural groups (Billikopf, 2009). Considering an individual's spiritual preferences and time orientation may help build more individualized health education and promote adherence to health recommendations. It would be beneficial to gather this information about the individual's culture at the beginning of the interaction so that it can be considered throughout the entire journey through the health care continuum.

Professionals working in stroke care should also consider an individual's understanding and interpretation of stroke. Results from this study indicate that people may understand stroke as an emergency, but may not always understand the specifics about stroke. Gaining a sense of what an individual already knows about stroke will help in preparing stroke education. Rogers (2003) Dissemination of Innovation Theory suggests that information (or innovation) is more likely to be adopted if presented in a way that is 1) relatively advantageous, 2)trialable (e.g., the person is easily able to try out the intervention before adoption), 3) observable, 4) not complex, and 5) compatible with a person's lifestyle and belief system..

Future Research

As the current study was exploratory in nature, it will serve as a basis for the investigator to assemble focus groups in the community and further investigate stroke in the African American community. These focus groups will provide additional insights into the community and will allow for tailoring of more specific questions to address areas of concern. Along with data gathered from this study, the investigator will be able to pre-test, review, and revise questions based using the community members in the focus group as 'experts' given their

membership in the community. Information from the current study as well as future focus groups will provide information prior to additional data collection.

Future research should also examine the anticipated response to stroke and other chronic health conditions by African Americans aged 18-54. Given that African Americans are at increased risk for stroke regardless of age, it is of interest to understand how younger adults view stroke and then compare their views with the views of older adults. It would be interesting to examine whether targeted, culturally appropriate stroke education with children and adolescents reduces the risk of stroke in adulthood and older adulthood.

Another line of research that may emerge from this study is in examining what is needed to bridge the gap between knowledge and action. Considering factors such as access to healthcare, racial disparities in health and health care, and socioeconomics along with personal factors such as spirituality, time orientation, and illness representation may give rise to answers as to why people respond in the ways that they do to health emergencies. It would be interesting to compare these factors across groups such as men and women, adult and older adult, as well as experience and no experience with health conditions.

Information on how people acquire stroke knowledge and through what channels is also important. A future study could examine dissemination of stroke information through news and entertainment media and how African Americans process this information. It would also be of interest to find out if entertainment media does have an influence African American's health behavior regarding stroke.

A final line of research to be pursued is examining why some stroke symptoms prompt people to call 9-1-1, while other symptoms are treated with an approach of wait and see or call

the physician to schedule an appointment. A hope for this research will be to understand what and why specific symptoms prompt someone to action.

Study Considerations

One consideration of this study is that participants were all recruited from the Kansas City metropolitan area which has several stroke accredited hospitals, stroke support groups, and stroke resources. A majority of the individuals in the study were members of the American Stroke Foundation or the Palestine Senior Citizens Activity Center. Through membership in these organizations and living in Kansas City the participants may have had more exposure to stroke information than the African American population at large.   Another study consideration is that no participants from Rehabilitation Institute of Kansas City (R!KC) were included in this study. After the research protocol had been administered to several participants it was deemed that individuals having had recent strokes and still in active therapies for stroke may have increased difficulty with completing the study. This opinion was based on the clinical experience (i.e., speech pathology) of the investigator. Having participants from this R!KC may have contributed to the diversity of responses made by participants in the study.

There is a relative degree of homogeneity with in the participants that must also be considered. A majority of participants were recruited from the Palestine Senior Citizens Activity Center as part of the convenience sample. PSCAC is associated with a local church in the Kansas City metropolitan area that is much known for offering services and outreach to the community in which it resides. Because of this, individuals recruited from PSCAC may hold similar beliefs with regard to spirituality, service, and health which may have influenced their responses.

Another study consideration is with regard to the assessments. The small number of participants taking the quantitative assessments makes it difficult to generalize the findings from the assessments to the population at large. The results from the assessments should be interpreted cautiously. However, the assessment results did provide information that allowed for a more through description of the participants in this study. Future studies could focus on the assessments with a larger participant group thereby allowing for more generalizability of the findings.

An additional consideration is the use ZPTI-short in the current study. The ZPTI-short does not capture all time orientations. Participant results for time orientation may have been different if the original ZPTI was used. Along these same lines, a broader assessment of spirituality may have been of benefit to capture the diversity of spiritual beliefs within the African American community.

Health literacy is a final study consideration. The current study did not specifically examine the participants' health literacy skills. The investigator was interested in understanding only the participants' knowledge of stroke and not general health information. While many health literacy assessments exist, the investigator could not find a specific health literacy assessment related to stroke. In future work, it may be of interest to measure general health literacy to understand its influence on stroke action.

Conclusions

Results from the current study found that African Americans regard stroke as an emergency and intend to respond to stroke by 'getting help'. 'Getting help' to these participants meant calling for emergency medical services or having a friend or family member transport them to the hospital. There is a critical time period from onset of acute stroke symptoms to

getting treatment that must be considered. Most sources on stroke recommend that individuals experiencing symptoms of stroke get to the emergency room within three hours for diagnosis and possible treatment with medications or surgical interventions that may reduce risk of death or significant disability (NSA, 2013).

African Americans have the highest risk of stroke compared to all other racial and ethnic groups in the United States (Kleindorfer, 2008). African Americans who sustain stroke are more likely to die or have significant disability after stroke (NSA, 2013). Some of the factors contributing to the increased risk of stroke in this community may stem from reasons relatively out of the individual's control such as access to health care, genetic predisposition to stroke, and socioeconomic factors. Yet, there are things that individuals in this community can do reduce the risk stroke (e.g., health check-ups) (NSA, 2013) and lessen the effects of stroke (e.g., calling emergency medical services and getting treatment immediately) (Fussman, 2010). The current study highlights an important consideration which is knowledge does not always translate into action. Arming this community with accurate and complete stroke knowledge and equally as important, assisting individuals in this community with developing plans of action should they experience stroke symptoms is an important first step in reducing this disparity.

Finally, in working with populations at risk of chronic health conditions it is important to understand the community from their perspective (The Community Tool Box KU, 2015). The Community Tool Box KU (2015) suggests that understanding a community from the perspective of its members, history, concerns, and needs may have great influence on how successful interventions within the community will be. This study highlights the importance of health education efforts by discussing what participants already know and exposing gaps in knowledge that may influence healthful behaviors. While this study specifically focused on African

Americans, all communities would benefit from more specific and focused health education efforts. This is especially true for communities at risk of the specific health conditions targeted by the health education interventions. In thinking about how to educate communities it is important to realize that the communities with which health educators come in contact may already have preconceived thoughts and ideas about specific health conditions. The health educator or practitioner must also be aware of her or his own assumptions and ideas about the health condition as well as her or his thoughts about community in which they are serving. The current study offers additional insights about stroke directly from members of the African American community that may be helpful to those professionals wishing to serve this community and the community itself.

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Appendices

Appendix A: Literature Review 1

Caregivers' Perceptions of Burden when Providing

Care to Loved Ones with Chronic Neurologic Health Conditions

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This document of one of three comprehensive reviews of the literature completed as a prerequisite for the Oral Comprehensive Examination in Therapeutic Science. This document was approved by a Comprehensive Examination committee on May 2, 2012.

Former First Lady Rosalyn Carter stated, "There are only four kinds of people in the world, those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers" (Rosalyn Carter Institute for Caregiving [RCI], 2010). The RCI for Caregiving was created to promote the better understanding of the caregiving experience and its influence on both the caregiver and the care recipient (RCI, 2010).

A "caregiver" is defined differently in the literature. Most definitions of caregivers are separated into informal and formal caregiving systems (Winslow, 2003). The term formal caregiver is used to refer to a paid professional who has some degree of training in providing skilled care (e.g., home health providers) (Winslow, 2003). In contrast, an informal caregiver refers to those people related to the patient as close kin, extended kin, or as a friend, or neighbor (Winslow, 2003). The generic term caregiver is used in this literature review to refer exclusively to informal caregiver.

Caregiving has become a normal and virtually expected part of life of many Americans due to the increase in the number of people with chronic health conditions (RCI, 2010). This is also true for adults who have chronic neurological health conditions such as Parkinson's disease, dementia, Alzheimer's disease, and stroke. Eighty percent of persons who survive a stroke will return to their communities and require some degree of caregiving (Chumbler, 2004), which is often provided by a family member or friend (RCI, 2010).

Family members may choose to provide healthcare for family members because it allows the person with a chronic health condition to continue to be a part of the family unit as well as the community (Schulz, Martire, & Klinger, 2005). Other families may choose to provide care for loved ones because of cultural expectations (Hinojosa, 2009). Families may find that

providing care in home is a necessity because of changes to health care legislation and the increasing cost of healthcare (Lim & Zebrack, 2004). There is also a shortage of healthcare professionals available to provide care and increasing life expectancy of patients, thus leaving the care of the patient to the family (Ekwall, et al., 2006).

The population worldwide continues to increase. There are approximately 35 million Americans, aged 65 and older, alive today (RCI, 2010). This figure suggests that by the year 2030 there will be some 71 million Americans age 65 and older (RCI, 2010). This rising number of older adults will also increase the number of adults who require care. Current estimates place the number of older adults needing daily care at approximately 12 million (RCI, 2010). Estimates on the current number of familial caregivers, who provide care to adults, ranges from approximately 25 million (Lim & Zebrack, 2004) to up to as many as 44 million (Wales, 2007 The rising number of caregivers and care recipients will likely have an influence on the health care industry, patient outcomes, and the economy.

The estimated economic value of the caregiver is approximately $257 billion, or 20% of all healthcare expenditure, if caregiving were a paid trade (Lim & Zebrack, 2004). Higher estimates of the economic value of the caregiver are approximately $375 billion dollars annually (RCI, 2010). This higher figure indicates that caregiving as a paid trade would equal the total expenditures for the Medicare Program ($342 billion in 2005) and Medicaid Program ($300 billion in 2005) (RCI, 2010). It is also estimated that caregiving expenditures are than that of long term care and home health care expenditures ($206.6 billion in 2005) and at least four times more than the total expenditure for formal home health care ($76.8 billion in 2005) (RCI, 2010).

Managing the needs and providing care for a person with a chronic neurological health condition may lead to heightened distress on the part of the caregiver. This review of the

literature will explore perceptions of caregivers about factors contributing to their own sense of burden and to changed needs once becoming a caregiver. Strategies for limiting negative impact on caregivers will be noted and discussed as part of this review.

While this review will focus primarily on the negative aspects of caregiving, it bears mentioning that there are numerous positive benefits to becoming a caregiver. Caregivers may find that they have increased life satisfaction when providing care (Center on Aging Society, 2004). The caregiver and care recipient may strengthen their relationship (Center on Aging Society, 2004). Additionally, some caregivers report an increase in their spirituality as a result in caregiving and find this to be both positive for themselves and their ability to provide care (Spurlock, 2005). Some caregivers will experience resilience in even the hardest of caregiving circumstances (Tedeschi & Kilmer, 2005). Others experience Posttraumatic Growth (PTG) and will grow because of the traumatic event, in this case caregiving, and therefore experience positive changes in their lives (Tedeschi & Kilmer, 2005). This author is in agreement with the literature that there are numerous positive experiences that come out of providing care. These positive experiences warrant further investigation as a strengths based way of providing caregiver interventions (Myers, 2003).

Background

The interest in understanding the caregiving experience is attributed to both the increasing number of caregivers and these caregivers' potential effects on patient outcomes (Lim & Zebras, 2004). Of particular interest are the perceived needs of caregivers that are shaped by the caregivers' perceptions of the caregiving experience. Caregivers express a perception of burden as well as satisfaction when providing care (Andren & Elmstahl, 2005). Typically research that looks at caregivers' perceptions of burden focus on the relationship between stress

and coping (Myers, 2003). Myers (2003) acknowledges that two theories surrounding stress and health are instrumental in understanding how to intervene.

The first theory is Schulz and Salthouse's General Model of the Stress Health Process (1999). This theory states that stressful situations begin when the care recipient exhibits some sort of limitation and then subsequently has a behavior that follows (Schulz & Salthouse, 1999 and Myers, 2003). The caregiver is then tasked with responding to that event in either a positive or negative way, which begins the cycle of positive or negative outcomes for the caregiver and care recipient (Schulz & Salthouse, 1999 and Myers, 2003). The negative response to the initial event can lead to negative feelings, such as anger and resentment, and eventually lead to the perceptions of caregiver burden (Schulz & Salthouse, 1999 and Myers, 2003).

The second theory described by Myer (2003) is Pearlin, et al.'s (2003) Conceptual Model of Caregiving Stress. This theory states that there are four domains: family network, social networks, caregiving history, and socioeconomic status (Pearlin, et al., 2003 and Myers, 2003). Pearlin, et al., (2003) goes on to describe the primary and secondary stressors (Myers, 2003). Primary stressors include those subjective and objective assessments of burden, whereas secondary stressors might include things such as finances or family relationships (Pearlin, et al., 2003 and Myers, 2003). Subjective reflections of the caregivers' experience can have an influence the caregiver and care recipient can have an effect on the both the caregiver and care recipient (Gort, et al., 2007).

Caregivers tend to have better physical health in the initial phases of the caregiving experience (RCI, 2010). The outcomes for both caregiver and care recipient tend to be overall positive when caregivers express perceptions of contentment or joy with the caregiving experience (Niyomthai, Putwatana, & Panpakdee, 2003). Blume (1999) found that caregivers to

persons with Alzheimer's disease experience a sense of hope and meaning when providing care. Caregivers who enjoy a positive caregiving experience are more likely to report a low level of family life events, moderate level of family hardiness, and overall positive sense of wellbeing (Niyomthai, Putwatana, & Panpakdee, 2003). A positive caregiving experience may lead to positive health and quality of life outcomes for the care recipient (Center on Aging Society, 2004). Additionally, caregivers will have better outcomes in terms of health and satisfaction if they view their role as caregiver as positive (Center on Aging Society, 2004).

However, some caregivers report a negative caregiving experience, which may have a negative influence on both the caregiver and care recipient. It is estimated that of all caregivers, 20-30% experience some adverse effect that can be directly related to caring (RCI, 2010). This negative caregiving experience is referred to as caregiver burden (Garlo, et al., 2010). Caregiver burden is defined as "the physical, financial, and psychosocial hardships of caring for a loved one struggling with a medical condition" (Garlo, et al., 2010). Burden is a perception of the caregiver that is believed to occur due to the interaction of a variety of factors.

Research cites emotional and psychological factors as major sources of perception of burden (Winslow, 2003). Financial stressors are also reported as a major source of caregiver burden (Thompson, et al., 2004). Researchers have also found that declining family relationships (Hughs, 1999), increased feelings of anger and hostility (Anthony-Bergstone, 1988), decreased physical health (Whitlatch, 1997), and decreased psychological and emotional well-being (Hughs, 1999) may also contribute to perceptions of burden in the caregiver.

The burden of caregiving may manifest in the caregiver as declining caregiver health, declining quality of life, and increased mortality rate (Garlo, et al., 2010). Current research also shows that caregivers who express greater perceptions of burden exhibit an increase in stress and

depression (del-Pino-Casdo, et al., 2011). Caregivers may experience decreased immunity, exhaustion, and self-neglect (RCI, 2010). Caregivers with heightened perceptions of burden are also at risk of substance use (including alcohol and drugs) and other negative health behaviors such as poor diet, lack of exercise, and decreased amounts of sleep (RCI, 2010). Approximately one in ten caregivers cites caregiving as a direct cause of their own declining health (RCI, 2010).

Care recipients are also at risk of negative outcomes because of caregiver perceptions of burden. The type and quality of care the caregiver is able to provide tends to weaken if the caregiver perceives a decline in their overall sense of well-being (Ostwald, 2009). The caregivers' sense of wellbeing can influence their own health and the relationship between the caregiver and care recipients. This could potentially lead to negative health outcomes for the person receiving care. For example, persons receiving care from a caregiver who reports a perceived sense of burden and exhibits signs depression are more likely to exhibit signs and symptoms of depression (Chumbler, 2004). Caregiver burden may also lead to care recipient poor participation in rehabilitation and increases the risk of early entry into a long term care facility (Chumbler, 2004). Additionally, the care recipient is also at an increased risk of abuse and neglect when the caregiver's needs are not attended to (RCI, 2010). The act of caregiving has numerous implications for the caregiver and the care recipient. Understanding the specific factors that lead perceptions of burden will help to identify and address the specific needs of the caregiver.

The caregivers' report of burden as well as contentment and joy typically encompasses as wide range of subjective feelings (Gort, et al., 2007). These feelings can be based on both internal and external factors such as finances, psychological conditions (e.g., depression), and physical health (Gort, et al., 2007). Often, medical professionals seek to quantify these subjective

reports with more objective data through the use of caregiver burden scales. Numerous caregiver scales provide some objective assessment of the amount of burden that the caregiver perceives (Gort, et al., 2007). Scales available include the Perceived Caregiver Burden Scale (PCB) and the Zarit Scale (ZS). The Zarit Scale and PCB are widely used because of their good reliability and validity (Gort, et al., 2007 and Gupta, 1999). Use of scales to quantify the caregiver experience allow for deeper exploration into the caregivers perceptions and may help medical and allied health professionals provided more person specific caregiver interventions.

Deeper exploration into the caregivers' perceptions of burden allow for identification of the multiple factors that contribute to perceptions of burden. One factor is the nature and type of chronic health condition of the person receiving care, which can affect the caregivers' perception of burden (Schultz, Martire, & Klinger, 2005). Garlo, et al., (2010) found that there were differences in caregivers' perceptions of burden that were providing care for persons with heart failure and for those providing care to persons with chronic obstructive pulmonary disease (COPD). Thus differences do exist; however, Garlo, et al. (2010) caution that when examining the differences in the type of chronic health condition and its relation to differing caregiver burden, direct comparisons within a single study would be more beneficial. Direct comparisons will allow for the detection of true differences versus differences in study methodology (Garlo, et al., 2010). Comparisons of caregiver perceptions of burden across different neurologic conditions is not within the scope of this review as it is intended to provide a broad overlook regarding caregiver burden with respect to care recipients who have chronic neurologic health conditions.

Caregiving to Persons with a Chronic Neurologic Condition

Caregiver burden often develops due to the numerous changes the caregiver experiences; it is thought to be a predictor of the caregivers' perceptions of strain and distress (Andren & Elmstahl, 2007). The caregiver to a person with a chronic neurologic condition will require different skill sets at different periods of time throughout the rehabilitation process (Andren& Elmstahl, 2007 and Ostwald, 2009). The care recipient experiences changes in physical, cognitive, and emotional statuses that differ in the level of severity and overall disablement, thus requiring the caregiver to adapt to these changes (Andren & Elmstahl, 2007 and Ostwald, 2009). The perceived sense of burden may be heightened in the initial stages of the rehabilitation process because of the rapid onset of these changes in the care recipient as in stroke (Ostwald, 2009) or the gradual but pervasive decline of skill seen as in dementia (Andren & Elmstahl, 2007) . Additionally, caregivers themselves experience a rapid onslaught of changes in their own lives (Ostwald, 2009). Changes in the emotional, psychological, financial, physical, and social aspects of their lives can influence the caregivers' perceived sense of burden (Andren & Elmstahl, 2007).

Social Impacts on Perceived Burden

Social Networks

In the initial stages of caring for someone with a neurologic health condition, the caregiver may experience changes in the social aspects of their lives. It is not atypical for caregivers to feel as though they are isolated (National Family Caregiver Association, 1994). Caregivers reported a decline in life satisfaction, in part due to decreased socialization opportunities (Coughlan & Humphrey, 1982) and changed relationships (Anderson, 1988).

Caregivers often report feelings of isolation because of loss of normalcy of their routines, including socializing (National Family Caregiver Association, 1994). Caregivers who once found themselves socially active may now be in the position of spending a majority of their time with the care recipient. This in turn may lead to the caregiver engaging in self-neglect behaviors, which can increase the risk of poor health outcomes for the caregiver (RCI, 2010).

Caregivers also report negative feelings about their social networks of non-caregivers who, in their opinion, do not understand what it means to be a caregiver (National Family Caregiver Association, 1994). This could have an impact on how caregivers respond to their social networks. Caregivers frequently have to be engaged with the health care professionals who service the medical needs of the care recipient (Love, et al., 2005), yet often these caregivers require assistance that cannot be given by the health care systems, such as assistance with everyday chores, grocery shopping, or even respite (Levine, 2000). Some caregivers, in an effort to preserve existing social relationships outside of the care recipient, do not seek help from others (Stajduhar & Davies, 1998).

The caregivers' social network may perceive that the caregiver could use assistance. The social network may seek to help the caregiver; however, they may withdraw offers of help and assume the caregiver is managing well if repeated attempts to help are not acknowledged (Worden, 2009). When caregivers find that the social network has stopped reaching out to them, they may then begin to feel as though their social network does not understand what their new caregiver role means (National Family Caregiver Association, 1994). This mismatch of communication may lead to decreased social support for the caregiver.

The social aspects of caregiving may also be dependent on the age of the caregiver. For example, caregivers providing care for patients with Motor Neuron Disease or Amyotrophic

Lateral Sclerosis (MND or ALS) may find that they become caregivers in the middle ages (40-65 years). Motor Neuron Disease is a degenerative neurologic condition said to affect some 350,000 persons annually (Love, 2005). MND typically begins in the middle ages and progresses to the point where the person with MND requires care (Love, 2005). In contrast, the incidence of stroke increases after age 55 and thus many spousal caregivers find themselves providing care later in life (National Stroke Association, n.d.).

The age at which a person becomes a caregiver has an influence on the person's caregiving experience. Older caregivers tend to have their own health concerns that greatly influence their ability to provide care (Ekwall, 2006). It is estimated that 80% of people aged 65 and older have at least one chronic health condition and 50% have at least two chronic health conditions (RCI, 2010). Older caregivers managing their own health may have difficulty coping with the potential burdens of caregiving especially if they have additional stressors (e.g., financial concerns prior to becoming a caregiver) (Ekwall, 2006). Middle age caregivers may have a caregiving experience that is distinct from the older caregiver.

Many of middle age caregivers have family and social responsibilities that existed prior to becoming caregivers (Love, et al, 2005). The caregiver's social networks are also engaged in family and social responsibilities, which may limit the potential social support to the caregiver (Wilkinson & Bittman, 2001; Love, et al. 2005). Carol Abaya, a journalist, has referred to people in this middle age group as the "sandwich generation." Abaya popularized this phrase after chronicling her own life as a caregiver to her children and aging parents in an article published in the *New York Times* by George James (1999).

People in the sandwich generation are males and females of middle age who find that they are providing care for children (or grandchildren) as well as aging parents (Abaya, no date

and James, 1999). The caregiver is caught, or "sandwiched," between two sets of care recipients, often with competing needs: the caregiver may find him or herself rearing children as well as responding to the changing needs of aging parents, with or without health ailments (Abaya, no date and James, 1999). The competing needs of the children and aging parents coupled with caring for someone with a neurologic health condition may increase the perception of burden in the caregiver. If caregivers are able to seek and receive support from their social network, they tend to cope much better with perceptions of caregiver burden even in the context of being in this sandwich generation (Waltrowicz, et al., 1996).

Social support for the caregiver is a valuable caregiver intervention tool (Love, et al, 2005). Caregivers with perception of increased burden often express a need for help with daily tasks; however, they may not always express a need for help with chores directly related to care of the patient (Garlo, et al, 2010). Social support may be a safeguard to some caregivers (Grant, et al., 2006), yet caregivers have a tendency to seek social support and distance themselves from that very support as time passes (Manne, 2003 and Grant, 2006). Caregivers may perceive that they do not have support from non-primary caregivers or their social network, even though it is the caregiver who in effect is creating the distance (Mane, 2003; Grant, 2006; and Shields, et al., 2004). Family relationships can be affected by this distance causing the caregiver to feel as though they do not have support from their family members (Shields, et al., 2004).

Caregiving can have potential negative consequences on family relationships (Shields, et al, 2004). Sixty-six respondents to a survey reported decreased familial relationships in the context of caregiving (Shields, et al. 2004). Caregivers who experienced familial relationship declines were at higher risk of mental health changes, including memory and behavior (Shields, et al., 2004). Niyomthai, et al (2005) found that strong family bonds were positively correlated

with caregiver well-being. Additionally, strong family bonds explained some 31% of the variance with caregiver well-being (Niyomthai, et al, 2005). Thus, caregivers' relationships with their families are a strong factor in caregiver well-being and have some influence in caregiver outcomes.

Difficulty with family relationships is not the only type of relationship that can be affected by caregiving. The marital strain of caregiving is well documented in the literature. This is particularly true for caregivers of spouses who have had strokes. Spousal caregivers to survivors of stroke and many other chronic neurological conditions are faced with caring for someone whose cognitive skills, social and emotional skills, ability to complete activities of daily living, and physical abilities may be declined from their baseline (Dennis, et al., 1998). Couples that have experienced a stroke often are more prepared in the event of subsequent stroke; however, the first stroke generally comes without warning, and both the caregiver and the patient undergo many changes (Dennis, et al., 1998). Caregivers typically feel as though they understand what to expect from the survivor of stroke in terms of health with proper patient and family education (Baumann, et al., 2011). However, these same caregivers may not as easily understand the influence that the stroke may have on familial and marital relations, especially in the context of a survivor with more subtle deficits (e.g., mental fatigue, emotional changes, and mildly decreased cognitive linguistic skills) (McCullagh, et al., 2005). Caregivers report that these subtle deficits often have more of an impact on their social life, lifestyle, and marriage than do more pronounced deficits (Baumann, et al., 2005).

Marital strain brought on by caregiving may be reflective of gender and social roles learned by men and women in childhood (Thompson, et al., 2004). This idea is reflected in how men and women experience caregiver burden differently. For example, men typically report a

feeling of "social injustice" when providing care, while women report more difficulty with the "physically demanding care provision tasks" (Baumann, et al., p.167, 2005). Women may also discuss the difficulties of the physical aspects of caregiving within the context of psychological or emotional realms (Sparks, 1998). This may explain why women may exhibit more psychological or emotional strain (Sparks, 1998).

A person's gender identity affects how he or she provides care irrespective of the relationship to the care recipient (Tiegs, et al., 2006). When one member of the couple has a stroke, it forces an examination of the role that each member of the couple had (Pierce, 2004). Women account for approximately 64% of all caregivers and account for a greater percentage of persons who report a perception of burden (80%) (Center on Aging Society, 2005). In mainstream American culture, men are socialized to be more instrumental, whereas women are socialized to be more intuitive (Worden, 2009). Women typically define their social roles in terms of relationships (e.g., wife, mother, and daughter) (Miller, 1990). Interestingly, all of these roles reflect some type of caregiving (Miller, 1990).

Men may be expected to be more to be more managerial in their caregiving, while women may be expected to be more responsible for holding the family together (Carrol, et al., 2008). Women in American society are typically responsible for the majority of caretaking roles, and therefore in the context of caregiving are expected to assume the role of spousal caregiver without much difficulty (Collins & Jones, 1997). A study by Hagedoorn, et al., (2002) looked at spousal caregivers of patients that survived cancer. While not specified if brain cancer was used as an inclusion category for participants, the study did find information about gender differences in caregiver burden. Hagedoorn, et al., (2002) found that women who felt that their social identity was one of caregiver experienced more caregiving distress when they did not feel

they were performing their caregiving duties well (Acitelli & Young, 1996). This was the same for male caregivers, although in general the female participants reported a higher degree of caregiver burden (Hagedoorn, et al. 2002). Spouses reporting more perceived burden engaged in increased supportive behaviors to the loved one (Hagedoorn, et al., 2002). Understanding gender roles occupied by the individual caregivers will be important in understanding the individual's caregiver role and perception of burden.

Finances

Financial considerations are identified as a potential factor in caregiver burden. Sixty percent of caregivers report that they continue outside employment while caring for a relative (Wales, 2007). Some caregivers choose to work, while others work because of economic necessity. Approximately 10% of all caregivers who work outside the home eventually have to scale back their hours to part time, and another 9% are forced to quit their jobs (Wales, 2007). Thirty-six percent of caregivers of survivors of stroke reduce their work hours or resign secondary to the demands of caregiving (Ko, et al., 2007). Thus, most caregivers who are employed prior to becoming caregivers will maintain some form of employment outside the home. The caregivers that continue to work are estimated to cost employers 33.6 billion dollars per year (Wales, 2007).

Ko, et al. (2007) measured physical health, depression, fatigue, family functioning, and family conflict in a study aimed at examining how employment outside the home impacted caregivers. Ko, et al. (2007) found that caregivers who were employed were at an increased risk of depression. However, these same caregivers were also more physically fit and had more assistance from others than their counterparts who were not employed outside the home.

A portion of long-term care expenditures for the care recipient is covered by various mixes of insurance, including Medicaid, Medicare, and private insurance (Center on Aging, 2004). However, many caregivers are faced with the fact that a great majority of the cost of caregiving will come out of pocket (Center on Aging Society, 2004). These costs include items not routinely covered by insurance as well as the caregiver's own needs. Sixty percent of caregivers report feeling as though they have enough financial resources to provide care (Center on Aging Society, 2004). On average, caregivers have more economic resources than do their non-caregiver peers (Center on Aging Society, 2004). In 2000, it was estimated that adult children providing care to a parent had approximately $104,000 in total assets while non-caregiver children had approximately $77,500 (Center on Aging Society, 2004). The annual household income of an adult child caregiver was estimated at $54,000 while non-caregiving children had an estimated income of $55,000 (Center on Aging Georgetown University, 2004). Caregivers who reported lower incomes tended to have the highest rates of reported perceived burden (Center on Aging Georgetown University, 2004).

Employment can have both positive and negative impacts on the caregiver. Many studies report that caregivers employed full time may experience a myriad of negative consequences; however, these consequences are typically stated in terms of financial impacts and not on the caregiver and care recipient impacts (Scharlach, 1994). For example, negative aspects of being a caregiver who is employed full time might be increased potential for habitual absenteeism and tardiness, lack of promotability, and decreased job satisfaction (Anastas, et al., 1987; Scharlach, 1994).

It is typically thought that caregivers who work will also be at an increased risk of caregiver burden; however, numerous studies show the potential benefits to caregivers working

outside the home (Scharlach, 1994). These benefits might include increased social support, respite, and feeling of satisfaction with completing something outside of caregiving (Goldstein, et al. 1981 and Scharlach, 1994).

Scharlach (1994) found that caregivers report both positive and negative aspects to being employed full time while providing care. These caregivers cited difficulty with managing time demands of multiple roles as the most difficult aspect of working and providing care (Scharlach, 1994). However, these same caregivers also indicated that they felt a sense of satisfaction in their ability to manage multiple roles (Scharlach, 1994). It is possible that working, even with its challenges to the caregiver, provides some psychological well-being (Stoller & Pugliesi, 1989 and Scharlach, 1994) and may act as a shield against many aspects of caregiver burden Goldstein, et al., 1981 and Scharlach, 1994).

Physical and Psychological Health

The physical and psychological/emotional aspects of caregiving are well documented in the literature. On average, caregivers tend to be more physically fit than their non-caregiver counterparts (RCI, 2010). However, some caregivers do report that they do not pay attention to their own health care as well as they should, thus placing those at an increased risk of chronic health conditions that impact their ability to provide care (Center on Aging Society, 2004). In a survey of caregivers in 2004 by Georgetown University's Center on Aging Society, 46% of caregivers reported having arthritis and another 39% of caregivers reported having hypertension. Other chronic health conditions reported included diabetes, cancer, chronic lung disease, heart conditions, and stroke (Center on Aging Society, 2004).

Caregivers who are able to manage their own health are also at risk for physical health changes. Thompson, et al. (2004) looked at the emotional and biological responses of male and female spousal caregivers for persons with Alzheimer's disease. Thompson and colleagues (2004) found that even with no statistically significant differences in social support, coping mechanisms, or regulatory T cells (cells responsible for immunologic function), expression of physiologic stress tended to be higher in the female participants. Caregivers were also at increased risk of decreased immunity and response to vaccinations as well as increased reports of respiratory infections (Vitaliano, et al., 1997).

In caring for a loved one with a neurologic impairment, the difficulty with managing one's own health may be a reflection of the care recipient's increased needs. For example, caregivers cited safety concerns, management of activities of daily living (ADLs), cognitive declines, and psychological/ behavioral changes as difficulties that they faced as caregivers during the first month post rehabilitation (Grant, et al., 2004). These reported difficulties lead to caregivers' perceptions of loss of independence, fatigue, lack of time and energy, and decreased social outlets, all of which could have negative health consequences (Grant, et al., 2004).

Heesacker, et al., (2009) looked at caregiver mental health at one, six, and twelve months post stroke survivor discharge. Heesacker, et al., (2009) found that at one-month post discharge, the biggest predictors of declines in caregiver mental health were a decreased sense of coherence, high perception of burden, experiencing depression, and a care recipient who required a significant amount of care. A care recipient who required a significant amount of care was one who demonstrated a significant memory or behavioral changes and/or significant motor impairments that led to decreased mental health functioning (Shields, et al., 2004).

Depression is a major concern with regard to caregiving. Caregiver perception of burden may serve as a good predictor of caregiver depression with prediction of caregiver depression being made as early as one month after the care recipient has had a stroke (Berg, et al., 2005). Berg, et al., (2005) estimated that 30 to 33% of caregivers were found to be depressed at an 18-month follow up using the Beck Depression scale. Severity of the stroke, age of the caregiver and care recipient, caregiver exhaustion (Berge, et al., 2005), difficulty with problem solving on the part of the caregiver, lack of caregiver preparation to provide care, and decreased health, and thus decreased social participation , are correlated with increased caregiver depression (Weaver, et al., 2004). Caregivers are also more likely than care recipients who have had strokes to exhibit depressive symptoms, and spousal caregivers were more likely to exhibit depressive symptoms than other familial caregivers (Berge, et al., 2005). The literature shows that future caregiver depression can be predicted by caregiver burden. The ability to understand the ramifications of caregiver burden is important in designing caregiver interventions aimed at addressing the needs of the caregiver.

<center>Caregiver Needs and Sense of Coherence</center>

In discussing what the needs of caregivers, are sense of coherence (SOC) may be one of the first places to begin (Ekwall, 2006). The idea of SOC appears in several caregiver studies, and the term was first coined by Aaron Antonovsky in 1987. Antonovsky was interested in understanding how some people, when faced with extremely stressful circumstances, remained healthy, while others, in less stressful circumstances, become sick (Antonovsky, 1987). SOC is thought to develop throughout childhood into adolescence and become more stable, and relatively unchangeable, in adulthood (Antonovsky, 1987). Sense of coherence is measured by the SOC scale developed by Antonovsky (Eriksson, 2006). There are three components that

make up one's sense of coherence: comprehensibility, manageability, and meaningfulness (Antonovsky, 1987). A strong sense of coherence allows a person to be able to reflect on both internal and external resources and then use these resources to find solutions and increase their effective coping and reduce tension (Eriksson, 2006). It is thought that meaningfulness is the most important of the three components of SOC to understanding an individual's ability to cope (Ekwall, 2006).

A caregiver's perception of burden when providing care can be influenced by their SOC. Finding meaning in caregiving and a strong SOC were found to be highly correlated (Blume, 1999). Caregivers with a higher SOC tend to be less problem oriented, handle stress more effectively, and in turn solve problems more efficiently (Blume, 1999 and Ekwall, 2006). Adult children caregivers with a strong SOC tend to exhibit low emotional arousal and higher perceived health (England, 1997). A person's SOC is useful as an internal strategy to handle crisis events (England, 1997). Allied health professionals should be aware of a person's SOC in facilitation of adult children to the role of caregiver to a parent (England, 1997).

SOC has emerged as an important aspect in caregiver wellbeing. Gallagher, et al. (1994) found that the SOC of caregivers to patients with dementia was able to predict approximately 29% of the variance in role overload, or burden. A strong SOC is positively correlated with a positive perceived health status as well as health promoting behavior (Johnsen, 1992). Thus, caregivers with a higher SOC are more likely to perceive themselves as experiencing more joy from caregiving because they are better able to solve problems and engage in successful health promoting behaviors (Blume, 1999). This may in part be due to the fact that the caregivers with higher SOC have good health promotion skills prior to becoming caregivers (Johnsen, 1992).

Taking into consideration how the caregiver is able to manage stressful situations is an important step in developing strategies and interventions to limit caregiver burden.

Strategies for Limiting Burden

In the current model of health care, the center of focus is typically on the patient. Typically, patients and families are looked at from the perspective of problems to be solved (Tedeschi & Kilmer, 2005). Families of adults with neurologic health conditions are often faced with the challenges of learning how to care for their loved ones with limited assistance (for review see Low, et al., 1999). Bakas, et al., 2002 completed a study with African American and white caregivers to examine their perceived needs when providing care for a loved one who had a stroke. Bakas, et al. (2002) found that there was more similarity amongst the African American and white respondents than might have been hypothesized. Caregivers reported needing education about strokes, assistance with managing behavior of the survivor of stroke, assistance with physical care, assistance with instrumental needs (e.g., transportation, finances, etc.), and assistance with coping with their own emotions (Bakas, 2002). All of the needs reported by the caregivers are supported by the literature as items that can increase perceived burden amongst caregivers as discussed earlier in this review

Caregivers would benefit from continuous education throughout the acute and rehabilitation phases of the hospitalization (Bakas, et al., 2002). Education might center on providing caregivers with information about the specifics on the condition and what they should expect at discharge. Caregivers reported that they were fearful of future strokes and that education about the warning signs of stroke helped alleviate some of the fears (Bakas, et al., 2002). Additionally, providing caregiver counseling in the acute stages might be beneficial, as caregiver

depression in the acute stages (early on in the hospitalization) may be a predictor of depression in the later stages post hospital discharge (Berg, et al., 2005).

In the qualitative study by Bakas, et al (2002), caregivers suggested that there be a "network of health professionals" they could access at any time. This idea is supported by the RCI as a way to help alleviate some of the burden perceived by caregivers. RCI also suggests that providing this continues access to health care providers should be reimbursable by government and third party insurers.

Helping the caregiver to establish a line of social support may also be beneficial (Bakas, et al., 2002). Caregivers with increased support were found to be at a decreased risk for reporting caregiver burden (Grant, et al., 2006). Caregivers themselves recommend that other caregivers should be encouraged to seek support and express needs to other family members and friends that could offer assistance (Bakas, et al., 2002). Caregivers also recommended that other caregivers engage in respite, have courage, be patient with themselves, have faith in God, and taking care of themselves physically (Bakas, et al., 2002).

Perhaps one of the most helpful strategies to limit caregiver burden is in how allied health and medical professionals discuss the upcoming role as caregiver with the patient (Brenner & Brenner, 2011). It cannot be forgotten that caregiving does afford some positive aspects to both the caregiver and care recipient, despite the research focusing on negative consequences (Myer, 2003). Like other illnesses and disabling conditions, caregiving should not be framed in negative terms (Ramanathan, 2010), and words such as "caregiver burden" might be phrased differently with the caregiver. Instead of medical and allied health professionals discussing negative aspects of caregiving as "burden," the use of the word "challenges" might present the caregiver with a more positive view of caregiving. The difference in using positive versus negative language may

potentially lead the caregiver into the new role with an upbeat attitude (Brenner & Brenner, 2011). The SOC literature states that when caregivers find their situations more manageable and feel that they will be able to meet any demands (Antonovsky, 1987), they tend to have an overall better caregiving experience, and in turn, the outcomes for the care recipient tend to be much better (Ekwall, 2006).

When caregivers are exposed to positive language from the allied health and medical professionals, they may be able to communicate better with the care recipient (Brenner & Brenner, 2011). Positive language is finding the strengths of the person with whom one is communicating (Tedeschi & Kilmer, 2005; Brenner & Brenner, 2011). Allied health professionals might model the use of positive language with the caregivers in an effort to have the caregiver do the same in response to the care recipient. The allied health professional would talk about what caregivers can do instead of what they cannot do. This positive communication between the caregiver and care recipient may lead to better caregiving, increased satisfaction, and overall improved caregiver and care recipient relationships (Brenner & Brenner, 2011).

Caregivers would also benefit from exploring the positive experiences that many other caregivers report (Myers, 2003). Exploring these positive experiences could come through the use of caregiver support groups or dialogue with medical and allied health professionals (Myers, 2003). Allied and medical health professionals should allow caregivers to not only express the challenges that they are facing but additionally explore what positive aspects the caregivers have gained by being caregivers (Myers, 2003). Caregivers might report experiencing personal growth, bettering of relationships, and feelings of pride and usefulness when providing care (Amirkhanyann & Wolf, 2003).

Approaching caregiving from a wellness or strengths based approach may help to empower caregivers and thereby lead them to engage in more health promoting activities (Myers, 2003). Wellness, as defined by Dunn (1961) in Meyers (2003) is "an integrated method of functioning which is oriented towards maximizing the potential of which the individual is capable" (p. 156). The idea of wellness ties in with strengths based approaches. In a strengths based approach the "focus is on client (whether a child, an adult, or a family) as bears of unique talents, skills, resources, life experiences, and unmet needs" (Tedeschi & Kilmer, p. 230, 2005). In the strengths based and wellness approaches, caregiver interventions are centered around assisting with effective decision making (for review see Lewis, et al., 2000), encouragement of leisure activities (Bedini & Phoenix, 1999 and Hawkins & Kultgen, 1990), and encouragement of maintaining the caregivers own health (Rogers, 1999).

Although there are ways that individual medical and allied health professionals can help alleviate potential perceptions of burden expressed by caregivers, changes will also need to come through policy and the way caregivers are treated on a larger scale (RCI, 2010). The literature overwhelmingly suggests that one way to address caregiver burden is by increasing the amount of research conducted about the caregiving experience. Research is needed in the area of understanding caregiver burden for persons with specific neurologic health conditions. For example, it may be of benefit to look at caregiver burden in stroke versus Alzheimer's dementia. More research is also needed to understand the effects of caregiver burden on different minority groups including socio-economic status (RIC, 2010).

Research on long-term outcomes of caregiving is also needed (RCI, 2010). This research could help in further understanding the needs and meeting the needs of caregivers (RCI, 2010). The RCI on Caregiving suggests that monitoring the health of caregivers and reporting the trends

in caregiver health to the Centers for Disease Control (CDC) may aide in prevention and treatment of negative aspects of caregiving. Additionally, monitoring of the caregiver experience and collection of data may lead to the framing of caregiving as a public health concern, thereby allowing for more evidenced based interventions and better outcomes for both the caregiver and care recipient (Talley & Crews, 2007).

The mechanics through which caregiver intervention is provided is another important aspect of caregiver interventions (RCI, 2010). As in other therapy interventions, interventions provided to caregivers are best provided in the most natural setting as possible with providers that are responsive to the caregivers needs and provide culturally competent care (RCI, 2010). The RCI on Caregiving suggests that caregiver interventions be provided to both the caregiver in environments like the doctor's office, the hospital where the primary medical services were received, churches, and at the caregiver's place of employment. The RCI suggests that caregivers are more likely to be successful at implementing these interventions when the interventions are provided in these more naturalistic settings.

Conclusion

Caregiving, whether provided or received, is an event that nearly every American will face. Some may become caregivers to aging parents while others will become caregivers to spouses, partners, siblings, friends, or neighbors. The role of caregiver presents both challenges and rewards that are directly related to the outcomes of the care recipients. Medical and allied health professionals are charged with understanding the role of caregiver and responding to the individual needs of the caregivers and families that are served.

This review focused primarily on the negative aspects associated with perceived caregiver burden; however, caregivers do experience positive outcomes from providing care as well. It may be of benefit for a future review to further explore positive aspects of caregiving such as strengthened relationships between caregiver and care recipient, increased spirituality on the part of the caregiver, and increased caregiver life satisfaction. A future review might also look at cultural differences in caregiving amongst caregivers to persons with chronic neurologic health conditions. Research that adds to the body of literature regarding the caregiving experience will aide allied and medical health professionals in structuring individual caregiving interventions that improve the outcomes for both caregiver and care recipient.

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Appendix B: Literature Review 2

Understanding Health Literacy: A Review of the Literature

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This document of one of three comprehensive reviews of the literature completed as a prerequisite for the Oral Comprehensive Examination in Therapeutic Science. This document was approved by a Comprehensive Examination committee on August 31, 2012.

Introduction

In a 1989 interview Aaron Antonovsky stated, "We people are perpetually bombarded by information; we are exposed to stressors that demand a new way of thinking and new conclusions. How we deal with information affects our health, make us move towards either health or sickness" (Ek, 2004, p. 141). The idea of how people deal with information as a factor in health outcomes recently has become the focus of many health initiatives. The modern health system is a changing field that requires consumers to adapt to those changes in order to maintain and manage their health successfully (Nielsen-Bohlman, 2004; Murrow & Oglesby, 1996).

The expectations of people with chronic health conditions have changed over the past half century (Baker et al, 1998). Advancements in medicine and technology have led to the survival of people who would have not survived major medical events 50 years ago (Baker, et al., 1998). As these advances continue, the roles and responsibilities of health care consumers also will continue to increase (Nielsen-Bohlman, et al, 2004). These health care consumers, along with their caregivers, will have to find ways to manage their health conditions (Kickbusch, 2001; Bodenheimer, et al, 2002; Perrin, 1998). Management of chronic health conditions can require a great amount of skill, knowledge, and advocacy for both survivors and their caregivers (Nielsen-Bohlman, et al, 2004; Murrow & Olgesby, 1996). A person must be able to obtain information about his or her health condition and understand his or her rights and responsibilities in order to successfully manage any health condition (Chang, 2007; Ek, 2004; Nielsen-Bohlman, et al, 2004). People search for, and are provided with, increasing amounts of information (Martensson & Hensing, 2011). Allowing people the independence to learn more about their health may help empower them to be active participants in their own health care and

management (Martensson & Hensing, 2011). Simply having information is not always

predictive of positive health outcomes however (Ek & Widen-Wulff, 2008).

The American Academy of Family Physicians (AAFP) defines patient education as the

"process of influencing patient behavior and producing changes in knowledge, attitudes, and

skills necessary to maintain or improve health" (AAFP, 2008, p. 1). Patient education generally

is regarded as a viable means to improve health outcomes (Nutbeam, 2008). Recent research

provides evidence that patient education alone is not an effective tool in improving health

outcomes (Nutbeam, 2008). Information rich educational programs have also been found to be

ineffective (Ek & Widen-Wulff, 2008).   Even the most effective education techniques and best

information do not always correlate with desired behavioral changes (Ek & Widen-Wulff, 2008).

Many programs lack effectiveness because there is a mismatch between the skills possessed by

the person and the content or delivery of the educational program (Ek & Widen-Wulff, 2008;

Nutbeam, 2008). Typically, programs have a heavy emphasis on educational attainment and

communication skills, which are not always skills possessed by the target audience (Nutbeam,

2008). Schwartzberg et al (2003) report findings from studies that looked at the readability of

health education materials targeted towards specific chronic health conditions (e.g., cancer,

diabetes, asthma, HIV) and found that a majority of the educational materials were written above

the reading level of most American adults (assumed to be at the eighth or ninth grade, per

Schwartzberg et al (2003)). This again shows that people may have difficulty putting into use

any written information they receive because it is inaccessible or incomprehensible to them

(Schwartzberg et al, 2003). People may not only have difficulty with comprehension of printed

content, but they may also experience poor comprehension when verbal information is presented

in an unnecessarily complex manner (e.g., use of medical jargon in patient interactions) (Paasche-Orlow & Wolf, 2007).

Another reason that these programs may not be successful is the way that people receive information (Chang, 2007). Today there are varieties of sources by which people obtain health information. Some sources are informal, such as education from family, friends, and other survivors, while other sources are formal and can include information gleaned from television programs, magazines, internet news, and other media designed to provide information and ultimately influence a person's health behaviors (Nutbeam, 2006; AAFP, 2008). Health care professionals that have daily contact with people are perhaps one of the most important sources of health information (Chang, 2007). The education given may consist of information designed to inform people about the disease process, how to monitor for changes, and what to do if help is needed (Monsivais, 2003). Health care professionals may provide health education via information as well as technical skills (Monsivais, 2003). There may be no assessment of whether or not a person is able to comprehend, process, and apply health information in order to produce a positive health outcome (Chang, 2007; Paasche-Orlow & Wolf, 2007). Some health care providers site lack of time during the interaction as a reason for not confirming understanding of health information (Paasche-Orlow & Wolf, 2007). Currently, there is not strong evidence that suggests that health care providers that confirm an individual's understanding of information gained during the encounter led to improved health outcomes, which may also explain health care providers' reluctance to devote interaction time to such a task (Paasche-Orlow & Wolf, 2007).

Socioeconomic status (SES) and educational attainment have a role in how people are able to use health related information (Williams et al, 2002). However, Williams et al (2002)

found that literacy in the context of health might be a better predictor of health than either SES or education even when controlling for these two variables. This has implications for the entire health care system. The way that health care professionals provide education, the types and content of the educational material used, and how interactions occur will be key factors in improving individual level and societal level health outcomes (Martensson & Hensing, 2011).

Health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, n.p.). Ek and Widen-Wulff (2008) describe health literacy as health information mastery. These researchers cite multiple studies that suggest that health literacy is an essential asset in changing people's health behaviors (Ek & Widen-Wulff, 2008; DeBuono, 2006; Rudd, Kirsch, & Yamamoto, 2004). Basic health information that requires adequate health literacy may include items such as understanding instructions from physicians, consent forms, appointment cards, insurance forms, and following dosing instructions on medication labels (Martensson & Hensing, 2011). Having adequate health literacy means that a person is able to utilize the skills necessary to promote good health (Martensson & Hensing, 2011). The definition of health literacy will be examined further later in this review.

Approximately 38% of Americans are considered to have limited health literacy (White, 2008). Inadequate health literacy may be described as an epidemic that stems from difficulty in understanding health related material or limited proficiency in English (DeBuono, 2006; White, 2008). Literacy and numeracy skills also influence health literacy (Nutbeam, 2008). The populations thought to be most at risk of having inadequate health literacy are older adults and people living in low socioeconomic conditions (Ek & Widen-Wulff, 2008). Nielsen-Bohlman et al (2004) suggest that even some of the most educated members of society are at risk for low

health literacy and may have difficulty with navigating the health system. It is even possible for health care employees to have limited health literacy (Nielsen-Bohlman et al, 2004). Thus, all people, regardless of race, nationality, gender, or socioeconomic status can be at risk for low health literacy (Ek & Widen-Wulff, 2008).

The World Health Organization describes health literacy as one of the determinants of health (WHO, 2012). Determinants of health are factors that shape how a person is able to access, understand, and ultimately utilize healthcare services in such a way as to make a difference in their health outcomes (Nutbeam, 2006). Health literacy may be the best predictor of a person's health status (DeBuono, 2006). Therefore, it is important that health care professionals have a clear definition of health literacy as well as a careful plan to continue to increase the health literacy of Americans.

This review of the literature will explore health literacy and its relationship to the management of chronic health conditions. A discussion on the definition of health literacy and how health literacy is assessed will be included in this review. The review will look at the differing means by which people become health literate and examine the strengths and weaknesses of each of these means. Finally, the role of health care professionals with direct contact with patients and caregivers will be noted and discussed.

This review will discuss the relationship between health literacy and management of chronic health conditions. It is noted, however, that more research is needed to establish a direct causal relationship between health literacy and health outcomes (Nielsen-Bohlman et al., 2004). A widely accepted belief exists that sees a causal relationship between health literacy and health outcomes (Nielsen-Bohlman et al, 2004). The literature appears to support a predictive, if not causal relationship (Nielsen-Bohlman et al., 2004). The belief is that people with marginal or

adequate literacy will have better health outcomes because they are better able to comprehend, process, and apply the information gained in health education programs (Baker, 1998). However, research has yet to establish definite causality between health literacy and health outcomes (Nielsen-Bohlman, et. al, 2004). It is difficult to establish an independent relationship between limited health literacy and health outcomes because of the potentially strong interconnections with other variables (e.g., educational attainment, race and ethnicity, and age) (Paasche-Orlow & Wolf, 2007). Paasche-Orlow and Wolf (2007) suggest that current research limits the ability to establish a causal relationship between health literacy and health outcomes because much of the research is cross-sectional which hinders the ability to establish a strong cause effect relationship. Therefore, while a causal relationship amongst health literacy and health outcomes is likely, it is important to note that there not yet any conclusive evidence that provides the specific nature of this relationship (Nielsen-Bohlman et Al., 2004).

Defining Chronic Health Condition

The review will focus on persons with chronic health conditions and their caregivers. Chronic health conditions may appear slowly, progress over the course of one or more years, and are not usually curable by surgery or medicine (e.g., glaucoma, Parkinson's disease, and diabetes) (Dugdale, 2011; AARP, 2009; Murrow & Oglesby, 1996). Other conditions may begin acutely and become chronic (e.g., heart attack) or have lasting effects that are chronic in nature (e.g., hemiparesis after stroke) (Centers for Disease Control, 2010; AARP, 2009). Chronic health conditions are differentiated from acute health conditions in that acute conditions appear suddenly and typically involve a rapid decline or bettering of symptoms (Dugdale, 2011). In 2005, the Centers for Disease Control (CDC) estimated that there were 133 million Americans

(i.e., one in two adults) with at least one chronic health condition. Twenty-five percent of people with chronic health conditions were estimated to have difficulty with at least one activity of daily living (CDC, 2010).

This review is limited to chronic health conditions because of the implications that chronic health conditions have on the individual and caregivers, society as a whole, and the health care system. Chronic health conditions are persistent in nature and require that the person and his or her caregivers provide a fair amount of time, energy, and often funding to the management of the disease (Murrow & Oglesby, 1996). People with chronic health conditions and their caregivers may require extensive training and education to manage the disease, which indicates that health literacy is of the utmost importance in the management of chronic health conditions (Murrow & Olgesby, 1996).

Defining Health Literacy

Defining Literacy

In 1993, the National Adult Literacy Survey found that approximately 20% of adult Americans were not considered functionally literate (Kirsch et al., 1993). The survey found that people who were not functionally literate had difficulty with reading tasks required in everyday life (Kirsch et al., 1993). Research on understanding literacy is not new. However, recently there has been more attention paid to how to define and assess literacy.

Argument exists among educators, policy makers, and researchers as to how to define literacy and determine when a person has met this definition (Richmond et al, 2005). The definition of literacy has changed since the beginning of formal education in the United States

(Richmond, et al, 2005). Historically, if a person could read and write, he or she would be considered literate (Shomos, 2010). Early United Nations Educational, Scientific, and Cultural Organization's (UNESCO) definitions of literacy considered a person literate if he or she had completed five years of schooling (Shomos, 2010). UNESCO's (2005) definition of literacy changed to be more reflective of the fact that literacy exists on a continuum and is not just reflective of a person's skills in reading and writing but includes skills in many different areas (Richmond, et al, 2005). UNESCO (2005) offers a definition of literacy that states the following:

> Literacy is the ability to identify, understand, interpret, create, communicate, and compute, using printed and written materials associated with varying contexts. Literacy involves a continuum of learning in enabling individuals to achieve his or her goals, develop his or her knowledge and potential, and participate fully in community and wider society. (Richmond, et al, 2005, p. 18; UNESCO, 2005, p. 21)

The United Nations Educational, Scientific, and Cultural Organization (UNESCO) cautions that no one definition of literacy encompasses its many facets (Richmond, et al, 2005). The definition proposed by UNESCO is intended to be a working definition of literacy that reflects a person's concept and use of their literacy skills (Richmond, et al, 2005).

The definition of literacy continues to evolve because of the changing nature of the workplace and communication responsibilities of people (Richmond, et al, 2005). Today people are required to do more than just read and write in all aspects of their lives, which gives rise to the concept of "situational literacies." These are a person's literacy skills in various areas (e.g., technology, health, etc.) (Richmond, et al, 2005). Thinking of literacy as situationally mediated allows for a more diverse definition of literacy that encompasses the social, cultural, and political

aspects of how people gain and use their literacy skills (Richmond, et al, 2005). Situational literacy also allows for further exploration of the idea of "functional literacy" (Richmond, et al, 2005). A person is considered functionally literate if he or she can obtain and use information in differing environments, including work, home, and community (Shomos, 2010; OECD, 2000). Functional literacy also includes being able to use one's literacy skills in the achievement of goals and in the development of knowledge (Shomos, 2010; OECD, 2000). Functional literacy would suggest that a person would be able to use their literacy skills to achieve their maximum potential in all areas (Shomos, 2010; OECD, 2000).

Literacy in the context of health is not also easily defined. Health is a concept that has social, cultural, and political implications (Nielsen-Bohlman, et al, 2004). Historically, health was regarded as the absence of physical illness (World Health Organization, 1948); however, as society and health care continues to change there has been more recognition that multiple factors go into producing a healthy society (Brundtland, 2002; World Health Organization, 1948). In 1948, the World Health Organization stated that to be healthy was more than just not having a disease or sickness; in order to be defined as healthy, a person would also have physical, social, and mental well-being. In 2002, the National Committee of Vital Statistics (NCVS) further defined health in functional terms. The committee proposed a broad view of functional health that included an individual's ability to carry out activities of daily living as well as engage in age appropriate life situations and society as a whole (NCVS, 2002). This definition of health, along with the 1948 WHO definition, shows that many factors must be considered when defining health (NCVS, 2002; WHO, 1948). Considering the definition of health as defined by the WHO (1948) and further defined by NCVS (2002) along with the UNESCO definition of literacy helps to conceptualize what a definition of health literacy must include.

Defining Health Literacy

Prior to the 1990s, health literacy was only considered in terms of how well a person could understand information passed on to them from health care professionals (White, 2008). Researchers began looking at health literacy and its relation to health outcomes in the 1990s (White, 2008). There now are two widely accepted definitions of health literacy. The U.S. Institute of Medicine (IOM) and Healthy People 2010 define health literacy as the following:

> The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions…based on the interaction of the individual's skills with health contexts…and broad social and cultural factors at home, at work, and in the community. (Ratzan & Parker, 2000, n.p.).

The World Health Organization (WHO) proposes a slightly different definition of health literacy that suggests it should be thought of more broadly; the definition includes reference to a person's ability to participate in society and have some control over everyday events (Nutbeam, 2008; Nutbeam, 2000). This definition is also reflective of the WHO (1945) definition of healthy. The WHO definition of health literacy is as follows:

> The cognitive and social skills, which determine the motivation and ability of individuals to gain access to, understand and use information in ways, which promote and maintain good health… [it is] more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment (WHO, 2007, n.p.).

Nielsen-Bohlman, et al, (2004) also include health services, education, culture, and language as important factors through which health literacy skills and capacities are mediated. These researchers suggest that health literacy has both social and individual factors that must be considered and that a person becomes health literate when the expectations, preferences, and skills of both the consumer and the provider are in harmony (Nielsen-Bohlman, et al, 2004).

The definitions of health literacy provided by the IOM and by the World Health Organization are similar in some regards but distinctly different in others (Nutbeam, 2008). Baker (2006) suggests that the IOM definition of health look at health literacy as a defined set of individual capacities. The capacities are thought to remain stable throughout a person's life unless improved by educational attainment or education programs or declined by aging or disease or infirmity (Baker, 2000). If the IOM definition of health literacy is used, one could assume that health literacy may be developed by providing people with educational intervention (Nutbeam, 2008). However, it has been proven that educational intervention alone is not very effective (Nutbeam, 2008). Additionally, the IOM definition would suggest that a person is capable of achieving a certain level of health literacy if the person has the capacity and motivation to learn (Baker, 2006). Baker (2006) suggests that the idea of knowledge attainment is reflective of health knowledge as a component of health literacy.

The World Health Organization definition looks at health literacy in terms of a person's skills rather than a person's capabilities and further suggests that individuals may gain skills needed to make them active participants in society (Nutbeam, 2008). These skills allow people to engage in their world and affect changes needed to be successful, which would include navigating the health system (Nutbeam, 2008). Nutbeam (2008) suggests that these individual skills are the building blocks for which additional complementary skills are built. Thus, the

difference between the IOM and WHO definitions of health literacy is in how the person is thought to acquire health literacy, either by building upon capacities through educational intervention or by using existing skills to grow new skills (Nutbeam, 2008). The World Health Organization essentially views health literacy as an asset, a concept distinct from general literacy, and a product of health education (Nutbeam, 2008). The Institute of Medicine definition views health literacy goal directed and useful in increasing compliance to medical recommendations (Nutbeam, 2008). Health literacy as an asset will be explored later in this review.

The IOM and WHO definitions of health literacy provide broad means to shape the idea of health literacy (Nutbeam, 2006). However, Nutbeam (2006) argues that there are three different types of health literacy. Each of the three types will enable a person to perform a specific skill (or set of skills) (Nutbeam, 2006; Freebody & Luke, 1990). Nutbeam (2006) defines the three types of health literacy are basic/functional literacy, communicative/interactive literacy, and critical literacy. Basic/functional literacy skills enable to a person to participate in everyday situations by having sufficient reading and writing skills (Nutbeam, 2006). Communicative/interactive literacy is combined with social skills to enable a person to obtain information, get meaning, and apply information to new situations (Nutbeam, 2006). Critical literacy enables the person to analyze information and gain control over situations (Nutbeam, 2006). These three types of literacy exist on a continuum, and at each level, the person gains more skill, independence, and empowerment to make health decisions (Nutbeam, 2006). The WHO definition of literacy essentially combines elements of both communicative/interactive literacy with critical literacy and provides for the social and personal benefits of being health literate (Nutbeam, 2006).

Health Literacy and Sense of Coherence

In considering the WHO definition of health literacy, it is important to discuss Sense of Coherence (SOC). This is the idea that if a person finds a situation to be comprehensible, manageable, and meaningful, he or she is more likely to find solutions to problems, increase effective coping skills, and reduce tension (Eriksson & Lindstrom , 2008; Antonvosky, 1987). Critical literacy, which is part of the WHO's definition of health literacy, suggests that when a person achieves critical literacy skills he begins to use this skill to gain control over circumstances (Nutbeam, 2006). Sense of Coherence and the WHO's definition of health literacy appear to complement each other. Both definitions suggest that given the right information, including the ability to use that information, people will be more likely to manage, control, and determine the outcomes of their own health (Antonvosky, 1987; WHO, 2007). Given this idea, health literacy becomes an important determinant of health.

The World Health Organization's Commission on Social Determinants of Health and Healthy People 2020 defines determinants of health as those things that when gathered together influence a person's health and wellbeing (CSDH, 2008). There several are categories of items that are thought to be determinants of health (CSDH, 2008; Healthy People 2020, 2012) include policymaking, social factors, health services, individual behaviors, and biology and genetics (Healthy People 2020, 2012). General literacy is considered an important determinant of health (Kickbusch, 2001). While health literacy may not fit neatly into one of the broad categories, it may underscore many of the other determinants of health, thus itself becoming a determinant of health (Perrin, 2008; Kickbusch, 2001).

Health literacy is an important aspect of health promotion. This is defined as strategies designed to make improvements to people's health knowledge, attitude, skills, and behaviors on

individual, societal, organizational, and political levels (WHO, 1986). Health promotion helps to strengthen a person's control over the modifiable determinants of health (Nutbeam, 2006). Organizations that engage in health promotion may look to health literacy as an outcome to measure the success of the program (Kickbusch, 2001). Health literacy also may be used as a tool in health promotion (Nutbeam, 2006). Outcomes of health promotion are hierarchical in nature and explain how health promotion activities, determinants of health, and health outcomes are related (Nutbeam, 2006; Nutbeam, 1996). Nutbeam (1996) provides a model that summarizes health promotion outcomes. In this model, health literacy falls under the category of health promotion outcomes (Nutbeam, 1996). In this model, health promotion outcomes are personal, social, and structural factors that may be changed to influence the determinants of health (Nutbeam, 2006). Health promotion activities are generally aimed at these targets (Nutbeam, 2006). Health literacy in this model is representative of a person's ability to access, understand, and use health information in such a way as to have a positive effect on his or her health outcome (Nutbeam, 2006).

Framing Health Literacy: Asset or Liability

Health literacy continues to emerge as an important aspect of health, yet it is typically discussed in a negative context (Nutbeam, 2008). Many health care professionals and researchers frame a person's decreased health literacy skills as a liability, with health literacy being described in terms of cost, burden, and disparity (Nutbeam, 2008). McLaughlin (2009) states that poor health literacy may lead to health disparities, poor health outcomes, decreased patient safety, and higher costs ($73 billion dollars annually). While the idea that poor health literacy can lead to poor outcomes is known, viewing health literacy as a problem may have some negative consequences as well. For example, if viewed as a liability, health literacy may

be restricted to only clinical interactions, thereby limiting the scope in which health literacy may be used (Nutbeam, 2008).

Nutbeam (2008) suggests that health literacy should be framed as an asset, because as an asset, the interpretation, evaluation, and use of health literacy are strengthened (Nutbeam, 2008). Health literacy as an asset means that it is no longer viewed as a problem that needs to be fixed but rather is viewed as a resource that can be used to improve the management of chronic health conditions and ultimately as a health promotion tool (Nutbeam, 2008). Health education and communication can be used in various settings and for much more than just individual health outcomes, if the product of health literacy is empowerment (Nutbeam, 2008). Nutbeam (2008) suggests that there could be increased awareness of the social determinates of health. These determinants of health may become modifiable because of the actions of the community (Nutbeam, 2008). People would be empowered to make change at the community and individual levels. They would gain skills that increase their confidence in navigating the health care system and communicating with health care providers (Nutbeam, 2008). Sorensen and Brand (2011) suggest that health literacy would be a strategic asset that would help to increase the overall health of the population and workforce. This would separate health literacy as its own concept, distinct from general literacy skills, that in effect becomes the outcome of health education and patient provider communications rather than just an influential factor in the outcome (Nutbeam, 2008).

Health literacy as an asset would task health care professionals with building upon the skills people have instead of focusing on remediation of deficits (Nutbeam, 2008). This shift in view may influence how assessments of health literacy are designed and ultimately how people are assessed by these assessments (Nutbeam, 2008). Industries other than health care may also

desire a role in health literacy if it is framed as an asset (Berkman, et al, 2010). Sorensen and Brand (2011) argue that corporations could contribute to the health literacy of people in such a way that is mutually beneficial for the employee, population at large, and the corporation. The authors suggest that businesses could engage in health literacy promotion in a number of ways. First, the authors suggest that existing programs in the corporation be integrated with health literacy activities (Sorensen & Brand, 2011). Second, corporations could engage in conversations with stakeholders about how best to approach health literacy (Sorensen & Brand, 2011). Finally, corporations could begin to develop an action plan to improve health literacy, thereby designing a framework from which the corporations or society could work (Sorensen & Brand, 2011). Corporations taking these actions not only position themselves as socially responsible but also arm their employees with the skill of health literacy (Sorensen & Brand, 2011)

Assessing Health Literacy

Defining health literacy has its challenges, as does assessing health literacy. There are several commercially available health literacy assessment tools. Paasche-Orlow, et al, (2004) and DeWalt, et al, (2004) describe several assessments used to measure a person's general reading ability and health literacy. Table 1 provides a summary of commonly used health literacy assessments. Currently, the most commonly used assessments are test reading ability and vocabulary skill in the context of health related information (Nutbeam, 2008; Nielsen-Bohlman, et. al, 2004).

Table 1: Commonly Used Assessments of Health Literacy[1]

Name of Assessment (Acronym)	Assessment Description	What is Assessed	Administration and Scoring Time	Score Provided
Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis, et al., 1993)	Commonly used assessment. Used to assess reading level. A fifty-item assessment. Examinee reads words aloud and associates the word to a similar word.	Pronunciation and word recognition of medical vocabulary words	2-3 min	Categorical score • $\leq$ 3rd grade • 4th to 6th grade • 7th to 8th grade • $\geq$ 9th grade
Rapid Estimate of Adult Literacy in Medicine Revised (REALM-R) (Bass, Wilson, Griffith, 2003)	Based on the REALM. This is a screening tool used to assess the potential risk of low health literacy. Eight item assessment. The examinee reads words aloud and associates the word to a similar word.	Pronunciation and word recognition of medical vocabulary words	<2 min	Score between 0-8, with a score <6 reflecting that a person is at risk of low health literacy
Short Assessment of Health Literacy for Spanish Adults (SAHLSA) (Lee, et al., 2010)	Based in part on the REALM. Assessment used to assess Spanish speakers health literacy	Pronunciation and association of medical vocabulary words	3-6 min	Score between 0-50; with a score of 0-37 reflecting inadequate health literacy and >38 reflecting adequate health literacy
Test of Functional Health Literacy (TOFHLA) (Parker, et al., 1995)	Widely known assessment. Uses actual health related materials (e.g., hospital instructions). Assesses comprehension of information. Sixty-seven items (50 related to reading comprehension, 17 related to numeracy).	Prose literacy Cloze items Numeracy	18-25 min	Categorical Score • Inadequate • Marginal • Adequate
Short Test of Functional Health Literacy (STOFHLA) (Baker, et al., 1999)	Shortened version of TOFHLA. Comprised of two reading passages	Prose literacy Cloze items Numeracy	5-12 min	Categorical Score • Inadequate • Marginal • Adequate

Single Item Literacy Screener (SILS) (Morris, et al., 2006)	A one-item assessment. The person responds by using a Likert scale (0-5, with 0 reflecting never requiring assistance and 5 reflecting always requiring assistance).	Identification of people that need help with printed health material (screening tool)	Not indicated	Categorical Score • >2: some level of difficulty with reading printed health material • <2: likely adequate ability to read printed health material
Newest Vital Sign (NVS) (Weiss, et al., 2005)	Examinees are asked several questions about an ice cream nutrition label. Developers suggest that the assessment informs health care professionals of a person's ability to remember numbers, do math calculations, problem solve and act on personal medical issues, and make decisions about what is safe. Available in both English and Spanish.	Prose literacy Numeracy Document literacy	3 min	Categorical Score • 0-1: High likelihood of limited health literacy • 2-3: Possibility of limited health literacy • 4-6: Adequate health literacy

[1]As cited in multiple sources *(DeWalt, et al, 2004; Paasche-Orlow, 2004; NC Program on Health Literacy, n.d.)*

When the health literacy assessments are considered along with the definitions of health literacy, a few limitations begin to emerge. Baker (2008) suggests that health literacy assessments must take into account the definition of health literacy when determining what items to assess. For example, Baker (2006) and Nutbeam (2008) argue that if the definition of health literacy encompasses the idea that a person must have knowledge, then the most commonly used assessments of health literacy do not provide an adequate assessment. None of the more commonly used health literacy assessments address the idea of knowledge, yet the definition

provided by the Institute of Medicine and the WHO would suggest knowledge as a critical piece in a person's health literacy (Nutbeam, 2008). Additionally, if health literacy truly involves an interaction between the system and the person in which the system serves, then limiting health literacy assessments to the individual only would not be appropriate (Nutbeam, 2008; Baker, 2006). Assessing only the individual does not account for the individual's relationship and interaction with the healthcare system (Nutbeam, 2008).

The Committee on Health Literacy found that assessment tools do not offer ways to differentiate between the types of abilities the person has (Nielsen-Bohlman, et. al, 2004). For example, the current tools cannot differentiate whether a person has difficulty with reading or simply difficulty with content knowledge (Nielsen-Bohlman, et. al, 2004). Furthermore, the tools do not account for differences in a person's cultural beliefs about health (Nielsen-Bohlman, et al, 2004). Current assessments do not account for the different ages and stages of life, which if they did would help keep health literacy in an appropriate context for the person (Nutbeam, 2008).

The Committee on Health Literacy suggests that having written and oral communication evaluation would be of benefit in a health literacy assessment to evaluate the range of communication abilities of the person (Nielsen-Bohlman, et al, 2004). An assessment of oral and written language along with social skills may be helpful in assessing the person's ability to navigate the health care system and advocate for his needs (Nutbeam, 2008). Health literacy is best assessed when cultural factors, conceptual knowledge, listening, speaking, numeracy, writing, and reading skills are all included in the assessment (Nielsen-Bohlman, et. al, 2004). Nutbeam (2008) adds that health literacy assessments should be able to measure how a person is

able to gain access to information, discriminate information, personalize information to his or her own needs, and apply information once it is obtained.

Health Literacy and Health Outcomes

Products of Adequate Health Literacy

People with adequate health literacy typically engage in health promoting behaviors and have better health outcomes (AAFP, 2008; Nielsen-Bohlman, et al, 2004; Baker, 1998). People with adequate health literacy may unite as communities and work together for health causes at the community level (Nutbeam, 2006). Individuals with adequate health literacy are more likely to engage in activities, such as exercise, regular checkups, and healthy eating, that are all thought to reduce a person's risk of illness, disease, and complications for illness and disease (AAFP, 2008). A person with adequate health literacy may also find it easier to navigate the health care system and may be more likely to seek treatment sooner and feel more confident in their ability to communicate their questions and needs to health care providers (Paasche-Orlow & Wolf, 2007). Adequate health literacy may useful in patient provider communications in that people with adequate health literacy are better able to adhere to medication and other health recommendations , provide better medical histories, and give accurate and relevant information to help guide diagnosis and treatment because they are able to understand what is being required of them (Williams, et al, 2002). People have a decreased likelihood of hospitalization when they have adequate health literacy (Baker, 1998). They also tend to report a higher sense of good health than do their peers with inadequate health literacy (Win & Schillinger, 2003).

People with adequate health literacy tend to have more disease specific, practical, and instrumental knowledge needed to manage successfully their chronic health conditions (Paasche-Orlow & Wolf, 2007; Kalichaman, et al, 2000; Williams, 1998). Schillinger, et al (2002) found that people with type two diabetes and adequate health literacy demonstrated better glycemic control and lower rates of retinopathy than did their peers with poorer health literacy. In another study, people diagnosed with HIV who presented with adequate health literacy were more likely to have undetectable viral loads, know their CD4 (an important immune cell) count, and understand the importance of a CD4 count (Kalichman, 2000). Men with prostate cancer who exhibited adequate health literacy were found to participate in decision making about their disease management (Kim, et. al, 2001).

People with adequate health literacy are thought to be better health advocates than their peers with insufficient health literacy (Tappe & Galer-Unti, 2001). Health advocacy is done at the level of both cases and causes (Carlisle, 2000). Advocacy on the case level is reflective of attempts advocate for vulnerable populations (Carlisle, 2000). Advocacy on the cause level is reflective of attempts to change structural and political barriers to equal access to health (Carlisle, 2000). There is a continued need for those in public health to be advocates for those that they serve (Carlisle, 2000). However, in health promotion the goal is to empower people to advocate for themselves (Carlisle, 2000). Health advocacy takes on two forms, representational and facilitational (Carlisle, 2000). Representational advocacy is reflective of public health initiatives designed to protect vulnerable populations (Carlisle, 2000). Facilitational advocacy is reflective of initiatives designed to empower people with the skills needed to take control and lobby for their own health (Carlisle, 2000). Critical health literacy is one step to empowerment

that enables people to advocate for their health on both the case and cause levels (Nutbeam, 2006).

The health literacy skills of individuals may also influence the health care system as a whole (AARP, 2004). Nielsen-Bohlman, et al, (2004) reports that there are financial advantages to improving the health literacy of health care consumers. It is noted that "health care consumer" is a term used to describe people who use health care services; however, Stavri (2001) suggests that consumer may not be an appropriate term as health care is not a consumable. For purposes of this review, the term health care consumer will be used, because while not a consumable, there are economic and political implications surrounding health care (Stavri, 2001). Nielsen-Bohlman, et al, (2004) cites a report by Baker, et al, (2002) that states that health expenditures for people with inadequate health literacy was much higher than for people with adequate health literacy (Nielsen-Bohlman, et. al, (2004). The study found that people with inadequate health literacy had more emergency room care and less outpatient care (Nielsen-Bohlman, et. al, 2004). People exhibiting inadequate health literacy may not fully understand health related information and in turn have to seek more services or more expensive care (e.g., Emergency Room services) (Murphy, et al, 1993). It is estimated that health care costs that stem from low or inadequate health literacy are as high as $73 billion annually (Friedland, 1998). Nielsen-Bohlman, et al, (2004) suggests that while there are few studies that specifically look at the relationship between health literacy and health care expenditures, the evidence that is available suggests that there is a relationship worth further investigation.

Becoming Health Literate

How Do People Become Health Literate?

Improving the health literacy of health care consumers is a responsibility mostly shouldered by health care professionals; however, other disciplines are also implicated in improving health literacy (Nielsen-Bohlman, et al, 2004). There is an interaction between the health care and educational systems, culture, and society that helps to improve an individual's health literacy (Nielsen-Bohlman, et al, 2004). People with inadequate general literacy skills, including verbal communication and numeracy, are at a greater risk of not having an opportunity to receive health education and are also at risk of not being able to use the health information that they do receive (Nutbeam, 2008). Children are provided with health information beginning in the kindergarten and throughout high school (Nielsen-Bohlman, et al, 2004; Tappe & Galer-Unti, 2001). There are certain health related skills that children are expected to possess as they continue through primary and secondary education (Tappe & Galer-Unti, 2001). For example, the Joint Committee on National Health Education Standards (1995) suggests that children in the eighth grade should have the skills necessary to work cooperatively when advocating for health, express health information and ideas, and identify barriers to communication (Tappe & Galer-Unti, 2001). Other programs may serve adults who do not acquire health literacy skills in school. The Adult Basic Education and Literacy program (ABEL) provides some basic skills in reading and math necessary to develop literacy skills (Nielsen-Bohlman, et al, 2004).

Health care professionals are responsible for promoting health literacy; however, many health care professionals are uncertain as to how to accomplish this task (Tappe & Galer-Unti, 2001). They do not recognize that the people to whom they provide care have inadequate health literacy (Paasche-Orlow & Wolf, 2007; AARP, 2004; AMA, 1999; Murphy, et al, 1993). AARP

(2004) reported that in an AMA survey, only 33% of physicians reported knowing about health literacy. Tappe and Galer-Unti (2001) suggest that health professionals should be trained in undergraduate and graduate level work in the understanding and promotion of health literacy and advocacy. The authors encourage universities and colleges to provide course work in health advocacy and education and to encourage student involvement in health advocacy and education (Tappe & Galer-Unti, 2001). Additionally, health professionals should engage in evaluation of health related material in an effort to help the health care consumer find the information he needs and use it appropriately (O'Sullivan, 2011). Providing information in easy to understand language supplemented by pictures, multimedia, and decision aids may increase the likelihood that a person will understand what the provider is trying to communicate (Paasche-Orlow & Wolf, 2007). Monsivais (2003) recommends that health care professionals provide health consumers with three items: information that is clear, time to work on skills gained from interactions with providers, and resources to help with management of care.

Where Do People Get Health Information?

People are inundated with a variety of information regarding health (Antonovsky, 1989 as cited in Ek, 2004). Yet, the type and quality of this information may be of concern. It is not common for individuals to have access to information in medical journals, which is not easily available to the public in terms of both ability to access and ability to comprehend the information (Monsivais, 2003). This leaves many people with the option of relying on less formal sources of information. Health information is available from print media, television, and internet sources (Cutilli, 2010; Nielsen-Bohlman, et al, 2004). Health seeking behavior, or consumer health information seeking behavior, is the terms used to describe how people get information about health, illness, and health promotion (Cutilli, 2010). The information people

receive regarding health may be contradictory at times (Nielsen-Bohlman, et al, 2004). People with inadequate health literacy may have difficulty sorting out all the information and in turn may not always use the information at their disposal (Nielsen-Bohlman, et al, 2004).

Diaz, et al (2002) conducted a survey to look at internet usage for health information amongst patients. The study found that 53.5% of patients admitted using the internet for medical information. Of those that use the internet for health information, 60%, thought that the information gained from the internet was the "same as" or "better than" information they had received from their physicians (Diaz, et al, 2002). Most patients in the survey did not inform their physicians of their usage of the internet for health information nor did the patients engage in any evaluation of the accuracy and trustworthiness of the material reviewed (Diaz, et al, 2002). This study suggests that many people are turning to the internet in an effort to gain more information about their health (Diaz, et al, 2002).

Younger adults tend to seek more information from the internet than do older adults; however, older adults who use the internet tend to use it more for health information than do younger adults (Cutilli, 2010). Hispanics and African Americans tend to use the internet less than European Americans (Cutilli, 2010). Even though minorities are less likely to use the internet for health information, this material is available to anyone who can access it. What is of concern is the type and quality of information that can be obtained from these sources, especially in the face of limited health literacy (Diaz, et al, 2002). Williams, et al (2000) states that health information written on 100% of the websites reviewed were written at or above a ninth grade level. This would present a challenge to those with limited health literacy, as they may not be able to understand and subsequently use the information (Williams, et al, 2000).

It is important that health care professionals know where individuals get their health care information (Cutilli, 2010). Kutner, et al, (2006) found that people with limited health literacy tended to use fewer sources for health information and relied more on television and radio as sources of information. Those with higher levels of health literacy used a more diverse mix of sources including internet, print media, television, family, friends, and health care professionals (Kutner, et al, 2006). Guiding an individual's use of the internet for health purposes poses a difficult challenge to health care professionals (O'Sullivan, 2011). Some health agencies may design specific health portals that limit the complexity of information to help individuals be successful with both navigation and usage of the information (Sarkar, et al, 2010). However, many people do not have access to health portals and rely on general internet searchers for health information.

O'Sullivan (2011) suggests that health care providers be willing to evaluate information available on the internet and make suggestions to their health care consumers. Fox (2009), as cited in O'Sullivan (2011), gives the acronym TRUTHFUL as a way for health care providers to help individuals evaluate the internet sources of health information. Fox (2009) suggests that nurses and their health consumers look for the technical aspects, reviewers, purpose, funding, and legitimacy when considering using information from an internet source (O'Sullivan, 2011). Health care providers who assist people with evaluating information are helping them to become more health literate (O'Sullivan, 2011). People with adequate health literacy experience better success using the health information that they obtain from the internet in such a way as to influence their health outcomes than do their peers with limited health literacy (O'Sullivan, 2011; Sarkar, et al, 2010; Diaz, et al, 2002).

What Kind Of Health Information Do People Seek?

Health information is a generic term used to describe information that can be used to improve one's health. People with chronic health conditions and their caregivers may seek information for a variety of reasons. Some seek information about their specific disease, while others look more into new treatments and technologies. People may also seek information to educate themselves on health care costs and funding. Vermaas and Winjgaert (2005) found that men and women seek different information online regarding health. The study suggests that men tend seek information on more topics including mental health, sensitive topics, new diseases, and new medications (Vermaas & Winjgaert, 2005). Women in the study were found to seek information on chronic health conditions and health insurance (Vermaas & Winjgaert, 2005). Women were also found to seek information for family and friends (Vermaas & Winjgaert, 2005). Vermaas and Winjgaert (2005) believe the difference in information seeking behaviors between men and women may be a reflection of women's roles as caregivers (Vermaas & Winjgaert, 2005).

Cultural differences also exist in the sources and types of information sought. Cutilli (2010) cites a study by Thompson, et al, (2008) that found African Americans searching for information about cancer were more likely to seek information regarding support services and medical referrals. Additionally, Cutilli (2010) cites studies that found that African Americans were more likely to seek their information from health professionals, whereas people of Hispanic descent were more likely to seek information from friends and relatives. Older adults also valued the information gathered from a physician over that of other sources (Cutilli, 2010). While this indicates that people are seeking health information, there does appear to be a disparity between an individual's willingness to seek information and the low rates of health

literacy (Cutilli, 2010). This suggests that although people have information, they may not know what to do with this information (Nutbeam, 2006).

Can a Person Be Too Health Informed?

The goal of health promotion and increasing health literacy among people is to empower people with the skills needed to have successful outcomes (Nutbeam, 2006). However, many health care professionals and researchers question if people can become overly health informed. Some patients may gather information from the internet to present to their physicians, yet many of these patients do not have the health literacy necessary to discern good versus bad information (O'Sullivan, 2011). This may lead to patients demanding medical tests, medications, and other procedures that may be of no benefit or inappropriate for their particular conditions (FOJP, 2004). The idea that people have too much health information has sparked some debate in recent years. A training video by QuantiaMD titled *Managing Difficult Patients* discusses this topic. A section called "The Patient that Knows too Much" gives physicians tools on how to work with patients that have an overabundance of health information. In the training video, four physicians (Roberts, Hickson, Scherger, and Haas), representing diverse medical specialties, discuss the challenges, legal risks, and solutions to "patients that know too much." Patients that have an abundance of health information may present themselves to physicians as arrogant and may discount the physician's expertise (Roberts, et al, n.d.). Hass comments that these patients 'cost time' because much the session is spent explaining information to the patient as well as correcting information that is incorrect (Roberts, et al, n.d., n.p.).

The physicians refer to patients that gather too much information from the internet as " cyberchondriacs" (Roberts, et al, n.d., n.p.). A patient with too much information can create a frustrating situation for the physician, which can lead to the physician not recognizing the

progression of other symptoms in the patient (Roberts, et al, n.d.). This might be due to the physician concentrating on the patient's anxiety and information rather than monitoring for changes in the physical health of the patient (Roberts, et al, n.d.). Jousting (i.e., professionals criticizing each other) is another potential outcome of patients with too much information (Roberts, et al, n.d.). The physicians in the video find that often patients who are not satisfied with what one provider has says seek services from another provider (Roberts, et al, n.d.). This may lead to the new provider questioning the diagnosis, treatment, or management of the prior provider (Roberts, et al, n.d.).

The video concludes with remarks on how physicians should work with "patients that know too much." The physicians state that other physicians should respect the patient's right to use the internet as a resource in understanding their particular conditions (Roberts, et al, n.d.). Patients should be the experts of their own bodies and health and physicians should be coaches that model and teach good clinical judgment (Roberts, et al, n.d.). Roberts, et al, (n.d.) agree that an important step is to evaluate the internet sources that patients use for accuracy.

The video segment "The Patient that Knew Too Much" was met with backlash due to the nature of the presentation. After searching several search engines, no scholarly review of the information in "The Patient that Knew Too Much" was found. However, a general internet search revealed patients and other health practitioners who were in disagreement that a patient could ever know too much (Cohen, 2011). The patients interviewed shared personal stories of when using the internet actually lead to an accurate diagnosis. One respondent shared a story of her experience as a caregiver and how she found information on the internet, shared it with a physician during a second opinion, and ultimately saved her mother's life (Cohen, 2011).

A representative of QuantiaMD has since stated that the title "The Patient that Knew too Much" was likely a poor wording choice and that the physicians in the video did not mean to suggest that a patient could ever know too much (Cohen, 2011). The representative states that the video is intended to help physicians deal with patients with certain psychiatric conditions, such as panic disorder (Cohen, 2011). However, many critics of the video suggest that the comments made felt more like a criticism of those patients who choose to research their health conditions online (Cohen, 2011). Hickson, one of the physicians in the video, states that the video was made to "focus on the doctor who may not appreciate the empowered patient, and to remind colleagues we have a duty to meet the patient where they are" (Cohen, 2011, n.p.). The patient advocates who responded to the Cohen (2011) interview stated that that often patients with more information may get better results with their health care. The advocates caution that patients should evaluate the information they retrieve from online sources and not overburden physicians with that information at the time of the appointment (Cohen, 2011). One suggestion is that patients communicate the information with the physician via email prior to the appointment (Cohen, 2011). FJOP (2004) also suggest that physicians treat patients and their information with professionalism and accommodate reasonable requests such as reviewing information sent prior to the appointment.

How Does A Health Literate Society Function?

Nielsen-Bohlman, et al (2004) describe how their committee believes a health literate American society functions. The authors state that in a health literate society, opportunities are available to all persons to improve health literacy (Nielsen-Bohlman, et al, 2004). People have the ability to use and evaluate health information available to them in promoting good health (Nielsen-Bohlman, et al, 2004). Health literacy is taught from kindergarten until twelfth grade,

not just when the person becomes ill (Nielsen-Bohlman, et al, 2004). Policies regarding health

are monitored and policy makers are held accountable for these policies (Nielsen-Bohlman, et al,

2004). Public health alerts are presented in such a way as to inform and allow people to take

action (Nielsen-Bohlman, et al, 2004). All health communications are presented in such a way

that everyone can understand, including people who do not speak English (Nielsen-Bohlman, et

al, 2004). Patients are afforded time and made to feel comfortable in discussions with their

health care providers (Nielsen-Bohlman, et al, 2004). People are able to understand informed

consent documents and make choices based on those documents (Nielsen-Bohlman, et al, 2004).

The researchers state that while this vision of a health literate society will be difficult to achieve,

it is important that work continue in order to give everyone a chance to benefit from optimal

health (Nielsen-Bohlman, et al, 2004).

Nielsen-Bohlman, et al (2004) makes several recommendations regarding how the United

States might achieve this vision of a health literate society. The authors describe in detail each of

the recommendations and give specific ways by which each of the recommendations should be

implemented. The themes that emerge in the recommendations include providing adequate

funding for promoting health literacy and developing tools, examining policy changes that

promote health literacy, providing education to consumers and health care professionals on

health literacy, and supporting research in the field of health literacy (Nielsen-Bohlman, et al,

2004).

Conclusion

A health literate society is recognized as a goal of many health agencies. Health literacy

is important in improving the health of individuals and society as a whole. Increasing health

literacy empowers people to take control of their individual health as well as advocate for

changes in policies that may affect their access to positive health outcomes. Providing people the means by which to improve their health literacy is of the utmost importance. As reflected in this review, improving health literacy in the population will involve changes at the individual, societal, and health care agency levels. How health literacy is assessed will also be an important factor in producing health literate individuals. Looking at it will require that health literacy be examined at the individual, social, and agency levels. There must also be a discussion of cultural factors in defining and assessing health literacy.

Several pieces of research look at information seeking and usage with regard to health literacy. Research suggests that people use the internet to gain information about their conditions as well as other health related topics. It may be of interest to look at how specific cultures access health information and what types of health information are targeted towards these cultures. This information could help guide researchers and health educators to understanding what specific cultures needs and values are regarding health information. This information may also lead to improving the type and quality of health information targeted towards specific cultures. Understanding the needs of a culture and meeting those needs may empower the people in that culture to manage their health conditions, increase their health literacy, and ultimately improve their overall health outcomes.

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Appendix C: Literature Review 3

Dissemination of Health Information: A Review of the Literature

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This document of one of three comprehensive reviews of the literature completed as a

prerequisite for the Oral Comprehensive Examination in Therapeutic Science. This document

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Healthcare consumers are encouraged to assume an active role in their healthcare decisions (Beacom & Newman, 2010). In part, this role requires that healthcare consumers actively find and utilize health related information in order to produce better health outcomes (Nutbeam, 2008; Cain & Mittman, 2002). This may present a challenge to many healthcare consumers because of the amount of health information available from a variety of formal and informal sources (Antonovsky, 1987). Changes to health policies, medical technologies, and information systems may influence the way individuals interact with the healthcare system (Cain & Mittman, 2002). Healthcare consumers must acquire health information that is relevant, accurate, and implementable; however, many healthcare consumers may feel frustrated with the amount, type, and quality of information they encounter (Nutbeam, 2008; Connell & Crawford, 1988). Health consumers' frustration may stem from difficulty accessing, processing, or using the information in a way that is meaningful to them (Ek, 2004; National Institute of Medicine, 2004). This may lead to healthcare consumers ceasing to look for information, inappropriately applying information, or being satisfied with a cursory and superficial assessment without seeking more details or alternate perspectives (National Institute of Medicine, 2004). Some of the difficulties encountered with health information may be explained by inadequate health literacy; however, health literacy alone may not account for all of the difficulty. How health information is disseminated to the healthcare consumer is likely to be a factor in why healthcare consumers may have difficulty interacting with health information.

Researchers and clinicians search for the best methods through which to disseminate health information to healthcare consumers that is accurate, accessible, and appealing to use. This review will examine how health information now is disseminated, with a focus on information disseminated to populations at risk for chronic health conditions. The review will

identify current trends in disseminating health information and will examine the merits of these methods. Two dissemination methods (i.e., entertainment media and informal web-based sources) will be analyzed. Recommendations for dissemination methods having high impact and positive benefit will be proposed and the contributing factors discussed as part of this review. This review is intentionally limited to chronic health conditions, recognizing the pervasive nature of these conditions and the on-going need for continuing education, information, resources, and support when confronted by the need to manage a chronic health condition.

Background

Persons with Chronic Health Conditions

Chronic health conditions are categorized as both non-communicable (e.g., stroke, heart disease, and diabetes) and communicable (e.g., HIV and tuberculosis) (Epping-Jordan et al., 2004). Approximately 50% of persons living in the United States have some type of chronic health condition (Centers for Disease Control, 2010). The commonality among these chronic health conditions is that the survival rate of these diseases and conditions have improved because of advancements in medicine and medical technologies (Baker et al., 1998). Chronic health conditions are persistent and require a great deal of management of the condition (Nielsen-Bohlman et al., 2004). The management of a chronic health condition is more than just management of the disease itself, but also includes the management of finances, time, and knowledge of the condition or disease (Murrow & Olgesby, 1996). Many individuals with chronic health conditions are motivated to manage their conditions because by doing so they may have improvements in overall health and quality of life (Fox, 2011).

Health Disparities

Often, people with chronic health conditions are also members of groups that are burdened by health disparities. Health disparities are widely researched and are known to have an effect on individuals living in lower socioeconomic status, having lower levels of education, and holding minority status (Beacom & Newman, 2010). Getting appropriate health information to those individuals that are affected by health disparities is important because it may help to improve overall health outcomes. When individuals have unequal access to information, a knowledge gap can be created. A knowledge gap occurs when access to information increases and a widening space is created between persons with access to health information and persons without access to health information. One of example of this potential for a knowledge gap occurs when there is unequal access to the internet. The internet has gained popularity as a health outlet in recent years, as it can provide information about a health condition, treatment, and support twenty-four hours a day. However, some individuals may not have access to the internet because of the cost of internet access in the home or difficulty with transportation to places (e.g., public libraries) that provide free internet access.

Inadequate health literacy and health disparities (including access to health information) are known to have negative influence on health outcomes. Yet, both health literacy and health disparities may be improved by examining the ways by which people become health educated (Blanck & Marshall, 2011). Part of becoming health educated may be based on how health information is passed from the researchers and the medical community to the layperson. Diffusion and dissemination of health information may be an important factor in reducing and eliminating health disparities as well as promoting health literacy.

Defining Diffusion and Dissemination

Dissemination of health information may be considered from the perspective of diffusion theory (Green et al., 2009), which originated with Everet Rogers as the prevailing authority on the diffusion and dissemination of innovations and information (Cain & Mittman, 2002). Rogers' conceptualization of diffusion will be used in this review. Rogers' research examines the way by which innovations spread among members of society (Rogers, 2003). Innovations are new ideas, information, products, or practices that are considered for possible adoption by the individual. Rogers (1995) suggests that communication channels, time, and the social system influence the spread of innovations. Rogers (2003) defines diffusion as the uncontrolled natural communication of innovation and information among members of society. Diffusion is typically measured in terms of penetration, which is the number of adopters (or users) per one thousand people (Bagchi, Kirs, & Lopez, 2008).

Diffusion occurs in both health and non-health related innovations. Examining non-health related innovation's diffusion into society might help to enhance the understanding of the diffusion process. For example, Rogers (1995) discusses the cellular phone as non-health related example of diffusion, an innovation many individuals can relate to. Cellular phones first came to market in the United States in 1983. The United States sold over one hundred thirty million cell phones during the first decade on market. This number grew rapidly during the 2000s in the United States and abroad. For example, between the years 2000 and 2004 , China saw the rate of cellular phone users increase from 65.82 users per 1000 to 214.77 per 1000 (Bagchi, K& Lopez, 2008). Today, estimates show that there are approximately six billion cell phone users worldwide ("MobiThinking," 2013). Several factors gave rise to the diffusion of the cellular telephone (Rogers, 2003). Initially, males in executive positions accounted for nearly all of the

adoption of cellular phones (Rogers, 2003). However, Rogers (2003) explains that cellular phones possessed the qualities of an innovation that made it attractive to a wider range of people. These attributes include timesavings, status, compatibility with existing technology, simple to operate, and ability to try out the product before purchasing it. All of these attributes fit into several categories proposed by Rogers (2003) that make an innovation more likely to be adopted. These categories will be discussed later in this review.

In comparison to diffusion, *dissemination* occurs with identification of a target audience and conscious effort of the communication of an innovation or information to that audience. A person with diabetes gaining disease-specific information about new treatments from a pamphlet given to them at a diabetes support group is an example of dissemination of information. Healthcare innovation and information may reach the public by either diffusion or dissemination (Rogers, 1995, p. 65). Owen et al, (2006) suggests that diffusion is the outcome of dissemination efforts and that dissemination of health innovations typically precedes overall diffusion. Rogers (1995) illustrates this idea in his text when he discusses the STOP AIDS Project in San Francisco.

The STOP AIDS project in the 1980s trained gay and bisexual men living with HIV/AIDS on how to conduct small community level groups aimed at sharing information about HIV/AIDS and safer sex practices (Rogers, 2003). The targeted populations for this intervention were gay and bisexual men in San Francisco. Kert Lewin's Small Group Communication and Diffusion of Innovations theories were the basis for the project (Bertrand, 2004). Prior to the initiation of the groups, the project coordinators held focus groups to get a sense of what was already known about HIV/AIDS in the targeted community. Small group meetings among males with or at risk for HIV/AIDS and media campaigns designed to educate about the disease were

initiated after collecting information from the focus groups. Both the small groups and media

campaign resulted in a rise in peer-to-peer communication of information. This was in part

because at the small group sessions, participants pledged to use safer sex practices as well as

hold small group meetings of their own. In the late 1980s, attendance at the small group sessions

began to decline because the program had "reached the *Critical Mass* among early adopters of

safer sex practices" (p. 116). *Critical Mass* occurs when there are sufficient adopters of an

innovation such that the innovation becomes self-sustaining (Rogers, 2003). STOP AIDS

experienced success and the program being partially credited for helping to reduce the number of

new HIV cases from 8,000 to 650 in the time span from 1983 to 1995.

Diffusion and Dissemination among Researchers and Clinicians

Diffusion and dissemination of innovation is not restricted to information regarding

healthcare nor is it restricted to the sharing of information from health care professional to the

person with chronic health conditions. Diffusion of innovation also occurs at the level of

researcher to clinician and vice versa (Green et al., 2009). In this case, information gained in

research or in clinical practice is communicated via a two-way channel with each recipient

sharing in a dialogue aimed at creating best evidence based practice (King, Hawe, & Wise,

1998).

As researchers develop new treatments and technologies, they are challenged with

determining how to move that information from the laboratory to healthcare providers who can

then implement the information into everyday practice. Knowledge translation is one of many

terms used to describe how information gets from researcher into practice by healthcare

providers (Estabrooks et al., 2006). Translational research may also include ideas such as " (a)

evidence based decision making, (b) research utilization, (c) innovation diffusion, (d) knowledge

transfer, (e) research dissemination, (f) research implementation, and (g) research uptake" (p. 28). There are yet any specific theories on knowledge translation, although Rogers' (1995) Diffusion of Innovations is the model that most closely aligns with knowledge translation.

Translational research may take on two forms, dissemination of scientific information, and dissemination of practical information.   Individuals in medicine may define translational research as taking information from the basic sciences and translating that information into new treatments, drugs, and medical devices (Woolf, 2008). Allied and public health professionals may interpret translational research to mean that research findings are translated into useful information that informs policy and practice for the population of interest. Either form of dissemination requires that the information is communicated in a way that is functional and usable by the intended audience (King, Hawe, & Wise, 1998). At this stage, information is not interpretable by the layperson, but it should be easily interpretable and usable, either in practice or clinical research, by the healthcare provider.

Ruttenberg et al. (2007) propose the use of the Semantic Web as an effective means to translate research among researchers and clinicians. The Semantic Web uses automatic processes that integrate and aggregate information from multiple sources. The researchers suggest that using the Semantic Web will allow for interdisciplinary search and use of research and thus aid in translational research.

From Dissemination to Implementation

Glasgow and Emmons (2007) suggest that dissemination and implementation of information are two distinct processes, with implementation serving as the final stage where information may be worked around constraints to get the information disseminated.

Implementation theory is concerned with healthcare providers' beliefs and decision making when confronted with using new practice methods suggested by research (Estabrooks et al., 2006). Much of the research with regard to implementation theory has found that even when healthcare providers agree with and intends to use information, there may be a disparity between the original research and the translation and usage of the research (Green et al., 2009). Green et al. (2009) suggests that the disparity may exist because some scientists may believe that information gathered from research automatically funnels down to providers a way that it is easily understandable and immediately usable. However, healthcare providers may not have access to the information provided by researchers. Healthcare providers may also opt to use traditional practice methods because of the applicability to their specific healthcare consumers.

Diffusion and dissemination occurs between researcher, clinician, and the person with a health condition. The communication of information is a two way process with all parties involved contributing to the discussion. This paper will focus specifically on the communication of information from the health care provider to the person with a chronic health condition. However, examples of diffusion among researchers and clinicians will be provided as the principles of diffusion hold true regardless the groups to which the information is being diffused.

Principles of Diffusion

Adoption of Innovation

Adoption of health innovations involves multiple concepts. Rogers (2003) defines adoption of an innovation as "a decision to make full use of an innovation as the best course of action available" (p. 21). Rogers (2003) suggests that there are several categories of adopters. These categories are roughly divided into the time it takes an individual to adopt an innovation.

Here, time to adopt is not represented as a defined temporal length of time (e.g., days, months, or years), but rather time is represented as the period from which introduction of the innovation occurs to the acceptance of the innovation by an individual. The amount of time from introduction of an innovation to adoption (i.e., cumulative adoption) may be represented using a logistic model (Rumelt, 2002). Diffusion of Innovation typically takes on an "s" shaped curve, which demonstrates how innovations typically diffuse rapidly into society and then encounter a period of slowed adoption. After this period, saturation usually occurs, which is represented by a flattening of the curve. However, since some innovations have a more rapid rate of diffusion, the slope of the s curve may be variable (Yuan, et al., 2010).

Categories of adopters were initially defined only in statistical terms (i.e., the number of standard deviations from the mean adoption time); however, a qualitative description of each of the adopter category was proposed (Berwick, 2003). Rogers (2003) suggests that there are five categories of adopters. Each of these distinct categories of people contains a set of behaviors and beliefs that may influence how they adopt a health innovation. The majority of individuals fall into the Early Adopter and Early Majority category of adopters as with both of these categories accounting for 34% of the total number of adopters.

Innovators account for 2.5% of adopters (Berwick, 2003; Rogers, 1995). These individuals adopt innovations at a rate of ≥2 standard deviations above the average rate of adoption (Berwick, 2003). Innovators may be described as venturesome, cosmopolite, having a high tolerance of risk and uncertainty, and having social networks that extend beyond there geographic boundaries (Cain & Mittman, 2002; Berwick, 2003; Rogers, 1995). Berwick (2003) suggests that the innovators are not opinion leaders in the community and may be considered by

those in their community to be impetuous. The "maverick physician" may be one example of a

person who is likely an innovator.

The *early adopters* are the group that follows the innovators in the hierarchy. Early

adopters typically adopt an innovation at a rate of one to two standard deviations above the

average adoption rate (Berwick, 2003). Early adopters are thought to be the opinion leaders of a

society, although they account for only 13.5% of adopters (Berwick, 2003; Rogers, 1995). These

individuals tend to have larger social circles than do other adopters. They also communicate

with innovators. Berwick (2003) suggests that early adopters in a health care setting are those

people who are given leadership or representational positions within the organization. They are

also more likely to be selected to engage with pharmaceutical representatives. Researchers

suggest that the other 85% of the population (Innovators and early adopters excluded) will not

adopt an innovation until the early adopters have done so (Rogers, 2003).

The *early majority* is the third group of adopters described by Rogers (2003). This group

of adopters embraces innovation by learning about it through individuals with whom they have

close contact (Berwick, 2003). Individuals in the early majority may be more open to learning

about innovations that have an immediate reliability to their current situations. They may also be

concerned more about personal familiarity with an innovation rather than the science and theory

behind it. These individuals may be described as "deliberate, highly interconnected within a peer

system and just ahead of average" (Cain & Mittman, 2002, p. 12).

The *late majority* makes up the next 34% of adopters (Berwick, 2003). The Early

Majority influences this group. This group will often adopt an innovation after it appears, as the

innovation is the new normal (Berwick, 2003). Additionally, this group tends to need proof that

an innovation will do what it purports it will do. Cain & Mittman (2002) describe the late

majority as skeptical and responsive to and limited on economic resources.

The last group in the hierarchy is the *laggards*. Laggards comprise 16% of adopters

(Rogers, 2003). Laggards are often perceived in a negative manner that suggests these

individuals are not open to change (Berwick, 2003). Yet, the laggards may also be viewed

positively as those individuals that are traditional and more discerning than the other adopters

(Berwick, 2003). Rogers (2003) describes the laggard as someone for whom "the point of

reverence is the past" (p. 265). Laggards are the last to adopt innovations and may be the most

difficult group to reach. These individuals may have financial and other hardships that make it

difficult to adopt innovations without some assurance that the innovation will be of benefit (Cain

& Mittman, 2002).

The Adoption Process

Each category of adopters goes through a similar process when deciding to adopt an

innovation. This process takes time and involves multiple steps (Cain & Mittman, 2002). The

Decision Process ultimately determines whether and how an individual will use an innovation.

Rogers (2003), defines the Decision Process as a hierarchy that progresses from (a) knowledge;

(b) persuasion; (c) decision; (d) implementation; and (e) confirmation. Knowledge occurs when

an individual becomes aware of an innovation. The individual must form an opinion about the

innovation. Individuals then try the innovation and determine whether or not they intend to

adopt the innovation (i.e., decision). Next, behavior changes begin to occur as the individual

fully integrates the innovation into his or her life (i.e., implementation). Finally, individuals

make final decisions regarding the innovation (i.e., confirmation). This may include continuing

to use the innovation, rejecting the innovation, or making changes to how the innovation is used

in daily life. Individuals typically go through each of these steps in order; however, exceptions to this rule may occur. Some individuals in a position of authority may require individuals to adopt an innovation. For example, Barnes Jewish Memorial Hospital began to require that all employees in the hospital receive the seasonal flu vaccine or be terminated (Hampton, 2009). In 2008, the hospital terminated eight employees who did not take the vaccine (i.e., adopt the innovation) because of personal beliefs.

Researchers consider diffusion and dissemination to occur at different stages in the Decision Process (King, Hawe, & Wise, 1998). Diffusion encompasses the entire decision process, while dissemination occurs during the knowledge and persuasion phases of adoption. This idea helps to strengthen the argument that dissemination is a part of diffusion and not a separate idea (Owen, et al., 2006). Dissemination viewed as part of diffusion may help to explain why knowledge alone will not support behavior change. The entire process of diffusion explains how individuals must not only acquire knowledge (i.e., health information), but must then continue through the decision process to make permanent behavior changes. This idea also highlights the importance examining not only the diffusion process but also an individual's implementation of health information after dissemination.

Implementation theory is described in the literature as the process by which researchers disseminate information to clinicians and how clinicians put this information into practice (Green et al., 2009). Researchers also examine how clinicians disseminate information to researchers. Healthcare consumers may have similar difficulty with healthcare information disseminated to them. Implementation theory suggests that even when healthcare providers agree with and intend to use information, there may be a disparity between the original research and the clinician's interpretation and implementation of the research. The authors suggest that the

disparity may exist because some scientists may believe that information gathered from research automatically funnels down to providers in such a way that it is easily understandable and immediately usable. However, healthcare providers may not have access to the information provided by researchers. Healthcare providers may also opt to use traditional practice methods because of the applicability to their specific healthcare consumers.

Increasing the Likelihood of Adoption of an Innovation

Many popular health fads can illustrate how an innovation disseminates into mainstream society. For example, makers of diet and weight loss products often employ effective dissemination techniques that may lead to mass adoption of an innovation. The Atkins Diet provides a current example of over acceptance of an innovation by the lay public. This review does not support nor refute any of the claims made by the inventors of the Atkins Diet. The Atkins diet is only used as an example of how proponents of an innovation increase its likelihood of adoption.

In 1973, Robert Atkins introduced the Atkin's Diet designed to help people lose weight quickly by increasing protein and fat intake and decreasing carbohydrate intake (Foster, et al., 2003). This innovation in weight loss proved to be very popular, selling over ten million copies of the companion book to the diet. Many people, including some medical professionals, adopted the innovation despite lack of randomized clinical trials showing evidence that the diet worked for general weight loss. There was evidence to support the use of the Atkins Diet as beneficial therapy for children with intractable epilepsy, yet the diet gained wide spread adoption for reasons that had not been thoroughly researched. (Kossoff, et al., 2006). Several key components drove the likelihood that the Atkins Diet would become popular with the

mainstream public. These key components are of interest because they may help to shape the methods by which other evidence-based innovations are disseminated.

Rogers (2003) cites 1) relative advantage, 2) trialability, 3) observability, 4) complexity, and 5) compatibility as important factors in adoption. Individuals tend to look more favorably upon innovations that offer some benefit or value to them (i.e., relative advantage). The Atkin's Diet offers individuals a reported quick and easy way to lose weight, which may have social, health, and financial benefits ("Atkins", 2013). For example, an individual who is obese that uses the program to lose weight may find their risk for other chronic health conditions is lessened.

Innovations that offer individuals the opportunity to try them before committing to them are also more likely to be adopted (i.e., trialability) (Rogers, 2003). A recent search of www.atkins.com, the website for the Atkin's Diet, revealed that the company offers consumers a free Atkin's Diet Kit that allows the consumer to read about the diet and try the diet on limited bases ("Atkins," 2013). Individuals experience what it is like to be on the Atkins Diet and make decisions based on those experiences.

Individuals tend to respond favorably to innovations whose results are evident to people around them (i.e., observability) (Rogers, 2003). Observable innovations are more likely to be adopted than those that are not. Inventors of the Atkin's Diet state that it gives users quick results ("Atkins," 2013). The website also includes personal testimonials with other dieters sharing their successes, such as the amount of weight lost and the amount of time taken to lose the weight. Thus, potential adopters can anticipate the results even before they adopt the innovation.

Easy to use innovations are more likely to be adopted than are complicated innovations (i.e., complexity) (Rogers, 2003). The Atkin's Diet guarantees users an easy to follow diet plan, access to support online any time of the day, and social support groups ("Atkins,"2013). Additionally, the Atkin's Diet states that any individual may readily begin and use the diet. Innovations that are simple to integrate into an individual's lifestyle, beliefs, and experience are more likely to be adopted. The Atkins Diet may teach health care providers about how best to reach the mainstream public. Combining these key components needed for successful adoption with the target audience, the early adopters, will aid in making a heath care innovation highly visible and desirable. To accomplish this, one goal may be to examine how individuals respond to innovations.

Responses to Innovations

Each individual with a chronic health conditions approaches health innovations and information differently (Rogers, 2005). It is important to consider how individuals respond to health information when initiating a diffusion or dissemination strategy. Many individuals come to the discussion about their health with preconceived ideas and beliefs about their conditions. Typically, these beliefs are held because of information the person has gathered. These beliefs may be factual, while others may have some foundation in fact, but in some regard, it is likely they will be incomplete or flawed. How individuals with chronic health conditions understand and use evidence-based information is important in the dissemination of information. Rogers (2005) suggests that preconceived beliefs may influence the outcome of the individual's acceptance or rejection of the innovation. Careful, evidenced based practioners may be able to guide people with chronic health conditions in the right direction with regard to health innovations, which may shape the responses of individuals. Individuals may enter the discussion

about the management of their health armed with better information that will be an aid in making decisions that are right for them at that particular time.

Diffusion of Innovation (DOI) theory suggests that individuals may choose to do one of three things with an innovation (Rogers, 2003). An individual may adopt the innovation (i.e., accept the innovation as is) or the individual may reject the innovation (i.e., choose not to adopt the innovation). Rogers (2003) suggests that discontinuance is another potential outcome. Discontinuance occurs when the individual rejects a previously adopted innovation in favor of a new or improved innovation. Individuals may also choose to adopt an innovation that was previously rejected.

Chin and Brewer (1993) offer an expansion on the idea of what individuals do with information. The researchers examined how children dealt with anomalous data they confronted in science classes. Chin and Brewer (1994, p. 4-13) suggest that when confronted with anomalous data, individuals may do one of the following:

- Ignore the information completely.

- Reject the information and explain why the information should be rejected.

- Exclude the information because it is not consistent with their beliefs.

- Hold the information in abeyance until such time that one's one theory can explain the new information.

- Reinterpret the information using one's own theory.

- Make peripheral changes to one's own theory and accept the new information.

- Make central changes by accepting the new information and making changes to one's own beliefs or accepting the new information as an alternative.

Although this paper examines dissemination of health information, the Chin and Brewer (1993) research is cited here because the model may help to explain what adults who encounter health information do with that information. Chin and Brewer (1993) suggest that encountering information that is different or in opposition to an individual's own beliefs or knowledge is essential to the learning process with regard to science. The researchers conclude that understanding how the students deal with anomalous data helps to understand the learning process as well as uncover the best methods by which to instruct. It is plausible that this idea holds true for the acquisition of health information as well. Research is available that examines how individuals acquire health information; however, there have yet to be any studies that directly discuss Chin and Brewer's (1993) model in this process. Applying the Chin and Brewer (1993) model to health information acquisition may offer a broader explanation of how people approach health information with which they are not familiar. It may be of interest to understand how to reach individuals at each stage in the model. For example, clinicians may need different strategies to target health information to an individual who is holding information in abeyance than to an individual who is excluding new information. By gaining a deeper understanding of each of these categories, health information could be delivered in a more personalized and focused manner.

Dissemination Mediums

People with chronic health conditions may seek health information to find new treatments, to supplement information provided by health care providers, or to learn more about their specific conditions (Cutilli, 2010). The specific ways by which individuals obtain health information for the purposes of improving their health and identifying potential risks to their health is defined as Health Information Seeking Behavior (HISB). There are numerous studies about HISB, and

while HISB is not the focus of this review, it is mentioned here because of the influence that dissemination of health information may have on HISB (and vice versa). An individual's socioeconomic status, educational attainment, culture, and beliefs about health may influence HISB. It is important to a dissemination of health information because it allows researchers and clinicians to understand what types of sources individuals use for health information.

Individuals typically seek information from trusted sources (Goody et al., 2001). Having an appreciation for which sources individuals trust may be useful in determining the best dissemination medium for an innovation. The idea of seeking information from trusted sources may be interpreted differently depending on who is commenting on the source. Most individuals, irrespective of age, race, gender, or socioeconomic standing, identify health care professional as the most trusted source for health information (Cuttilli, 2010). These same individuals have different secondary trusted sources. Capstrat (2010) argued that asking individuals what their most reliable (e.g., trusted) source may not provide the picture intended.

Web Based Sources

When individuals were asked where they go for information on a day-to-day basis, the data yielded slightly different results. Most individuals cited physicians as the most trusted source, followed closely by advocacy groups, pharmacists, nurses, and Google search. When the question was modified to reflect where individuals go most frequently for information, the majority of the respondents (44%) stated their physicians. However, the second largest percentage of respondents cited Google as their most frequent go to source. Part of the appeal of Google is that this health information source offers individuals 1) Relative Advantage, 2) Trialability, 3) Observability, 4) Complexity, and 5) Compatibility, all of which are important in making an innovation more likely to be adopted (Rogers, 2003). In this context, the innovation

is not the health information itself, but rather it is the dissemination technique. The

dissemination technique is what helps the individual gain access to the health information.

   Media Complementarity Theory suggests that the internet is typically used as a

complementary, rather than primary, source of health information despite its popularity (Tian &

Robinson, 2008). However, even if the internet is used only as a secondary source to the

physician, many people continue to use the internet as a health information source. It is

estimated that 75-80% of people who use the internet do so for health information (Beacom &

Newman, 2010). The internet is so widely used that it is likely it influences how healthcare

consumers understand and ultimately take action regarding their health (Murray, et al., 2003).

      The internet is a largely unregulated entity that allows virtually anyone to become an

expert, including an expert in health information. The way in which people interact with the

internet has changed since the mid-2000s (Scanfeld, 2004). Prior to 2004, most individuals had a

passive role with the internet. People mostly consumed information online, and there was rarely

a two-way exchange. *Web 2.0* is the term that describes how people interact with the internet

today. As of 2004, new software capabilities allow people to take more of an interactive role

with the web. People have the ability to rate items, post reviews, and share information. These

capabilities have also extended to health related information. The terms Health 2.0 and Medicine

2.0 discuss the ways by which people use online capabilities for health related topics. There are

numerous examples of health websites available for use. For example, www.healthboards.com is

an online health community where individuals (e.g., lay public, patients, doctors, and other

healthcare professionals) register and post questions about overall health and specific symptoms

(Healthboards, n.d.). Members in the community may respond to questions with advice or share

stories about their experiences.

Gimenez-Perez, et al., (2005) conducted a random sample of health websites aimed at Type 2 Diabetes treatment to assess for the dissemination of patient-oriented evidence that matters (POEM). POEM is the term that describes how available health information improves a person with a chronic health condition's life or life expectancy. The goal of information on the websites they researched was to communicate to health consumers' information that can be used to make decisions about their healthcare in an unbiased way. This includes information about benefits and risks of diagnostic interventions, prevention, and therapies. The researchers found that information contained within online health websites largely failed to communicate this information. Most websites focused on positive information and did not offer health consumers information about negative findings. For example, the researchers found that there was little information regarding "the lack of effect of tight blood glucose control on quality of life" (p. 690). Gimenez-Perez et al., (2005) suggest that the overall content of health information on the websites in the study was adequate yet incomplete. This is problematic because the information does not allow healthcare consumers to make a completely informed decision. The researchers conclude that there is likely a lack of quality evidence based information being disseminated to health care consumers on the internet.

Cyberchondriacs

Recently, attention has been given to the creation of the "cyberchondriac." Keller et al. (2008) suggest, "people are searching the internet for answers are already very likely sensitive to their symptoms and somatic sensations, as in the case of hypochondriacs" (p. 75). Smith et al. (2005) define the cyberchondriac broadly as someone who uses the internet to obtain health information. Taylor (2002) narrows the definition of cyberchondriac based on information gathered in a Harris Interactive Poll targeted at internet users. Taylor (2002) suggests that

cyberchondriacs are individuals that search for health information online at least three times per month (Taylor, 2002). These individuals are younger with more educational attainment than the lay public. They typically use search engines in lieu of specific websites (e.g., e-health sites); however, they are more likely to visit more verified sites (e.g., government, academic, and pharmaceutical).

Most researchers who study cyberchondriacs agree that health consumers should be informed about their health status and health needs (Smith et al., 2005). The concern is that these individuals may have difficulty with deciphering good versus bad information (Keller et al., 2008; Smith et al., 2005). These individuals may be more likely to demand treatments for conditions that may not have evidence of effectiveness or safety based on information they have gathered from the internet (Smith et al., 2005). This may be problematic given the concerns with the trustworthiness of information online.

Social media and online support groups.

Social media sites (e.g., Facebook, Myspace, and Twitter) have grown in popularity in recent years with approximately 147.8 million people in the United States alone using these sites (emarketer, 2011). Social media sites are those websites whose content is largely user generated (Kaplan & Haenlein, 2010). There are also online health support groups that in some capacity function as a social media sites. Some individuals with chronic health conditions may find support in online health communities that lead to improvements in overall health (Shaw, 2011). Online social media sites may also facilitate social networking similar to social networking in real life. Shaw (2011) found that people with Type 2 Diabetes were willing to use social media sites to learn about and discuss health related issues. There were no significant differences between race with regard to the willingness to use these sites. Additionally, the population

studied included respondents from rural and suburban locations in the Southeastern United States. This may suggest that using social media to discuss health can reach people in underserved geographic locations.

Several studies have examined the use of social media sites and the influence these sites have on persons with chronic health conditions. Coulson et al. (2007) performed a content analysis on an online health board for people with Huntington's disease. The results of this study indicated that the online support group offered more than just health information, but also " a) emotional support, b) network support, c) esteem support, and d) tangible assistance" (p. 8-10). Shaw and Johnson (2011) conducted a survey of online health information users with Type 2 Diabetes and found that social media outlets (e.g., Facebook and Twitter) are useful in promoting positive health behaviors. Lorig et al. (2008) report that individuals with chronic health conditions that access cites created as support networks for individuals with specific chronic health conditions tend to have overall improvements in their symptoms and health behavior as well as a reduce need to access health services.

The internet may be a useful tool in the dissemination of health information. The internet, especially social media, offers a relatively accessible, anonymous, and convenient way to house and disseminate health information (Vance, Howe, & Dellavalle, 2009). Many industries take advantage of the internet's ability to help information spread rapidly. This may be accomplished through the marketing and promotion of products, goods, and services via information placed strategically online, contests, online only promotions, and other interactive online features. However, health care organizations have yet fully to use the internet's capabilities in the dissemination of health information.

While there are many positive attributes to using the internet as a dissemination medium, there challenges remain as well. Of primary concern is the trustworthiness of information found online. The solution becomes one of disseminating accurate sufficient information online so that health consumers can get the information desired (Taylor, 2002).

Education-Entertainment Based Sources of Health Information

Connell and Crawford (1988) conducted a survey in Pennsylvania that found television was identified as the secondary source of health information only behind printed materials. While this study is somewhat dated, it does raise the issue of dissemination of health information through mass media. Mass media in this review will include television and radio sources of entertainment. Media has been a source of information for several years. Wade and Schramm (1969) discussed the use of mass media in health, science, and public affairs. The researchers used existing data from four national surveys to examine the influence of education on information seeking through popular media. The findings of this research suggest that individuals with more education and higher incomes use multiple media sources for information. Mass media has an influence on science knowledge in the public. Wade and Schramm (1969) used Sputnik to show the increase of lay public conversations around space and science as well as the increase in knowledge about satellites. The researchers comment that while there was an increase in the amount of science knowledge, it was more political in nature rather than scientific because of the method by which it was presented (e.g., Soviet versus United States space race). This study is over 40 years old, yet it may offer insight into using mass media to disseminate health information.

Popular television shows may be thought of as having a certain degree of influence over the lay public (Lane, 2001). Some researchers suggest that it is in the nature of television as well

as its programming to persuade people. Television uses multiple modalities to communicate messages (i.e., audio and visual) and has the potential to reach large audiences. Persuasion is one-step in the Decision Process (Rogers, 2003). Persuasion may be defined as "human communication designed to influence the autonomous judgments and actions of others" (Simons, 2001, p.7). Simons (2001) suggests that persuasion is a form of influence that does not use coercion or material inducements to change the way an individual thinks, feels, or acts. Television may have all the properties of innovations that are more likely to be adopted (e.g., trialability, observability, and relative advantage) when viewed through the lens of diffusion. Television may also help to give the properties of successful innovations to the innovations that it promotes (e.g., ideas and products).

Entertainment-education defined.

Singhal and Rogers (1989) suggest that there exists the opinion that mass media is either educational or entertaining. However, Singhal and Rogers (1999) argue that mass media can be both educational and entertaining without sacrificing the value of either purpose. The term Entertainment-Education describes the use of mass media to disseminate a message that promotes knowledge, affects attitudes, and creates change regarding a particular subject. Many examples of Entertainment-Education are found in the promotion of health information. This is especially true in the case of social health issues (e.g., HIV) and chronic health conditions. Research suggests that Entertainment-Education is successful in part because of the development of parasocial relationships between the viewer and the actor (Papa, et al., 2000). Parasocial relationships develop when the program viewer perceives the character to be similar to himself (or others in his social group), a role model, a comforter, or a counselor. Ultimately, if this relationship is formed, the viewer may change their behavior based on that relationship. DOI

theory might suggest that the viewer has trialability of the message for consideration of adoption (Rogers, 2003).

The literature documents several instances of behavior change based on Entertainment-Education. One of the most cited examples is the Indian radio soap opera, Tinka Sukh (Happiness Lies in Small Things) (Singhal, et al., 1998). Tinka Sukh was a 104 episode Entertainment-Education program targeted toward family planning, reducing the spread of HIV, and promoting women's rights (e.g., arranged marriage and dowries) in India. The program aired from 1996 to 1997 and was credited with initiating a letter writing campaign. Viewers wrote letters to the broadcasters and commented on what the program taught them and how they would implement these lessons in their own lives. The program created strong parasocial relationships, thus influencing behavior change.

Numerous examples exist of this type of targeted Entertainment-Education (e.g., Sesame Street) (Papa, et al., 2000). There are also examples of embedded messages in popular television shows (Moyer-Guse, et al., 2008). For example, the popular television *Friends* dealt with condom effectiveness and the soap opera, the *Bold and the Beautiful*, dealt with HIV. Moyer-Guse, et al. (2008) suggests that prosocial messages embedded in television shows may influence viewers. The Centers for Disease Control (CDC) works with television writers and producers on the accuracy of health related messages in television shows (Wilson & Beck, 2002). Other health agencies have also worked with television shows to promote accurate dissemination of health information. The Kaiser Family Foundation worked with writers and producers of the prime time hospital drama, *ER*, on accuracy of information regarding sexually transmitted disease, HIV, and teen pregnancy. A telephone survey on individual responses to both the health education and entertainment value of *ER* revealed that individuals viewing the show were

interested in both the entertainment and the health information (Brodie et al., 2001). The researchers noted that it was difficult to determine from this study what lasting changes in behavior were made based on brief exposure to these episodes.

New Trends in Health Television

In the mid-1990s, television saw a shift from scripted dramas and sitcoms to reality television (Christenson & Ivancin, 2006). Reality television offered viewers the chance to see everyday people experiencing many facets of life. These programs sometimes diffused health messages subtly. For example, MTV's *The Real World* introduced Pedro Zamora, a man diagnosed with HIV. The series documented Zamora's triumphs and struggles with the disease. The series was credited with being one of the first to put a human face to the HIV/AIDS epidemic. As the popularity of reality television grew, there began to be a more targeted approach to health education. Television shows like *The Biggest Loser*, *Life in the ER*, and *Miracle Workers* purposefully used health as the main objective in the storyline. Christenson and Ivancin (2006) argue that these television programs were both useful and detrimental. The programs were useful because they brought information about health to the masses. The programs were detrimental in that they sometimes highlighted unattainable standards of beauty, popularity, and sexuality. Many of the shows also featured such rare disorders and conditions that the information was not usable to the majority of watchers.

Recently, television shows have emerged that are entirely centered on providing health education. Programs like *The Dr. Oz Show* and *The Doctors* discuss current health related topics such as diseases, medications, and alternative treatments. A search of the literature revealed there to be little current research as to the validity and trustworthiness of the information

presented on these types of shows. One reason for the popularity of these shows may lie in how the information on the shows is disseminated.

The Cable News Network (CNN) aired an entire special on the "Oprah Effect" in reference to television host Oprah Winfrey's popularity and subsequent ability to influence the buying habits, and sometimes behaviors, of those who watch her show (Peck, 1996). Oprah's popularity helped to launch the television career of Dr. Mehmet Oz, a cardiologist (Specter, 2013). Oprah featured Dr. Oz on the Oprah Winfrey Show several times before naming him America's Doctor. Dr. Oz now has an hour-long television show designed to educate people on health related topics (e.g., mental health, chronic health conditions, relationships, and wellness). The Dr. Oz Show is not the only television show that disseminates health information. Numerous other health related television shows have gained popularity. Examples of these shows include *The Doctors, The Dr. Phil Show,* and *Dr. Drew on Call*.

Much of the success of these shows is due to the ability of the television personality to engage with the audience, talk to viewers about topics that they may not otherwise share with their own physicians, and use language that is easily understood (Specter, 2013). However, critics of these health shows question whether the shows communicate the best evidence available. There is consensus that some of the advice given on these programs is rooted in scientific evidence. For example, Dr. Oz routinely encourages viewers to engage in a healthy diet and exercise for optimal health. However, some of the information presented on these same television shows makes claims that lack scientific evidence. In the March 2012 edition of *Woman's World*, Dr. Oz reports that consuming safflower oil (specifically Conjugated Linoleic Acid, CLA) can help a person "lose six pounds and five inches without dieting or working out" (p.18). While this claim is not entirely untrue, much of the literature to date on CLA has been

with regard to mice (Blankson, 2000). There are few studies that examine the effects of CLA in humans and its effects cannot be ruled as safe or effective. Despite the incomplete evidence, people continue to use safflower oil or CLA in pill form as a weight loss solution.

In the Specter (2013) interview, Dr. Oz defends his position of presenting information to the public that may have incomplete scientific evidence by saying that

> Modern medicine [is] a "civil war" waged between conventional physicians and those who are open to alternative cures for maladies ranging from anxiety to cancer… it is [his] mission to walk the line that divides them (p. 6).

While the information presented on *The Dr. Oz Show*, as well as other health related television shows, may be incomplete, it may have testimonial support. This testimonial support often highlights the best possible results and may not be reflective of actual results (Appiah, 2007).

When DOI theory is considered, using these testimonials may provide information that makes the innovation more likely to be adopted (Appiah, 2007). For example, testimonials present potential adopters with all the categories that make innovations appealing (i.e., observability, trialability, relative advantage, compatibility, and complexity). People who give testimonials are often portrayed as average people who have the same successes and difficulties as the individuals to whom the product is marketed (O'Guinn et al., 2000). Individuals are more likely to be persuaded by average people that give the testimonials than they are by celebrities or experts (Murray, 1997).

Best Dissemination Methods of Health Information

Use Multiple Dissemination Mediums

Research shows that there are positive and negative aspects to using the internet and television as dissemination sources. The question then becomes one of what are the best methods of dissemination through these mediums. This question may best be answered by examining how best to communicate via these mediums and questioning to whom the communication should be directed.

Scullion (2002) recommends that the medium by which information is to be disseminated should align with the needs and values of the targeted audience. Most researchers agree that this means that a variety of mediums (e.g., television, internet, magazines, and newspapers) may be used in successful dissemination. Health literacy, availability, motivation, interest, and access are all factors that require consideration in the selection of a medium.

The Hip-Hop Doc is an example of how using the right medium with the appropriate audience may affect positive behavioral changes. Oliadjie Williams, a physician at Columbia Medical Center, designed a program to disseminate information about stroke to children in the urban areas of New York City (Williams, 2010). Dr. Williams combines hip-hop music with accurate information about stroke. The goal of the program is to get the information to children so that they are better educated about stroke but also to help them to recognize signs of stroke in their family members. Dr. Williams reports that he saw statistically significant results in the amount of knowledge children gained about stroke. While Dr. Williams' program successfully targeted children, other programs have targeted individuals thought to be the opinion leaders.

Target the Opinion Leaders

Singhal and Rogers (2003) present several methods by which to disseminate information in their text *Combating AIDS: Communication Strategies in Action*. The researchers recommend targeting the opinion leaders of the community as a communication vehicle. In San Francisco, the individuals working on the Stop AIDS Project sought homosexual men who were popular. These individuals were given additional training in the transmission of HIV/AIDS, condoms, and information about referrals for testing, counseling, and services. These men were able to spread the word about HIV/AIDS, and therefore, as discussed previously, the Stop AIDS Project was successful. Identification of the opinion leaders requires investigating the community in which the innovation or information is to be disseminated (Rogers, 1995).

The early adopters are thought to be the opinion leaders of a community (Berwick, 2003; Rogers, 1995). These opinion leaders exist in the lay pubic as well as health care professional communities, yet the strategies for engaging these individuals are similar. Berwick (2003) suggests that it is important to support and give time to the early adopters so that they may test innovations. This helps to alleviate any doubt that the early adopter might have about the innovation. The activities of the early adopters should also be observable to the early majority. The early majority follows the activities of the early adopter, which indicates these activities must be seen.

Ensure Popular Sources are Trustworthy

Another consideration in dissemination of health information is the trustworthiness of the information. Trustworthiness of information is a concern regardless of the medium. Health related articles in scholarly journals may be difficult to access and to interpret in a meaningful,

implementable way (Coomarasamy, 2001). Similarly, healthcare professionals may at times find reading these articles difficult and thus the information may not get to the healthcare consumer (Scillion, 2002). Scillion (2002) suggests that research should be communicated so that it highlights the relative advantages (e.g., efficiency), is focused on the positive aspects, and details how to apply the information. He suggests that by doing this, healthcare professionals are more likely to adopt the innovation.

After information is passed down from researcher to healthcare provider, a next step might be to ensure that the quality of health information is maintained. One way to improve the quality of health information online may be to encourage trusted health sources to promote themselves. Park et al. (2011) found that non-profit health organizations (e.g., Prostate Care International) have a strong presence in social media sites as compared to other health agencies. The researchers conducted a content analysis and found that while these organizations had a strong presence, they did not utilize all of the capabilities of the social networking sites (e.g., blogging, news feeds, games, and interactive polls). DOI theory suggests that compatibility is an important aspect in the adoption of an innovation. Individuals are more likely to adopt an innovation that they feel fits into their lives (Rogers, 2005). People who use the internet for information other than health frequently engage in looking at news feeds, taking quizzes, and playing games (Vance, Howe, & Dellavalle, 2009). It is likely that since these channels are routinely found on social media sites, that this correct information may be diffused among members in the individual's social network.

Another way by which dissemination of evidenced based health information may be promoted is through educating the lay public about how to identify credible information. Fox (2009) suggests that the acronym TRUTHFUL is a structured way by which to evaluate internet

based sources. Individuals evaluate the technical aspects, reviewers, purpose, funding, and legitimacy of each website prior to using the information found on the website.

The website, www.quackwatch.com, assists healthcare providers and healthcare consumers identify false and misleading health information on the web and through other sources. One of the missions of the operators of the website is to "improve the quality of health information online" and to "attack misleading advertising online" (Barrett, 2012, n.p.). Quack Watch maintains several websites that are a clearinghouse of information aimed at specific topics. For example, www.cancertreatmentwatch.com is a website dedicated to debunking non-evidence based cancer treatments. Websites like Quack Watch help in dissemination efforts because they allow for promotion of evidence and may in turn help to filter out some of the misleading information.

Give the Target Population the Information They Want

Myers (2003) reported on information gathered from the American College of Preventive Medicine Audience Analysis Project. This project examined audience needs of health information and communication channels. Phase one of the project was a focus group that included several healthcare providers. These groups revealed that in dissemination of health information a) detailed, but brief, accounts of information are preferred, b) information that is relevant to the audience is best, and c) getting information on how to do something is just as important as what to do. While focus groups were conducted with healthcare providers, it is plausible that similar responses would be found in the lay public.

Ensure Access to the Information

An important aspect of dissemination is to ensure that the target audience has access to the information (Gallop, 1997). Several programs have worked towards this goal by researching an individual's ability to access health information. Gallop (1997) researched the health needs of older, urban, African American women and found that the library was a favored information source of the respondents. Similarly, Kreps (2004) concluded that libraries were helpful in giving access to online health information to individuals that might not otherwise have it. The study reviewed digital divide pilot projects that had community-based resources that provided information about cancer to underserved populations. The projects included access to online information at senior centers (e.g., The LUCI Project) and at community; technology centers (e.g., The Head Start Project). The projects have been successful and may be useful as models for future projects.

<div align="center">

Conclusion

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Dissemination of health information is an important step in improving the health and quality of life of individuals with chronic health conditions. Effective dissemination strategies include using the best dissemination methods with the appropriate target audience and providing accurate and trustworthy information. A future review might examine the use of the Chinn and Brewer (1993) model of how individuals deal with anomalous data. This review could provide information as to how best to structure dissemination techniques for individuals in the various stages of adoption.

This review examined some of the challenges to use of specific dissemination strategies (e.g., web based sources and entertainment-education). However, future research should

consider the barriers to using such dissemination strategies. This research could include a discussion on workplace cultural barriers and changing these cultural barriers to disseminate appropriate health information.

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Appendix D: Raw Audio Transcripts

Q1: Tell me what you know about stroke.

Well, I know it kinda of make your mouth, make your facial uh, what am I trying to tell you, uh, oh Lord, uh make your face, different uh, oh lord, what am I trying to say…Uh, yeah, your mouth twisted and all that. No, that's all I know. Um, hum, um hum.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

I don't know.

<What are the warning signs of stroke>

 I think if you could feel numb and blurry eyed.

<What do you think causes stroke>

Well I am going to say maybe hypertension, um hum

<How long do you believe stroke lasts>

Well if if if you go to therapy it shouldn't last too long

<Do you think stroke gets better>

No, I don't

<How do you think a stroke affects a person's life>
In some ways it might be good and in some ways it might be bad.

<How might it be good>

Well you keep trying, taking therapy, um hum, with therapy.

<How might it be bad>

Just feeling sorry for yourself.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Well I would try to call 9-1-1

Q3: If you thought you were having a stroke, what would you do?

I would try to call 9-1-1 if I get to the phone.

Q4: Is there anything else you would like to tell me about stroke?

I can't think of anything

Q1: Tell me what you know about stroke.

Um it could kill you

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

Um basically, um I try to eat the right things to stay away from all those issues

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Um, basically, they probably grab they heart or actually call for help

<so they would physically do something>

Right. They go like this; Or breathing…Yea <participant makes a motion clutching heart and rapid breathing>

<What do you think causes stroke>

The wrong food.

<What do you mean>

Yeah, you got liquor stores on each corner and you got its different things then how you eat, it could get you too. Because if you don't eat right, it could build up and you are gone.

<What would be better for them to eat>

Um, they should be eating foods with no sodium, green vegetables, and drink plenty of water.

Because when it comes to pop, that is no good. Sugar and salt is no good for you

\<How about diet soda\>

That is worse. Because that is the man saying that it's full of salt…it is full of sodium. It's just worse. It's almost like if I'm going to give you a pint of alcohol. Um, salt. Um hum.

\<How long does stroke last\>

Um no more than five (5) or six (6) minutes.

\<Does stroke get better\>

It depends in how far they let it go. If they can take of themself it would be gone.

\<Can you describe the treatments for stroke\>

Um, no, not right off. I just know that if you eat right.

\<Eating right helps make stroke better\>

Um hum.

\<how do you think stroke affects a person's life?

It would go backwards.

They can't see or they can't walk…something like that.

Yeah

Q2: If your friend or family member looked like they were having a stroke, what would you do?

First thing I would do is get on the floor, help them breathe, and call 9-1-1. Right now…right now!

Q3: If you thought you were having a stroke, what would you do?

I would do the same thing…I would get on the phone, call 9-1-1. Come and get me, take me to the hospital.

Q4: Is there anything else you would like to tell me about stroke?

You covered everything.

Q1: Tell me what you know about stroke.

I don't know nothing about stroke

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

I really don't know because I never been around one that's had a stroke

<What are the warning signs of stroke? > (Client shrugs shoulders

<What do you think causes stroke?>

<How long do you believe this illness lasts?>

<Does stroke get better>

<Can you describe the treatments for stroke?>

<How do you think a stroke effects a person's life?>

Client unable to answer this question. States "I don't know" each time she is asked. Observed her to shrug shoulders and shake head throughout this line of questioning

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Call 9-1-1

Q3: If you thought you were having a stroke, what would you do?

Same thing, call 9-1-1

Q4: Is there anything else you would like to tell me about stroke?

No

Q1 (part 1): Tell me what you know about stroke.

Well, I know you have to stay on a certain diet, ok, get your BP up to high and I know that sometimes I've know people with real bad headaches have had a stroke. And I know you can't have a lot of salt and you have to eat certain foods so that you won't have a stroke. Watch your blood pressure and I know that uh I think exercise helps when you do you {keep} from having a stroke. Can't think of too much more.

<Ok. I think you did a fantastic job! That was pretty good.>

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke

  Well, sometimes, they will complain of a headache. They might get a little sweaty and uh, and mainly I hear them talk of a headache all the time. You know I have a blood pressure machine at home and so if it is a family member I go and get the BP machine and take their BP and see how high it is. I know if it is too high I tell em you gone stroke if you don't do some of the right things you suppose to do and get it down. And I know anything that says it's uh 1…180 over something over 200 is stroke time.

< It is, it absolutely is. Do you know what a good BP is supposed to be?>

Somewhere from about 120 over 80. And I do know that the top number is the heartbeat and the bottom number is the blood pressure.

< That is good. Nice job.>

Q2: If your friend or family member looked like they were having a stroke, what would you do?

First thing I gonna do is call 9-1-1 and let them come and triage them and see. And let them see if that is what is really going on so they can cart them on out to the hospital.

Q3: If you thought you were having a stroke, what would you do?

First thing I would do is call my neighbor to take my BP to see and if I think it is up and it is stroke time then I will be telling them to call 9-1-1 so I can get to the hospital.

Q4: Is there anything else you would like to tell me about stroke?

No, I don't think so. We might have covered everything. I might go home and think of a whole lot of things after that.

< Well, I will be here next Wed and the Wed after that if you want to pop in and tell me what you've thought of>

Ok, well as far as I can think of I can't think of anything else.

Q1: Tell me what you know about stroke

Um, well I know if you have one you need to get help as soon as possible. And, is stroke the one where you have the synonym…face…FAST…FACE. If you have slurred speech…and um. I am trying to think of what FAST stands for, but I can't think of it. A lot of times if you have stroke you can be incapacitated and you won't be able to take care of yourself. Which I don't want anybody to be changing my diapers or I don't even want to have diapers. I would prefer not to have that if I could possible stop it. I don't know anybody that has actually had a stroke, other than the man next door. Oh, and the girl in the book club…but you wouldn't actually know it because she doesn't slur or anything. She just says she has a hard time remembering things, which I do my self so that is just normal. But it incapacitates you so you have to have someone to help you.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

Um, I don't think they'd be able to talk really well. They'd be slurring their speech. They definitely wouldn't feel good. They probably would maybe lose their balance, or feel a little bit off kilter. They might even just pass out. Maybe their face would be numb or they would have some numbness in their bodies.

< What do you think causes a stroke?>

High blood pressure. Stress. Um, I don't know if it's got anything to do with aneurysms but if it is something out of their control, like an aneurysm, and it just happens. Being overweight…not exercising enough, smoking…all these bad habits that we have…that love to do. Too much sex, I don't know. I would know about that, I'm just saying. (Laughing)

<How long do you think a stroke lasts? Do you think it is a short term or lifelong thing?>

No, because they have so much modern medicine, modern techniques that they have. They can reverse them if you get there ahead enough. The lady in our book club says she has had one but I wouldn't know if she hadn't told me. You know…

< So a person that has had a stroke, how do you think it affects their everyday life?>

Well it makes it difficult for them to care for themselves if they don't have someone there to help them, especially if their memory is not very good. Uh then their motor skills will be affected. I don't know why but sometimes people get ashamed when they need help after …they don't want to ask for help…but that wouldn't bother me know because I'd be calling everybody I know…hey I need some help. But people get embarrassed by that and I don't know why. I don't think I would be. Thank God I have not had one and praise the Lord I don't want to have one, Jesus. Let me help somebody that has had one. It affects their lifestyle. They won't be as independent as they would be. They would be able to drive or just do the normal everyday things that we do for ourselves and take for granted.

Q2: **If your friend or family member looked like they were having a stroke, what would you do?**

Dial 9-1-1. That would be the first thing I would do because I figure I wouldn't really know what to do so if I dial 9-1-1 they could talk me through what I needed to do…I don't know what I would need to do, get a pillow or something, but they could tell me why you're waiting for the ambulance, go get this or get that, turn their head a certain way or…something. So, I think that would be what I would do. I would probably scream or something. Call 9-1-1 and scream while I am talking to 9-1-1. Probably cry and everything else.

Q3: If you thought you were having a stroke, what would you do?

Um…hopefully I would be able to dial 9-1-1. I don't know what else I would do if no one else was in the house. I guess I would have to lay there until help came. If nobody's there, if I can't dial 9-1-1, I would pray.

Q4: Is there anything else you would like to tell me about stroke?

Can't think of anything…I just pray to God that I don't have one. I would love to help people that have had one, but nobody in my family has had one and I am thankful for that. It can be a very debilitating disease to have something like that happen to you.

Q1: Tell me what you know about stroke.

Not a whole lot. Most that one person that kind of had one. They mouth was kind of twisted and I try to get them to go to the doctor and they didn't want to go. So later on they realized that something wrong with them when they right hand started bothering them. So they went to the doctor. They found out they had a stroke and that they also could have another one following that one.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

< What do you think it would be like if someone were beginning to have a stroke?>

Maybe someone grabbing for they chest or rubbing they arm.

< What do you think causes stroke?>

Now that I don't know. Maybe stress

< Any other kind of health conditions?>

Probably if they have some kind of diabetes you know cancer, something like that. Worry. Might cause them to have stroke.

< Do you think stroke gets better if you have had one?>

I think if you follow the doctor's orders, take your medication it will get better.

< Do you know about any treatments for stroke?>

Yes, my son he didn't have a stroke. He had a HA and they put splints in his heart. I also had a brother, he had the same thing and they also put splints in his heart.

< What was that for?>

Open the valves up

< So blood could flow?>

Yes, yes, so blood could flow.

< How do you think a stroke might affect a person's life?>

I mean, some people that it will affect about them going to do things like doing yard work and handy man work, you know. They may not be able to do that, especially climb on high buildings. They might not be able to do that type of work because they 'fraid they might get sick and fall.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Dial 9-1-1

Q3: If you thought you were having a stroke, what would you do?

Well if I have a button on my burglar alarm. And if I make it to the bathroom, I have a button I can push for paramedic.

Q4: Is there anything else you would like to tell me about stroke?

 Um, no, there is nothing else I can think of on stroke.

Q1: Tell me what you know about stroke.

Stroke can be a debilitating condition that can cause a certain paralysis even some brain damage it affects speech as well as walking and thinking your cognitive skills. It can be caused from a surge of blood pressure going through the brain causing it not to react in the normal way thus inhibiting bodily functions and movements. I have had people who have been walking very cautiously along a wall and I was following them out of the building. Ok you don't look good, you don't sound good, I need to drive you home. Um, and she insisted that she could make it any way. I did not sit well after I let her get in the car. I followed her home and I went in and said "you are going to the hospital". We got her there, they put her on the gurney, and she went into a full blown stroke. So it was a good thing that we got her there and she went into full blown stroke in the emergency room. I have also had another person who was feeling the tingling going down the left side of the arm it was losing strength in it and we ask them to do a couple of things with the tongue to stick it out to smile. And he looked and could not do it and ended up falling to the floor. Where he went into the stroke and we got him on to the hospital. The first person recovered completely and the second person the gait was somewhat off but the blood pressure had always been somewhat out of control.

< Why do you think the first person was so apprehensive to go to the hospital?>

Stubborn, hard headed, strong willed, and determined. You don't know what you are talking about, what do you mean I don't look well? And she was already an elder, she was already past 60.

<Even though she had the symptoms herself, she wasn't able to make a connection to say "hey, I need to go">

 Correct.

< How about the second person, were they more willing to go because it was more of a 'severe thing'?>

It was more of a severe thing and once he passed out on the kitchen floor he had no choice.

< Ok.>

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

<Participant provided through response through question #1>

Q3: If you thought you were having a stroke, what would you do?

If I was having a stroke and if I were alone I would dial 9-1-1 and I would tell the lady I feel like I am about to have a stroke. And these are the things I am feeling…I am feeling the excessive tingleness going down my left arm. I am getting short of breath, it could be heart attack or stroke, but I don't know. Um, I feel like my mouth and face are beginning to twist to one side and I need you to come check on me like n-o-w.

< Would there ever be any reason for you to put off calling 9-1-1 if you had those symptoms?>

No, no. NO reason for me because we already paid for the services since my husband has some health conditions. We need to pay for these services so that if anyone of us needed to call 9-1-1, the cost would not be a factor.

< Why would you call 9-1-1? Why do you think it is important?>

To get immediate help. It's necessary to keep the symptoms from getting more severe or the affects of it from being long lasting. I believe the sooner you get help the quicker and the more recovery you will have or the greater you will be able to come back to you semblance of normal.

********ADDITIONAL AUDIO DATA******

< This is "stroke will improve only with God's help" an explanation of the answer.>

I believe that it is a matter of God and that stroke will improve with God's help, but not only. God has given man wisdom and knowledge to use whatever is necessary for man. But also know that my enemy cannot cause anything to happen to me without God's permission. That is what I believe. So, it is a matter of God and with God's help, I will improve. But, I also need to know that I need to follow the instructions of the physician.

Q4: Is there anything else you would like to tell me about stroke?

< First question, is there anything else that you would like to tell me about stroke that I haven't covered?>

Well, I know that there are those that may say they are having mini-strokes, or what is called a TIA. And there is usually speaking of some tingling or something going up and down their neck, or feeling like something is crawling. Sometimes they've even complained that there may be some pain associated with it where the stiffness or the stuff is coming back and they will just say I need to lay down and rest and we will check the blood pressure and make sure that is all it is…let's just slow your roll, stop and breath…um sometimes I ask them do I need to call the doctor "no, no, I'm a call them tomorrow" Tomorrow is not going to be soon enough for me so I insist that they call.

< What do you think TIA's are?>

Limited as my understanding is, it is almost like the blood is not able to flow as freely through the body as it needs to be at that time to cause that excessive tingling or something else is being hindered. So it is like did you not take your blood thinner or take your baby aspirin, what is it that you did not take yet. Most of the time it is like 2-3 days that they would not have taken it.

< Do you think if someone were experiencing a TIA, what do you think they should do? Should they go immediately to the doctor, call, wait?>

I think they should call their doctor immediately. That's what I think. I think they should always make sure I don't need to bring them on in or get someone to bring them in.

< How do you think people differentiate between a TIA versus a full blown stroke? How do people conceptualize that in their heads?>

Um, the TIA doesn't last as long and within 3-5 minutes it may be gone. Or the full blown stroke may linger on and on or be a lot longer than 3-5 minutes.

< My other follow up question is, you said when you with people having strokes you chose to drive them versus call 9-1-1. Why did you chose to drive them?>

I knew how long the hospital was and I knew how long it would take them to get there and it's called the urgency of the situation. I can drive, I can put on my flashers, and I have had the police to follow me before, to the emergency room without any consequences.

< Alright, is there anything else I missed?>

Nope

Q1: Tell me what you know about stroke.

Um, well you, I know I, um that it causes nerve damage when you have one it's like you sweaty sometimes you feel faint like your blood pressure usually skyrockets you might feel some tingling in the arm or in the face area left or right. Um, you might urinate on yourself. Uh, I think sometimes when people have strokes they think they having a heart attack and you may notice some difference in facial features like twisted mouth or twisted limbs or limbs you can't move them or may affect your gait you could start salivating because of the facial muscles or whatever. I guess that is about it.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

I think they would go into some type of blank stare or gaze or something. It would probably be pretty frightening for them because unless they have any type of medical knowledge they would not know what was going on with them. I think sometimes it is a looked at as Bell's palsy at first because that has facial features. Like I said it would be frightening.

<What do you think causes stroke?>

I know high blood pressure, not taking care of yourself, your diet, need to exercise, and to keep up on your health exams. You normally are twice a year and have lab work done.

<How long do you believe this illness lasts?>

I think you can have what you call mini-stroke that can just keep going and going. If they are not attended to then you could die.

<Does stroke get better?>

Once you have had one as long as you seek medical attention and do what they tell you to do. It depends on the type of stroke whether or not your limbs are affected. You may not get back to a normal life but you bounce back. I think if your overall body is in pretty good shape, then I think that you could. It just depends on how bad the stroke is.

<Can you describe the treatments for stroke?>

I know to get the blood pressure under control. Nutrition that's one. Making sure that your cholesterol is …keep in touch with your lab that is how you know if you are going in that direction.

<How do you think a stroke effects a person's life?>

It can be very what should I say life changing because if they have a severe stroke where they limbs and facial features are affected it can be very life changing. Matter of fact you would have to start a new life. I mean to be able to um go to therapy physical therapy vocational therapy you know to see the extent of what you can come back from.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

If they could talk I would ask them what is the matter. Depending on what they tell me I've been able to look at people, well I have been in nursing, let me put that out there, let me tell you the truth, but um and I think there is a difference in a heart attack and a stroke, but I think a stroke continues to go on into a different direction than a heart attack.

Q3: If you thought you were having a stroke, what would you do?

If I could I would take my pulse. I would look in the mirror and if I knew this was not something my body normally does I would know something is definitely wrong and I would call 9-1-1.

Q4: Is there anything else you would like to tell me about stroke?

No

Q1: Tell me what you know about stroke.

Very little. I can't say.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

I think it would be drowsiness. Lack of understanding. They may fall. Drowsiness, dizziness. Stress for the most part causes stroke.

<Does stroke get better?>

It varies. I think the stroke its self can't, but the person can get better.

<Can you describe the treatments for stroke?>

At present no.

<How do you think a stroke effects a person's life?>

It could disable them from doing a lot of things. It may bother their sight, ears, right whole body could be affected or just one part.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

I would try to sit or lay them down as soon as possible. I would call the doctor or the police as soon as it happened so they would not have a chance to go too far

Q3: If you thought you were having a stroke, what would you do?

I would find somewhere to sit down or laydown very soon. I would also try to find a telephone to call the doctor, my wife that would be the first one.

Q4: Is there anything else you would like to tell me about stroke?

I need to know more about it.

Q1: Tell me what you know about stroke.

Well I really didn't know anything about it until it happened and it affected my balance and that is the reason I have to have the walker and this one side of my leg, this leg I have a problem raising it up. If affected that it affected my memory and there are people in my church that have known me all my life and I have known them and I don't know them now. I don't recognize them, they let me know so I tell them I have had a stroke and that is the reason that I don't know who you are. No not really.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

Well I think what brought it on was that I had a lady that I had been taking care of I was in charge of her money and I had been saving it in a bank and she was in a nursing home down in independence and her people came here from Omaha and they decided they wanted to take her home and I gave it to them and I didn't get a receipt and I did this with the agreement of the lady who I was in charge of and she knew about it …it seems like the nursing home got curious about the woman and what she did with her money and she might been a little leery acting like she didn't know about her money and I said I wonder if she gonna lie and make them people think that I stole her money and I was upset about it and that had talked about putting me in jail cause I had stole her money and that's what brought it on. I was under a lot of stress. Um, my girlfriend had called my house and I didn't answer the house and she know that was unusual and she got in her car and came to the house and found me in the bathroom and they took me out to the hospital. I was in the bathroom on the floor with water running in the wash basin, hot water. I don't know anything about it. This is what she told me. Oh, that has been some years ago.

<What else do you think causes stroke?>

Well I don't know what else brings a stroke on. I know that [stress] is what brought my on. I thought I was going to jail. Yea yea, oh lord what am I going to do? Is this woman gonna lie and say I stole her money and she hadn't been like that but she told the truth.

<How do you think a stroke effects a person's life?>

Well I am doing better. Well I think mine will from the results that I have seen now. I don't see myself getting over this with my leg an me using this walker. But I don't use it in my apartment. Normal things when I walk around in my building sometime I just use a cane. When I am out this is what I use [walker] because I feel secure. And I do fall cause I trip sometimes over my own feet over this foot. Well it sometimes my toes catch. That is what I am talking about. I be going somewhere and making a turn and lose my balance and down I go. Because if you fall you'd hit your head or something and there you are. Well that [hit head against brick wall] has happened…it happened in front of my building against a brick wall. It was hard hit but it didn't hurt me. It started bleeding and the people in the building run out and grab something and put

over my head to stop the bleeding and in the meantime called the ambulance. No I didn't pass out. I didn't really want to go to the hospital but they made me go. And then they want to charge me wooo it was over a thousand dollars and they kept me there four hours and I didn't do nothing. And they didn't have to take no stiches or nothing. But they slapped that thousand dollars and send it to me. I said oh no.

I can't go like I used to see cause different things that are happening. I like music and I used to go to concerts in the park and I used to go to the GEM Theater and I keep up with all that stuff on 18th street. I used to. When my niece came to visit that's when we took her and we went to the blue room. I got down there and wasn't nothing but white folks. It's changed period and the white men was trying to flirt. White guys trying to flirt and this white guy at the table there with his friend looking right at me trying to catch my attention. I just played cool act like I didn't even see it.

Oh yea, oh no, oh no.

<Can you describe the treatments for stroke?>

I don't know [treatments].

2: If your friend or family member looked like they were having a stroke, what would you do?

I'd take them to the hospital. I would call 9-1-1.

Q3: If you thought you were having a stroke, what would you do?

Call 9-1-1

Q4: Is there anything else you would like to tell me about stroke?

No

Q1: Tell me what you know about stroke.

Well my grandfather died with a stroke. Not that I was present that the time he passed. My mother had a mini-stroke she fell off the side of the porch once, not that it was debilitating but the doctor did say that she had it. And that is the extent of my knowledge. I haven't had any firsthand knowledge.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

Well I have been seeing stuff on TV a lot. They say they say you get pain radiating…no that's heart problems radiating up and down the left arm. Uh I think confusion and loss of some difference in the way a person talks and maybe some reaction in the way them move or walk. I have never seen it happen.

<What do you think causes stroke?>

Oh I think high blood pressure and stresses…different kinds of stresses that we have in our lives that we don't get rid of. [how to get rid of] practice yoga, practice it chi and meditation five minutes in the day and prayer and different things that take your mind away from it and realizing what can you do about it? Is there is there something you can do about…if there is nothing well then put it out of your mind. Do something else that is positive. Move, exercises, take a walk up and down the stairs, and laughter…I forgot about that. Laughter is so good for getting rid of stress.

<Can you describe the treatments for stroke?>

Just from reading different kinds of physical therapy that I have observed that is all I know. I have visited in nursing homes.

<How do you think a stroke effects a person's life?>

It might depending on the severity of it make you less independent, make you become incapacitated in different ways, speech, write with your hands, eat or whatever…different kinds of mobility. I imagine it would affect that greatly loss of your independence.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Lord, call 9-1-1 I guess…I don't know what else I would do. Probably try to sit them up if they fall…but that's not right, you are not supposed to move them. I really don't know except call 9-1-1

Q3: If you thought you were having a stroke, what would you do?

Call 9-1-1 if I can get to the phone and I don't wear one of these buttons because I have never needed to but you know that thing you wear from alarms like a life alert. But a person who had one would do that.

[Call 9-1-1 why] they are supposed to be able to treat immediate emergency situations of every kind and they have been trained supposedly to treat immediately and transport you to the emergency room. I keep my membership in MAST paid up.

Q4: Is there anything else you would like to tell me about stroke?

Not that I can think of

Q1: Tell me what you know about stroke.

I know that it is a serious condition. I know that it can kill you, it can disable you, it can destroy your life.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

Um, your body feels weird. You have like a slight headache. You feel tingling in like your arms or legs. Just a weird feeling from what I have seen on television and other folks have described what they have felt and went to the emergency room, come to find out they were having a stroke. So pretty much, uh, vision problems and started having a slight headache and their hands felt numb, tingling sensation and weak in the legs or something like that that they were not able to lift the leg or had to push themselves to move. This is what I have heard personally from ones that have had strokes, friends and family that I have known.

<What do you think causes stroke?>

A good pork chop, bacon, no uh, I just um

< So poor diet>

Yes! Poor diet not really taking care of yourself. An unhealthy lifestyle, I think.

< How long do you think stroke lasts?>

For a lifetime.

<Does stroke get better>

No…I don't, from what I have seen in family members, no. And they do start eating healthy and do things that they are supposed to especially care for other family members and going to the doctors. I think they do get a little better but it is still there. A person like me looking at the person is like "oh my!" But to them they do, they will say that I have gotten a lot better, based on them. But I, no…

< Do you still notice some of those residuals?>

Yes, and that is worrisome to me when they so "oh, I am doing a lot better" because I have seen a person that actually have a stroke, someone that I work with had a stroke and they are back at work now and they did get better but you still can see some of the…all of a sudden she starts dragging her leg again…but uh, then a few hours later she is walking normal. So no, I think it gets better, but there is still something there.

<Can you describe the treatments for stroke?>

No

<How do you think a stroke affects a person's life?>

It really…from a scale of 1-10, I think it is a 10

< So, it really has an impact on their life>

Yes, I really do. From what I have seen and what people tell me, yes

< So what specifics areas? Is it just all physical, is it just emotional is it psychological.>

From what I've seen it is pretty much physical. No psychological the ones that I do know its ok. But what I see is physical and that's what bothers me is the physical part.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Pretty much I don't know what it looks like to have a stroke. I know it looks weird so I would mention that the side of your face looks weird, are you having a headache. Your face looks different. And then I would think back and say that could be a sign of stroke so I would say something, mention it to them.

< What kind of action might you prompt them to take?>

I would say, well lets go to your doctor, let's call or either, well, hum, depending on who it is and you know some people are different so. If I notice if they are slurring their speech or the side of their face I would say come on lets go to the emergency room. I would take them to the emergency room or call 9-1-1. But depending on the situation pretty much call 9-1-1.

Q3: If you thought you were having a stroke, what would you do?

I'd call my daughter.

< Why>

I don't know, but that is the first thing I think of when I am in fear. I know that I should call 9-1-1 or should call my doctor but and a lot of my friends are the same way. I would call my daughter. I know that is probably wrong of me to do, but I would yeah, I would call my daughter and say I don't think I am feeling well, I think something is wrong. Yes, I would call my daughter first. Just in case it is not what I really think…but pretty much out of fear because I don't want to deal with the police, firemen, and all that. And then sometimes it could be out of embarrassment. But I would pretty much call my daughter.

<I'd like to ask you a follow up question. Does your daughter have medical training?>

Yes

Q4: Is there anything else you would like to tell me about stroke?

   I appreciate what research that you all are doing especially African American men and women because there is really a lot that we don't know. We assume a headache is just a headache. I…stroke..is scary to me.

<Thank you>

You're welcome

Q1: Tell me what you know about stroke.

I know that it is a silent killer. It affects Afro Americans more than other communities. I know that the signs are numbness, disorientation, blurred speech, and sometimes there is numbness in your hands or your feet. Sometimes there is a twisting in your mouth.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

They would be going through being disorganized not knowing who they were…there may be some drooping. No it doesn't persist for ever because there is PT, OT, and SLP that can help them regain a normal life. Sometimes there are affects that can last forever…arms or their feet or something like that so it is yes and no.

<Can you describe the treatments for stroke?>

Medication, watching your diet, high blood pressure, exercising, keeping doctor visit, getting a good doctor. Eating properly, exercise. Knowing the symptoms to be proactive versus reactive.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Get them calm and dial 9-1-1

Q3: If you thought you were having a stroke, what would you do?

Hopefully, I would be able to dial 9-1-1

Q4: Is there anything else you would like to tell me about stroke?

I think we as a people, afro Americans, need to get more information about stroke, we need to be more proactive versus reactive. We need to get healthy life styles, get up and get moving because it is really taking us away. Stroke and diabetes and heart those three are related.

Q1: Tell me what you know about stroke.

Um I know that the speech becomes impaired. Your face can become distorted you can lose numbness in your limbs arms. Their babbling symptom of having a stroke or eyesight may leave you.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

There is inconsistency with speech eyesight became blurred they are incoherent.

<What do you think causes stroke?>

Um, less blood flow through the arteries…it could be something going in the brain that we can't see taking care of themselves not eating the right food.

<Does stroke get better?>

If you take care of yourself and do what the doctors tell you to do…you can live with it but I don't think it ever gets back to where it was. I believe that the victim can live

<Can you describe the treatments for stroke?>

There is rehabilitation therapy, in home or in the actual rehab place and it takes time and patience.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

My first response would be to call 9-1-1 and explain to them what I am seeing he or she do

Q3: If you thought you were having a stroke, what would you do?

Try to call for help if I am able to or make enough noise so someone comes. I learned that with strokes that the first 5 minutes are crucial for oxygen getting to the brain. First 5 minutes are crucial because can debilitate them if help is not gotten right away.

Q4: Is there anything else you would like to tell me about stroke?

Rehabilitation takes a minute. It depends on the individual and how much they want to get back to their independence, their lives and their family

Q1: Tell me what you know about stroke.

I know that it uh in some people will cause paralysis on one side of the body often caused by high blood pressure can be very devastating affects African Americans more than other races probably because of the high blood pressure.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

Weakness on one side blurry vision, difficulty remembering something, but weakness is the primary symptom.

It depends on the individual. Sometimes after a person has had a stroke he becomes depressed and sometimes some people will change the way they live, their eating habits and physical activity. One of the main causes of stroke is high blood pressure and one of the main causes of that is diet. So once you change that after you have had a stroke…a lot of people will improve.

Once you have had a stroke a change in diet and taking your medication is paramount. If you are in the process of having a stork and get to the hospital in time 3 or 4 hours then there is medication that can be given that will decrease the symptoms. There is always risk in taking any medication. But with taking this IV medicine used to decrease a clot you can have some bleeding.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Have them lie down and call an ambulance or take them to the hospital immediately so they can be given that medicine with in the certain time.

Q3: If you thought you were having a stroke, what would you do?

Call my son and tell him to come and get me and take me to the hospital. If no one was around or available, I would call an ambulance.

Q4: Is there anything else you would like to tell me about stroke?

Well I think stroke can be devastating especially if you have a family and you are the bread winner if you have a family. If you live alone it can be devastating because it may mean you can no longer live alone and you may need to go to a home. Stroke has lots and lots of things that can cause havoc in a person's life.

Yes, because a 40 50 year old is in the prime of their life. A person my age, 60 70 they have done it, it has nearly as devastating.

I think we need to start teaching children in grade school kindergarten about eating properly, taking care of their bodies. I feel strongly about that. I have two grand kids who live with me and a granddaughter who is overweight and I have been pretty on to her about weight loss eating properly. You can have a hamburger, McDonalds, but you can't have it every day. You have to eat your vegetables. You need to exercise.

I think lack of education in families is primary. If we can educate the kids who can then talk to their parents and say my nurse, doctor, teacher says that we shouldn't have that it would have a big impact on young adults. Especially since we have so many young people having children now, I think it is paramount that we educate them. And I think that kids have a big influence on parents so if we educate the kids they will go home and tell the parents no I can't have that and I think it would be very helpful.

Q1: Tell me what you know about stroke.

I don't know much. Doctors said that I had 10 mini-strokes but I am not sure. Man, my arm felt funny and I nearly passed out. But I didn't know it was a stroke. It was the Superbowl and I was having a party. My friends came over and they were eating. I was down there with them then I started to feel bad so I went upstairs to take a nap.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

I don't know. Probably like me…arm numb, um…I just didn't feel right you know. I called my girlfriend at the time and she was like you need to go to the doctor.

<What are the warning signs of stroke?>

I don't know, not feeling good? I just know I did not feel good.

<What do you think causes stroke?>

My kidney problem was found after my strokes. Maybe my kidney problem caused it.

<Anything else?>

I don't know.

<How long do you think stoke lasts?>

Mine lasted until I went to the doctor. I still have problems with this arm. But I am not sure.

<Does stroke get better?>

No. I have to go to dialysis now. I can't work and go and do things like I used to.

<Can you describe the treatment for stroke?>

No.

<How do you think a stroke affects a person's life?>

They can't do nothing no more. I can't even work like I used to.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

See what I can do to help them. If they look bad, get them to the doctor.

If they need a doctor we can get them there to get help. If not maybe they just need to rest. I didn't go to the doctor for 3 days when my kidneys went real bad, I refused, then I passed out and they took me anyway.

<Why would you call 9-1-1 or wait?>

I don't know nothing about stroke. They probably just need to rest. I don't like doctors and hospitals. Man, I am afraid of needles.

Q3: If you thought you were having a stroke, what would you do?

Just wait to see if it was going away. I called my girlfriend and she made me go. I didn't feel like I needed to go. That just a lot of money for hospitals and doctors and stuff. I ain't got that type of money. Then you get there and ain't nothing wrong and you still pay.

Q4: Is there anything else you would like to tell me about stroke?

No. Are you finished?

Q1: Tell me what you know about stroke.

What I know about stroke…is that a stroke you can recover to some degree. I don't know as much as I should know and I don't know the cause of it. It can be helped.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

Uh…someone beginning to have a stroke. You can look and tell. Face weakness, if stroke does have characteristics you should be able to recognize. Twisting of the face uh limbs weak…falling…speech…I think probably more.

<What do you think causes stroke?>

High blood pressure along with diabetes, I think high blood pressure seems to be what I believe.

<Does stroke get better?>

Yes stroke does get better

<Can you describe the treatments for stroke?>

The treatment is OT and PT is treatment, speech therapy is good, but OT and PT has to be someone that really cares, and not just a job for them…they have to work with you.

<How do you think a stroke effects a person's life?>

A stroke can affect your life if you let it because there is going to be some things that you can or can't do. It is just a mind over matter. You can recover to some degree but you have to have a mind to want to recover.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

First thing is call 9-1-1 cause I feel that the faster they get treatment the better off they are

Q3: If you thought you were having a stroke, what would you do?

Call 9-1-1. [When you were having your stroke, what did you first do, call 9-1-1] no! Like when I was in Texas and didn't realize what a stroke was…so I didn't call 9-1-1

Q4: Is there anything else you would like to tell me about stroke?

No just the more you know the better off you are because it such a debilitating thing that can and will affect your life the more you know the better off you are because I didn't know nothing about a stoke.

Q1: Tell me what you know about stroke.

I know more about stroke now because actually before I had a stroke I was having TIA's and at the time I didn't know it. I would get up in the middle of the night and I couldn't walk. I was sitting in a meeting and it was like this sheet came over my eyes and um it wouldn't go away. Now I know that it is a symptom. Both those times I just kept on going because it passed after a while because things ok. Another one during the middle of the night I had to go to the bathroom and I couldn't walk and instead of me calling my son to call 9-1-1 I am crawling to the bathroom. And then crawled back to bed. At that time I didn't know, I knew something was wrong and I should've called and at least talked to my doctor and get in to see my doctor. It passed and at the time I am thinking that go to the doctors nothing going on now wasting money and wasting time from work.

Now I know that I need to take my medicine regularly and let the doctor know of anything that just doesn't seem right. I was feeling an extra heaviness on my affected side last year and I was referred to my neurologist and they followed up and did the scan, I passed out. So even though I went in thinking I was having a TIA…I called 9-1-1. For me I remember them telling me if I feel anything that feels out of the ordinary call 9-1-1. I was still thinking I don't want to call 9-1-1 and have them take me to the hospital but now since I've had the stroke I call 9-1-1 and go ahead and go to the ER and let them decide what is going on. The last time I went they did find out that I needed a pace maker so it helps you to find out…it may not be a stroke but it may be something else that is going on. I know now it is best to call 9-1-1 and let them assess and see what is going on with you.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

Um, weakness in your hands or legs, like you can't grip anything or you are having blurred vision, slurred speech, not able to walk, not able to lift up one or both of your arms.

<What do you think causes stroke?>

Um, the blood pressure being out of control, overweight, um uh too much consuming too much salt in your diet.

<How long do you believe this illness lasts?>

It varies so much from everybody that has a stroke so you may have symptoms that last a life time and you may have some things that you will eventually no longer affect you. Everybody is different even if they have the same kind of stroke.

<Can you describe the treatments for stroke?>

Lose weight, cut down/cut back on salt intake, take blood pressure and all other medications, keep up with doctors' appointments and any tests that they have you to take.

<How do you think a stroke effects a person's life?>

Can change [life] dramatically just in an instance, you are feeling well and living your life and it stops you from being able to do your job your taking care of yourself, your thought process. That is one part that I forget because I can't get upset when other people forget I have had a stroke because it has really affected my brain. And cause a lot of times I will say I can do this and I sit back and think wait a minute, let me rethink this. Your brain and thought process and just working things through and that's kind of a thing that people don't see. I have to sit down and write out more things and it takes me longer.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Call 9-1-1. Because it is nothing that I can physically do and I know now that there is a medication that if you are there within 60-90 days [believe she means minutes] that they can give you so it won't be so severe. And knowing that when the ambulance gets there they are able to do so much to stabilize the person and knowing which hospital to take you to cause of one of the times when I was trying to go to the hospital, I won't say what the hospital is, but I was trying to go where my doctor is and they were calling the ER and the ER told them that there wasn't a doctor on site but they referred them to take me to a hospital that is actually closer so it is very important to call 9-1-1 and let those professionals do what they know to do.

Q3: If you thought you were having a stroke, what would you do?

Call 9-1-1

Q4: Is there anything else you would like to tell me about stroke?

The biggest thing that I …well there are two things…one is everyone's stroke is different and you don't know what is wrong by looking at someone and because it does affect the brain sometimes you can't tell that someone has had a stroke and just to give them encouragement and know not everyone's stroke is the same and that that person that has had the stroke seek personal goals for yourself. As you are getting better you will see different changes yourself that other people may not see. If you set little milestones for yourself and that will keep you encouraged to let you know that you are getting better.

Q1: Tell me what you know about stroke.

What do I know about stroke? Very little. I know it's some type of cardio vascular problems or blockage or something. Other than that very little.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

For me…oh, probably the same if someone were having a heart attack or high blood pressure, or fainting. Probably feeling the same as someone having those symptoms. Um, dizziness, speech not blurring of the speech, or you know limpness.

<What do you think causes stroke?>

There you got me … hypertension/high blood pressure.

<How long do you believe this illness lasts?>

Um, a short time if it is taken care of or treated.

<Can you describe the treatments for stroke?>

No

<How do you think a stroke effects a person's life?>

I am not sure how it would affect someone's life.

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Tell them to see a doctor…go to the hospital.

Q3: If you thought you were having a stroke, what would you do?

Lay down…if I thought I was having a stroke. I just feel like that something must be going on with me psychologically or psychically that I need to just rest.

Q4: Is there anything else you would like to tell me about stroke?

No…not that I know of

Q1: Tell me what you know about stroke.

I know that it can happen suddenly. I know that there are baby strokes and that there are big strokes. It can affect your memory and movement.

Q1 Part 2: Tell me what it would be like if someone were beginning to have a stroke.

Maybe tingling, headache, confusion, I think visual changes, behavioral. What I have experienced with a relative confusion, going back in time, a little paranoid, not recognizing people, talking about things in the past.

<What do you think causes stroke?>

High blood pressure, diabetes, blood clots, narrowing of veins

<How long do you believe this illness lasts?>

They stroke can happen multiple times. Once you have one you can count on more coming.

<Does stroke get better?>

I think if there is early intervention there is some help.

<Can you describe the treatments for stroke?>

No…I want to say aspirin but that doesn't seem right. Blood thinners…I always hear about aspirin for heart attacks…taking aspirin if you feel like the symptoms are going.

<How do you think a stroke effects a person's life?>

Lot of doctor visits, change in how they are living their lives, maybe more dependent on others

Q2: If your friend or family member looked like they were having a stroke, what would you do?

Give them aspirin…well I would call 9-1-1 and then ask if it is ok to give an aspirin. I am allergic to Nsaids…so I wouldn't want to just jump and do that

Q3: If you thought you were having a stroke, what would you do?

I would let someone know, a neighbor…if I am home alone , if I am able to I would call 9-1-1 and try to get an ambulance I wouldn't attempt to drive myself. 9-1-1 for intervention…they would come with something that might help me and get me where I need to be as soon as possible

Q4: Is there anything else you would like to tell me about stroke?

Um, no I think that everything is well covered and I learned some things from your questions.

Appendix E: Participants List of Stroke Symptoms

Symptoms

Weakness
Unsteady Gait
Blurry Vision
Headache
Loss of balance
Slurred speech
Unable to walk
Unable to talk
Weird Sensation
Dizziness
Numbness
Tingling
Disorientation
Double vision
Twisting of face/facial droop
Falling
Dribble down mouth
Faint/pass out
Stiff hands
Shortness of breath
High blood pressure
Stressed
Higher cholesterol
Wanting to eat salt
Shaking
Difficulty talking
Behavior change
Loss of motor control
Forgetfulness
Out of body sensation
Do not know the symptoms
Eyes crossing

Appendix F: Qualitative Research Protocol

Approved by the KU Medical Center Humans Subjects in Research Committee

Protocol # STUDY00001240

Research Protocol

Participant Code: _____

Date of Data Collection: _____

Collection Site: _____

Data Collector Name: _____

General Instructions:

1. Administer all questions in all sections to all participants
2. Remember to fill in the client contact sheet at the end of the visit

Component 1 and 3: Qualitative

1. Begin audio recording of participant's narrative at the beginning of the contact
2. Ask each question listed with probes as necessary
3. Collect field notes (jot down words, phrases the warrant further probes, or deeper investigation)

Component 2: Quantitative

1. Do not probe for further information
2. Administer these questions as written

Demographic Questionnaire and Health Conditions Index

<Do NOT audio record>

1. **What is your age?** _____

2. **Which of the following best describes where you grew up?**

	Rural area or countryside
	A small town
	A suburb
	A city

3. **What is the highest level of education you completed?**

	Grades 1-11
	High School Diploma
	Some college
	Associates degree
	Bachelor's degree
	Master's degree
	Doctorate
	Law
	Other

4. **What is your marital status?**

	Married
	Domestic Partner
	Separated
	Divorced
	Widowed
	Single/never married

5. **What are you current living arrangements?**

	Live alone
	Live with spouse or domestic partner
	Live with friends or other relatives

6. **Do you receive care from anyone?**   Yes   No

7. **Are you the primary care provider to anyone?**   Yes   No

8. **Which of the following best describes your current main daily activities and/or responsibilities?**

	Working full time
	Working part time
	Unemployed or laid off
	Looking for work
	Homemaker
	Retired
	Volunteer

9. **I would like to get a sense of how income affects your life. What is your average monthly income?**

   _____

10. **Please tell me which of the current health conditions you currently have. You may respond by saying "yes" or "no" each time I list a health condition.**

	Asthma or Emphysema		Arthritis
	Diabetes		High blood pressure
	Heart Disease or Heart attack		Stroke
	Stomach problems		Cancer of any kind
	Osteoporosis (or weak bones)		High cholesterol
	Painful joints		Eye problems (like cataracts, glaucoma, detached retina)

<End demographic questionnaire, continue to component 1>

Component 1

<Begin audio recording now>

Q1 (part 1):	Tell me what you know about stroke.

Write Field Notes Below:

Q1, Part 2	Tell me what it would be like if someone were beginning to have a stroke.
Possible Alternate Questions: (use if participant has difficulty with understanding Q1, Part 2. Alternate Question used? Yes No Which Question? (Circle on right)	• What are the warning signs of stroke? • How would you know if someone was having a stroke? • What are the symptoms of stroke?
Probe Questions Probe Question used? Yes No Which Question? (Circle on right)	• What do you think causes stroke? • How long do you believe this illness lasts? • Does stroke get better? • Can you describe the treatments for stroke? • How do you think a stroke effects a person's life?

Write Field Notes below:

Q2:	If your friend or family member looked like they were having a stroke, what would you do?

Write Field Notes Below:

Q3:	If you thought you were having a stroke, what would you do? Follow up question: Why would you <insert participants response>

Write Field Notes Below:

What do you know about stroke?

What it would be like if someone were beginning to have a stroke?

If your friend or family member looked like they were having a stroke, what would you do?

<End Audio Recording BEFORE Proceeding>

Component 2 Assessments

Instructions to participant: "I have a few more questions to ask you. This time, I will either show you a picture with a "yes" or "no" or numbers to have you choose your answer. "

<Administer Assessments>

Component 3

<Begin Audio Recording NOW>

Instructions: Ask the participant the following question and document field notes.

Q1: "Is there anything else you would like to tell me about stroke?"

Write down field notes:

Is there anything else you would like to tell me about stroke?