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The purpose of this study was to determine how experienced home health nurses perceive elder self-neglect. An additional purpose of the study was to explore steps these nurses employ to intervene when self-neglect is suspected.

Self-neglect is a complex phenomenon that is poorly understood. Salient features of this phenomenon include the failure of individuals to take the steps needed to provide for their basic needs, comfort and safety. Common presentations have been described as disheveled, unkempt individuals living in cluttered, filthy homes. Yet, these individuals give no indication there is any cause for concern.

Although self-neglect can be found in the literature dating back to the late 1960's, there is a paucity of research of this phenomenon. Previous studies have focused on describing the manifestations of self-neglect, and a few have offered definitions. However, to date, there is a wide range of definitions of self-neglect and thus, a lack of clarity in understanding the phenomenon. Because self-neglect is manifested as a failure to provide for personal needs as well as maintaining the living environment, home health nurses are poised to identify these individuals. However, only three studies were found focused on nurses, and none of those studies focused on nurses who make home visits. This is the first study of self-neglect focused on home health nurse perceptions of the phenomenon.

This qualitative, descriptive design of home health nurses (N=16) revealed nurses' perceptions that resulted in five global themes: (a) armor, (b) psychological derivation, (c) seclusion, (d) nonconformity with self-care conventions, and (e) nurses' responses. These nurses could readily identify signs of self-neglect in their clients including nonconformity with self-care conventions and seclusion. They provided their definition for this phenomenon but reported

receiving no education on self-neglect either in their pre-licensure programs or since entering practice. These home health nurses identified both facilitators and barriers to providing nursing care to this population, and experienced ethical questions of autonomy and beneficence in providing that care. Study participants attributed self-neglect to psychological issues, although expressed that none of these clients were medically diagnosed with a mental illness or disorder.

The results of this study have implications for nursing education and practice as well as public policy decisions. Further studies on self-neglect are needed to develop educational strategies to inform nursing practice. Exploration of the impact that public policy has on these elders who are vulnerable and marginalized is paramount. Nurses should assume lead roles in future studies of self-neglect.

NURSE PERCEPTIONS OF ELDER SELF-NEGLECT

by

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Approved by

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Committee Chair

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To Bobby, for your constant love and support.  
You have supported me through everything I ever wanted to do.  
Without you none of this would have been possible.

Also, to my sons, Robert Alexander and Caleb Jeremiah,  
and my grandsons, Colby Tanner and Isaiah Levi

I love you all more than you will ever know.

APPROVAL PAGE

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## CHAPTER I

### BACKGROUND

#### **Introduction**

Older adults comprise a larger portion of the population with each passing year. The segment of the United States population aged 65 and older is expected to climb to 88.5 million by 2050, compared with an estimated 40.2 million elderly in 2010 (Vincent & Velkoff, 2010). A significant number of these Americans will be in the upper range of the age group, aged 80 and older (Vincent & Velkoff, 2010). Older adults have more chronic conditions, are prescribed more medications to treat those conditions, and have greater numbers of hospital, rehabilitation facility and nursing home admissions (Federal Interagency Forum on Aging-Related Statistics, 2012) compared to other age groups. Medicare is the “federal health insurance program ... for individuals aged 65 and older” (American Association for Retired Persons [AARP], 2012, p.1). Healthcare expenditures for Medicare alone grew from 1.2 trillion dollars in 2000 to almost 2.6 trillion dollars in 2010 (Centers for Medicare and Medicaid Services [CMS], 2012). Therefore, a greater proportion of financial resources, both public and private, is spent on healthcare as people age.

Healthcare costs in the United States constituted 13.8% of the gross domestic product (GDP) in 2000, and ballooned to 17.9% of the GDP in 2010 (CMS, 2012); likely due to the growing elderly population. “The United States spends a larger share of its

gross domestic product (GDP) on health care than any other industrialized country” (AHRQ, 2002, p.1). Prevention of illness or exacerbation of chronic illness is one method to control these escalating costs. Less widely discussed is the fact that some older adults fail to take the steps needed to care for themselves, and despite increased medical needs, either avoid medical care or fail to adhere to the medical regimen prescribed for them. This phenomenon is known as self-neglect. Health conditions that could be easily prevented or controlled may be exacerbated when these older adults who self-neglect are not identified and treated. Uncontrolled health conditions increase the risk of hospitalizations, the need for rehabilitative services and nursing home admissions, further burdening both private and governmental funding for healthcare.

### **Problem Statement**

Signs of self-neglect are disturbing to others, and as such, self-neglect is the single most nationally reported issue to Adult Protective Services (APS). Of greater concern is that many more cases go unreported (National Committee for the Prevention of Elder Abuse [NCPEA], 2008; Pickens et al., 2007). Self-neglect is predominantly seen in older community-dwelling individuals (Badr, Hossain & Iqbal, 2005; Bozinovski, 2000; Braye, Orr, & Preston-Shoot, 2011; Dyer, Goodwin, Pickens-Pace, Burnett, & Kelly, 2007; Mauk, 2011; Pavlik, Hyman, Festa, & Dyer, 2001) but is largely misunderstood.

Self-neglect lacks conceptualization and may be defined differently depending on the perspective of the professional providing care (Lauder, 1999a). Although studies conducted on self-neglect have used similar terms to define it, no consistent definition

has been adopted (Ballard, 2010; Braye et al., 2011; Dick, 2006; Dong, Wilson, Mendes de Leon, & Evans, 2009; Gibbons, & Ludwick, 2006; Lauder, Anderson, & Barclay, 2005a). In general, self-neglect is characterized by: (a) a lack of attention to the basic human physical needs such as nutrition and hygiene, (b) social isolation, and (c) lack of attention to medical needs (Ballard, 2010; Bozinovski, 2000; Braye et al., 2011; Burnett, Regev et al., 2006; Lauder, Ludwig, Zeller & Winchell, 2006).

Reports of self-neglect are frequent (NCPEA, 2008). Yet, when signs of self-neglect are noted and are accompanied by a perceived absence of physical or mental disability, the observer often questions whether the behaviors are independent choices of the individual that should be honored (Braye et al., 2011; Payne & Gainey, 2005).

Protecting and promoting autonomy and independence is a vital component of nursing practice and therefore a central element in the Code of Ethics for Nurses (American Nurses Association, 2001). Although observations of self-neglect are disturbing, nurses may be conflicted with the obligation to protect the individual's autonomy versus the duty to protect the individual from harm. Thus, a lack of understanding of self-neglect leaves nurses in a professional quandary as to how to effectively care for these individuals.

Self-neglect bears problematic implications for individuals who self-neglect and for others around these individuals. Self-neglecters often disregard their living areas as well as themselves. At the extremes, self-neglecters live in squalid conditions (Abrams, Lachs, McAvay, Keohane, & Bruce, 2002; Braye et al., 2011; Macmillan & Shaw, 1966) and may hoard things (Abrams et al., 2002; Braye et al., 2011; Macmillan & Shaw, 1966)

such as animals and garbage. These actions not only place these individuals at risk of harm; but also, are offensive to others who may subsequently avoid these individuals. This avoidance leads to social isolation and exacerbates the vulnerability of the individual. Consequently, self-neglect results in poor health conditions and public safety risks (Abrams et al., 2002; Braye et al., 2011; Dong, Simon, Beck, & Evans, 2010). Further, when the condition is severe and left untreated, premature death may occur (Braye et al., 2011; Burnett, Regev et al., 2006; Dong, Wilson et al., 2009; Lachs, Williams, O'Brien, Pillemer, & Charlson, 1998). Therefore, significant consequences result from self-neglect in the older adult.

When elder abuse or neglect occurs from the actions of others, healthcare professionals including nurses respond with an increased social consciousness and a call to protect the elder. Protection of elders in the United States is so highly valued that national legislation mandates each state develop avenues to protect vulnerable adults (Dong, Simon, Mendes de Leon et al., 2009; Franzini & Dyer, 2008). Unfortunately, this is not the case in self-neglect, perhaps as a result of a lack of understanding of the phenomenon.

With the aging of the baby boomer generation and the exponential growth of the numbers of elderly, there is a high probability of greater numbers of cases of elder self-neglect. Given the health consequences of self-neglect, the connection between self-neglect and the elderly population, an increasing elderly population, and the absence of a clear definition for self-neglect used by healthcare professionals, further research to gain an understanding of self-neglect is crucial in protecting and improving the health of this



vulnerable population. Coupled with the lack of understanding of self-neglect, there is a paucity of research on this phenomenon. This is especially true regarding the impact that perspectives of healthcare professionals have on outcomes for the self-neglecting individual. This lack of evidence to underpin practice decisions translates into an inability to educate nurses and home health aides on self-neglect and thus, an inability to effectively address self-neglect from a nursing perspective.

### **Purpose of Study**

The purpose of this study was to explore experienced home health nurses' perspectives of self-neglect in the elderly. This exploration focused on: (a) definitions for elder self-neglect used by the home health nurse, (b) how elder self-neglect was identified by the home health nurse, and (c) steps usually taken by the home health nurse to address the individual's needs when elder self-neglect was suspected.

### **Background and Significance**

According to Erickson's theory of development (1982), independently caring for self is a fundamental drive of human beings beginning with the toddler stage. Advancing age does not negate the desire to maintain independence or to adhere to personal goals and aspirations. However, when self-neglect is present, the desire to care for self independently appears to be lacking. The act of self-neglect exerts devastating consequences on the individual (Adams & Johnson, 1998; Aung, Burnett, Smith & Dyer, 2006; Braye et al., 2011; Choi, Kim, & Asseff, 2009) and when severe, for those associated with the individual as well. It is intuitive that failing to meet basic physical, medical, social, and safety needs will result in negative health consequences. More

obscure is an understanding of why an individual would fail to meet those basic human needs when no obvious physical or mental disability is evident. Untreated or uncontrolled mental health disorders such as depression or cognitive impairment may involve self-neglect (Abrams, 2002, Dyer et al., 2007); however, it is currently unknown whether elder self-neglect may result from mental health disorders or a different etiology. In fact, one of the conundrums with the identification of self-neglect is that there is no medical diagnosis related to cognitive impairment or mental health disorders. A greater understanding of this phenomenon is paramount as the first step in developing interventions to interrupt the cycle prior to the occurrence of negative outcomes for these vulnerable individuals.

Self-neglect is not a new concept; in fact, it is found in the health literature dating back to at least 1966. Yet almost 60 years later, little is known about this phenomenon. Few studies of self-neglect have been undertaken, and those studies have centered on describing behaviors seen in those who self-neglect and on correlates of self-neglect. There remains no consensus definition, no tested theories, and no targeted interventions or treatment (Braye et al., 2011) for self-neglect. Insufficient information on this phenomenon translates into a lack of evidence on which to build best healthcare practices and policies to protect these vulnerable older adults from negative health consequences while protecting their autonomy. The majority of information on self-neglect is found in the social literature as many of these clients are seen by Adult Protective Services (APS). While a hallmark consequence of self-neglect is impaired health status, surprisingly few studies have included healthcare practitioners (Adams & Johnson, 1998; Gibbons, 2009;

Iris, Ridings & Conrad, 2009; Lauder, 1999a; Lauder et al., 2005b; Lauder et al., 2006).

This is a significant gap in nursing science.

Although self-neglect is glaringly evident in the living environment of the individual (Abrams et al., 2002; Braye et al., 2011; Macmillan & Shaw, 1966), it may not be noticed when the individual is seen outside of that environment. Practitioners who make home visits, such as nurses and social workers employed by home health agencies are uniquely positioned to assess for self-neglect; unfortunately, to date few studies focusing on self-neglect have included nurses (Adams & Johnson, 1998; Ernst & Smith, 2012; Lauder et al., 2006). In the published reports of self-neglect, information given included the use of 18 hospital nurses and 10 community health nurses in one study (Adams & Johnson, 1998); 40 public health nurses in another (Lauder et al., 2006), with no distinction of whether those nurses made home visits; and an unknown number of social worker and registered nurse teams in the final study including nurses (Ernst & Smith, 2012). There are over three million registered nurses in the workforce (U.S. Department of Health and Human Services [USDHHS], 2010) with home health nurses making approximately 121 million visits each year (National Association for Home Care & Hospice, 2010). If just one percent of those visits targeted individuals with self-neglect, this would represent over 1.2 million individuals who self-neglect. Given this estimate of home health nurse visits made to individuals who self-neglect and the numbers of nurses in the healthcare workforce, an appallingly low number of nurses are represented in studies of self-neglect.

Several studies have included social workers, largely as a result of their professional position with APS agencies (Dong, Mendes de Leon, Evans et al., 2009; Dong, Simon, Beck et al., 2010; Dong, Simon & Evans, 2009; Dong, Simon, Mendes de Leon et al, 2009; Dyer et al., 2007; Ernst & Smith, 2011; Ernst & Smith, 2012). Of the three published studies that included nurses, the 1998 study of 28 nurses (Adams & Johnson, 1998) described perceptions nurses held of gross self-neglect. Only 10 of the nurses interviewed (N=28) were nurses who made home visits, and the study was conducted in the United Kingdom. The second study described factors that influenced the decisions made by 40 nurses in Ohio (Lauder et. al, 2006). In particular, the second study focused on describing factors that influenced the nurse's decisions regarding whether individuals were capable of making independent decisions for their health needs and whether these individuals should be treated against their wishes (Lauder et al., 2006). The final study of nurses compared the approaches between a social worker and a team comprised of a social worker and registered nurse in caring for clients with self-neglect (Ernst & Smith, 2012). None of these studies had comparative findings and thus, a gap in the understanding of this phenomenon continues. More importantly, no studies from this country were found exploring the perceptions and actions of front line health providers, American home health nurses, in relation to self-neglect.

Home health nurses are uniquely positioned to identify self-neglect during home visits; however, to date there has been no research focused on these key stakeholders. Development of common definitions and a consensus understanding of the phenomenon of self-neglect are prerequisites for developing prevention and treatment efforts for health

professionals who encounter these individuals. Despite what is known on self-neglect, this fundamental knowledge has not been developed. Although several have proposed definitions, no consensus definition has been adopted. The National Center on Elder Abuse [NCEA] (1998) proposed the following definition for self-neglect.

Self-neglect is characterized as the behavior of an elderly person that threatens his/her own health or safety. Self-neglect generally manifests itself in an older person as a refusal or failure to provide himself/herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated), and safety precautions. The definition of self-neglect excludes a situation in which a mentally competent older person, who understands the consequences of his/her decisions, makes a conscious and voluntary decision to engage in acts that threaten his/her health or safety as a matter of personal choice (p.3-3).

The National Adult Protective Services Association (2008) proposed a similar definition for self-neglect.

Self-neglect is the result of an adult's inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including (a) obtaining essential food, clothing, shelter, and medical care; (b) obtaining goods and services necessary to maintain physical health, mental health, or general safety; and/or (c) managing one's own financial affairs. Choice of lifestyle or living arrangement is not, in itself, evidence of self-neglect (p. 5).

Both of these definitions by national organizations focus on the failure of the self-neglecting individual to take steps to maintain his/her integrity, or wholeness. All uses of self-neglect found in publication utilized some form of these two definitions, with the exact application of the definition varying widely. It has been proposed that the definition of self-neglect changes depending on the context and the situation of the individual (O'Brien, Thibault, Turner, & Laird-Fick, 2000); further adding to the difficulty

of establishing a clear definition and in interpreting the behaviors that may constitute this phenomenon.

There have always been individuals who have neglected their homes and their own personal hygiene as well as their personal belongings. “Such persons have been labeled eccentrics, hermits and witches. They were considered strange and often lived on the social and physical peripheries of their communities” (Bozinovski, 2000, p. 38). What is novel however, is an increasing awareness of the phenomenon coupled with the increasing elderly population of the United States related to the aging of the baby boomer generation. While the Baby Boomer generation is characterized by independence (Anetzberger & Teaster, 2010; Morris, Mueller & Jones, 2010), self-direction (Morris et al., 2010; Worsley, Wang & Hunter, 2010), and the search for knowledge, health and wellness (Anetzberger & Teaster, 2010; Worsley, Wang & Hunter, 2010); likely self-neglect will be evident in the boomer generation as well. If indeed self-neglect is seen in the boomer generation, the increased numbers of aging boomers will result in much greater numbers of those who self-neglect. This could create an immeasurable problem in terms of negative health outcomes, increased healthcare costs, and public health concerns.

### **Conceptual Model**

Levine’s Conservation Model (Figure 1) provided a guiding orientation for this qualitative study on the perceptions of self-neglect held by home health nurses. Use of a qualitative approach to understanding self-neglect did not provide an avenue for testing this theory; instead, the model served as the lens through which the information revealed

from the study was explored and understood. Qualitative research provides a method to understand phenomena by allowing for describing and explaining the data (Morse & Field, 1995). The use of a conceptual model centered on nursing was expected to provide a broader understanding of the perceptions held by nurses who care for clients who self-neglect. This study employed a naturalist paradigm, which holds that there are multiple truths that are evident only in the experiences of the participants (Lincoln & Guba, 1985). A basic assumption of this study was that the truth is housed within the participant, and that gaining an emic view of self-neglect from the nurses engaged in the work of caring for those who self-neglect was the only way to hear their truth. Levine's model was predicated on the assumption that nurses act to assist the patient to conserve, or remain whole. Gaining an emic view from home health nurses who care for self-neglecters is essential in defining and understanding self-neglect, and thus, creating the foundation to address care for these individuals.

Self-neglect is a process that threatens the ability of the individual to maintain his or her integrity, as well as the individual's ability to function as a whole being. Levine (1966) proposed that individuals may not be able to independently act to maintain their integrity, and when this happens it is the responsibility of the nurse to intervene to protect the wholeness of the individual. To appropriately intervene in cases of self-neglect, the nurse must first be able to recognize it. Once self-neglect is identified, the nurse must be able to accurately employ resources to intervene on behalf of the individual who lacks the ability to do this for him or herself. Currently, the science of self-neglect lacks information on self-neglect as it is understood by nurses.

It is the responsibility of the nurse to assist the individual to adapt to threats in the internal and external environment to maintain a balance. Nursing assessment is the key to ensuring the healthcare team has the information to determine appropriate actions to help the client with this balance. Levine (1967) termed this balance “Conservation.” In Levine’s model “Health”, “Wholeness” and “Conservation” are synonymous (Fawcett, 2005). Adaptation to internal and external stressors is the action that the individual, or the nurse assisting the individual, undertakes to help maintain conservation.

Wholeness or conservation and conversely self-neglect are complex, multidimensional concepts. No one concept, ability or action functions independently to lead to conservation. This is evident in the four principles of the model, which include energy, structural integrity, personal integrity and social integrity conservation (Levine, 1967). These four principles function in concert, with each principle comprising an important element of the model to support conservation (wholeness). If any of the principles are not intact, wholeness is not supported and thus, is lacking.

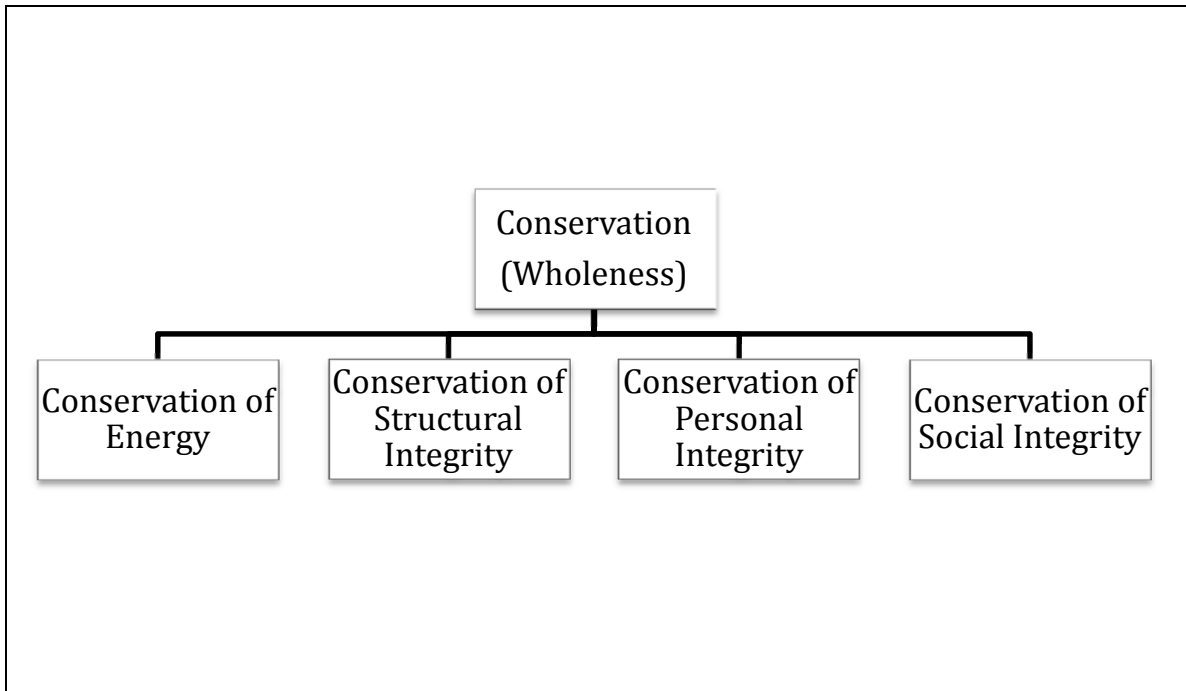
The first principle in the model is the principle of energy conservation. The principle of conservation of energy extends beyond simply conserving energy that might be intuitive in nursing care of individuals suffering a physiological pathology or condition, such as a broken bone or major surgery. Conservation of energy includes a balance between energy intake and the body’s use of energy. Self-neglecters most often fail to provide for their nutritional needs, thus their energy intake is impaired. When conservation of energy is not present, as in the case of the self-neglecting individual not meeting nutritional needs, impairment of structural integrity is at risk (Levine, 1967).



Conservation of structural integrity is the second principle in Levine's model and is evident in the individual's ability to maintain the physical structure of the body required for adequate function (Levine, 1967). This principle is also intuitive in nursing care as the nurse assists the client with activities that the client may be unable to attend to independently. Levine claimed that the act of nursing is a conservation activity (Levine, 1973). Nursing actions are restorative in nature and assist the client in maintaining a sense of self or personal integrity.

The principle of conservation of personal integrity is the next principle in the model and is that sense of self or independence that develops in each person as they move through the stages of psychosocial development, beginning at birth and ending only in death. All humans have a construction of who they are, their personal identity. A sense of personal identify becomes central to how an individual conducts themselves in the world and interacts with others. Levine (1967) offered a reminder to nurses that human beings are a culmination of mind and body, inclusive of emotions and the soul. Therefore, nurses are obligated to care for the client holistically to protect the client's personal integrity. The ability to retain that sense of self or personal integrity becomes central to the psychological wholeness of the individual and as such, is an integral part of life itself.

Figure 1. Levine's Conservation Model



Finally, the principle of conservation of social integrity is an extension of personal integrity in that each individual is part of a larger group, whether that is a family, community, professional, or other entity (Levine, 1967). Social integrity then is an extension of self and part of the identity of the individual. “The human being knows himself in his reflection of his dynamic relationship with other human beings” (Levine, 1967, p. 56). This is an important acknowledgement for nurses in effectively caring for the individual, protecting their identity as a member of a group, and thus, their wholeness. Understanding social integrity is also important for nurses to be able to effectively provide care for larger groups, protecting the integrity of communities and populations.

Maintaining wholeness is multidimensional and entails an individual maintaining a delicate balance of energy to successfully adapt to changes in their internal and external environment. Successful adaptation translates to continued physical and psychological health. Maintenance of structural and personal integrity allows the individual to maintain a sense of self and the ability to interact appropriately in the social environment. A basic tenet of nursing is assisting individuals with interruptions in their normal states of physical or psychological health.

This model provides a strong foundation for qualitative inquiry. While integrity and wholeness are essential tenets of nursing care, this specific model provides a lens to explore the phenomenon of self-neglect through four principles of wholeness: energy, structural integrity, personal integrity, and social integrity. The focus of home health nursing is assisting individuals back to their former level of independence. Thus, approaching home health nursing care with wholeness as the outcome is intuitive for independence to occur. Levine's conservation model of nursing provides an appropriate framework for understanding nurses' perceptions of self-neglect and to illuminate the nursing approach to care of a client with self-neglect. The ability to analyze and interpret the qualitative data revealed in this research from a nursing perspective is important in widening the scope of the science of self-neglect and providing evidence on which to build nursing policy and practice.

## **Definitions**

The following definitions are provided as relevant for this proposed study.

1. Self-neglect is conceptualized as an overall failure to provide for self-needs in the absence of obvious physical or mental disability.
2. Home health nurse is an experienced nurse who is (or has been) employed to care for clients in their homes. These are licensed registered nurses with at least two years of experience in home health.
3. Elderly refers to the individual aged 65 and older.
4. Facilitators are defined as concepts that help to promote or bring about change.
5. Barriers are defined as concepts that prevent or make something more difficult.
6. Interventions are defined as steps nurses take to provide care for their home health clients.

## **Specific Aims**

The aims of this study were to (a) explore awareness and perceptions that experienced home health nurses had of self-neglect, (b) explore how nurses identify and define self-neglect, and (c) identify the steps usually taken by nurses to intervene and assist the client to wholeness when self-neglect was suspected. It has been proposed that individuals construct their own understanding of concepts based on their professional perspective and value system (Lauder, 1999a). What was not clear was whether nurses were able to define and identify self-neglect, or whether home health nurses have common definitions or identifying attributes used for self-neglect. Understanding nurses' perceptions of self-neglect will add to the science of self-neglect by informing the

development of processes to identify individuals who self-neglect and by providing information on which to create a foundation to address care decisions for these individuals prior to negative health consequences. Additionally, understanding how nurses approach self-neglect will serve to inform the design of professional nursing education, nursing practice, and public policy. Levine's conservation model provides guidance for exploring this phenomenon. Because the researcher serves as the instrument in qualitative inquiry, the researcher employed the four principles of the model to answer the following research questions.

### **Research Questions**

1. What are home health nurse's perceptions of self-neglect?
2. How do home health nurses identify self-neglect?
3. What actions do home health nurses employ to intervene with self-neglect?
4. What are the facilitators and barriers to identifying self-neglect for home health nurses?
5. What are the facilitators and barriers to intervening with self-neglect for home health nurses?

Probe questions were employed to facilitate further discussion on self-neglect and to illicit additional perceptions home health nurses had of self-neglect and the care of elderly clients who exhibit signs of self-neglect.

### **Assumptions**

Specific assumptions underpinned this study. The first assumption was the belief that the reality of self-neglect is integrally tied to the subjective experiences of the

individual, and there are multiple realities for this concept of study. Thus, a home health nurse will have an idea of self-neglect that may differ from the nurse who has an alternate practice area or focus, from a physician, or from a family member. While the principal investigator (PI) attempted to bracket in the research process, the PI's reality may also be represented in this qualitative study as interpretation of the data may reflect the PI's experiences and thus, bias'. It was also assumed that study participants would share their subjective experiences with the PI, providing honest and accurate information on their perceptions of self-neglect. The final assumption was that the data revealed in this qualitative study would provide understanding for the concept of study rather than delineation of a cause and effect relationship.

### **Summary**

This study should add to the current science of self-neglect. Little is known about this complex and concerning phenomenon. In spite of nurses working in the home health arena, where self-neglect is most often noted, there is a dearth of information on the perceptions of self-neglect held by nurses. Constructing this knowledge should contribute to development of methods to prevent and intervene on this phenomenon that results in enormous individual and social consequences. Much of the science that has been developed on self-neglect utilized data previously collected by social workers and other adult protective services personnel. Knowledge of the nurse's understanding and approaches to caring for a client with self-neglect is virtually absent from the literature. Thus, nurses' voices are silent on this phenomenon. Therefore, exploring perspectives of nurses was expected to provide valuable information regarding the approach nurses take

to care for clients who self-neglect. This knowledge should contribute to a foundation on which to design education on self-neglect for nursing personnel, as well as interventions to interrupt the cascading events that can lead to poor health status, functional decline, and loss of independence. With the resultant severe consequences from self-neglect coupled with the increasing numbers of elderly, development of knowledge of this phenomenon could result in lower healthcare spending, the development of important public policy directed to the care of elders, and greater quality of life for seniors by preventing self-neglect.

## CHAPTER II

### LITERATURE REVIEW

#### **Introduction**

This chapter provides a comprehensive review of the literature. It begins with an overview of self-neglect, details the current science on elder self-neglect, and presents healthcare providers' perspectives on elder self-neglect. Finally, theoretical views on self-neglect are discussed.

#### **Overview**

Self-neglect is an alarming phenomenon that occurs predominately in the elderly population (Ballard, 2010; Braye et al., 2011; Dyer & Goins, 2000; Dyer, Goodwin, et al., 2007; Gibbons, 2007) and has significant implications for elders who self-neglect (Abrams et al, 2002; Aung et al., 2006; Braye et al., 2011; Burnett, Coverdale et al., 2006; Choi et al., 2009; Dong, Mendes de Leon et al., 2009; Dong, Simon, Beck et al., 2010; Dong, Simon, Mendes de Leon et al., 2009; Ernst & Smith 2011; Lachs et al., 1998; Macmillan & Shaw, 1966), as well as for the families and neighbors of those affected (Day & Leahy-Warren, 2008; Dick, 2006; Dyer, Franzini et al., 2008; Iris et al., 2010; Poythress, Burnett, Naik, Pickens & Dyer, 2006; Sengstock, Thibault & Zaranek, 2008; Snowdon & Halliday, 2009). It is the most frequently reported issue to Adult Protective Services (APS) nationally (Braye et al., 2011; Burnett, Coverdale et al., 2006; Burnett, Regev et al., 2006; Dyer & Goins, 2000; Dyer, Goodwin et al., 2007) and is



suspected to be underreported (Dong, Simon, Mendes de Leon et al., 2009; NCPEA, 2008; Pickens et al., 2007). However, the ability to quantify the number of cases that may go unreported is not possible due to an incomplete understanding of this phenomenon and the paucity of research in this area (Dong, Simon, Mendes de Leon et al., 2009).

Currently, demographic and economic changes are occurring that make it critical to address elder self-neglect. Both the elderly population and health care spending are growing exponentially (CMS, 2012; Shrestha & Heisler, 2011). Self-neglect is costly in terms of multiple reports to police, public health and social services agencies, animal control personnel, and repeated medical interventions (K. Quinn, personal communication, October 17, 2012; National Adult Protective Services Association [NAPSA], 2011; NCEA, 2006). As the type of elder abuse most frequently reported to Adult Protective Services, self-neglect is also costly in terms of man-hours expended on this one type of elder mistreatment. The science of self-neglect is grossly underdeveloped, despite being a topic that has been in the literature almost 60 years. Most of the scientific work on self-neglect has focused on describing the phenomenon, and the divergence in understanding this phenomenon may depend on the perspective of the observer or care provider. In summary, very little is known about self-neglect and even less is known about how nurses identify self-neglect and the steps they take when self-neglect is suspected. Understanding the perspective of nurses providing care to individuals who self-neglect is important for further development of the science of self-neglect and to design processes to successfully intervene with self-neglect.

This chapter provides a review of the literature on elder self-neglect as it relates to healthcare providers. Given that self-neglect is most evident in the personal environment of the individual, home health nurses are perfectly suited to assess individuals for self-neglect and to act as the liaison between the individual and other professionals. Although home health nurses are uniquely positioned to identify and intervene in cases of self-neglect, the nursing discipline has been relatively silent in self-neglect research. Closing this gap in the science of self-neglect would result in greater understanding of the phenomenon, improved timeliness of intervening with these individuals, and ultimately, better outcomes for those affected by self-neglect. In this study, the perceptions that home health nurses have of self-neglect were explored.

### **Current Science on Elder Self-Neglect**

Individuals who self-neglect fail to take the steps needed to provide the most basic of needs, even when there is no clearly defined cause preventing them from doing so and no identified basis for the failure. The majority of elders who self-neglect “are legally competent” (Ernst & Smith, 2011, p. 290), although their actions seem to conflict with what many would term competent. Self-neglect is identified through a cadre of behaviors rather than a single sign or symptom. There are several correlates of self-neglect, but no research to date has identified specific causal factors. Self-neglect is not consistently identified even by the professionals who must intervene with this phenomenon, nor are the risks of self-neglect known to the general public or those involved in developing public policy (NCPEA, 2008). Not enough is known about this phenomenon to infer that self-neglect will occur in a specific population following a

precipitating event or assessment finding, nor to develop public policy to address the issues that accompany self-neglect. Further development of the science of elder self-neglect will require a more complete understanding from multiple vantage points, or lenses, including healthcare personnel who interact with elders exhibiting these behaviors. It is through inquiry such as this study that further discovery can be made that will inform development of the trajectory of self-neglect.

Self-neglect has been described as a constellation of symptoms rather than as a single identifying attribute (Lauder, 2001). Commonalities exist in those who self-neglect, but there is currently no knowledge of one absolute defining behavior or attribute. An overall failure to take steps needed to provide for basic personal needs is the salient feature of self-neglect. This overall failure is evidenced in those who self-neglect as poor personal hygiene (Adams & Johnson, 1998; Clark, Mankikar & Gray, 1975; Dyer, Kelly et al., 2006; Dyer et al., 2007; Kelly, Dyer, Pavlik, Doody & Jogerst, 2008; Lauder, 2001; Macmillan & Shaw, 1966; McDermott, 2008; NCEA, 1998; Poythress et al., 2006; Tierney et al., 2004), filthy living conditions (Adams & Johnson, 1998; Clark et al., 1975; Dyer, Kelly et al., 2006; Dyer et al., 2007; Lauder, 2001; Lauder et al., 2005a; Kelly et al., 2008; Macmillan & Shaw, 1966; McDermott, 2008; NCEA, 1998; Poythress et al., 2006), hoarding (Adams & Johnson, 1998; Lauder et al., 2005a; McDermott, 2008; Poythress et al., 2006) lack of meeting basic energy needs through eating (Adams & Johnson, 1998; Dong, Simon, Beck et al., 2010; Lauder, 2001; NCEA, 1998; Tierney et al., 2004), failure to seek medical care when needed (Dyer, Kelly et al., 2006; Tierney et al., 2004), or lack of adherence to medical advice in spite of adequate

resources to meet those needs (Adams & Johnson, 1998; Dyer, Kelly et al., 2006; Tierney et al., 2004). In extreme cases, individuals who self-neglect ignore medical advice even when sustaining life depends on following recommended treatment (Dyer, Kelly et al., 2006).

Other descriptions of self-neglect have included correlates of self-neglect such as social withdrawal (Burnett, Coverdale et al. 2006; Burnett, Regev et al., 2006; Mauk, 2011), living alone (Burnett, Regev et al., 2006; Culberson et al., 2011; Macmillan & Shaw, 1966; Payne & Gainey, 2005), and inadequate social support (Burnett, Regev et al., 2006; Dong, Simon & Evans, 2010; Dyer, Goodwin et al., 2007; Kutame, 2007; Macmillan & Shaw, 1966); all possibly being factors compounding the underreporting of self-neglect (Mauk, 2011). Further, greater risks of negative health consequences are possible with longer durations of these behaviors. Depression (Abrams, 2002; Burnett, Coverdale et al., 2006; Burnett, Regev et al., 2006; Choi et al., 2009; Culberson et al., 2011; Dyer, Goodwin et al., 2007) and cognitive dysfunction (Abrams et al., 2002; Dong, Simon, Wilson et al., 2010; Dyer, Goodwin et al., 2007; Kutame, 2007; Kelly, Dyer et al., 2008; Tierney et al., 2004) are also associated with self-neglect. Whether depression and cognitive dysfunction occur as the result of long-term social isolation or conversely whether the elder isolates him or herself due to depression and cognitive dysfunction are currently unknown. Elders who self-neglect have reported experiencing a sense of abandonment by others, negative life events, and a subsequent mistrust of others (Bozinovski, 2000). Macmillan and Shaw (1966) concluded the bizarre behaviors and social isolation seen in self-neglect were the “expression of a hostile attitude to and a

rejection of the outside community” (p. 1036). Social isolation may be a method either to keep others at bay to prevent further hurtful interactions, or a consequence of behaviors common to self-neglecters; although at present there is no evidence to support this.

It seems intuitive that elders who self-neglect lack adequate decision-making abilities as they do not take the steps to ensure their own health and survival even when they have the physical ability to do so. Decision making and problem solving are obviously dependent upon cognitive abilities (Diehl, Willis & Schaie, 1995; Park & Gutches, 2000; Park, Morrell, Frieske & Kincaid, 1992), however there is no support for the assumption that all elders who self-neglect have cognitive deficits (Abrams, et al., 2002; Burnett, Regev et al., 2006; Dyer, et al., 2007; Franzini & Dyer, 2008; Lauder et al., 2005a; Lauder, et al., 2005b; National Center on Elder Abuse [NCEA], 2007; Reyes-Ortiz, 2006; Tierny et al., 2004). Personal choice has been suggested as the rationale for neglecting personal care and the care of the personal environment (Gibbons, 2007; Leibbrandt, 2007). Thus, further research on decision making in elders who self-neglect is needed.

Researchers, to date, have provided descriptions of self-neglect; thus, many behaviors, attributes and correlates are known. What is not known is how home health nurses link behaviors and attributes to identify elder self-neglect, and thus, begin an effective treatment plan. There are currently no known causal factors, no consistently accepted definitions, and no tested theories for elder self-neglect. Developing that knowledge will require inquiry that is multi-focal and includes the perspectives of key stakeholders. Current approaches to intervening with self-neglect are limited by the lack

of knowledge of this phenomenon, forcing interventions that address each of the behaviors rather than a comprehensive approach. Developing a comprehensive approach is also complicated by the fact that these indicative behaviors are not all present in each case, and cases may have features that seem contradictory. For example, an elder who self-neglects may live in squalor, yet take steps to provide for their personal hygiene (Lauder et al., 2005a). The science of self-neglect is currently void of absolute identifiers of self-neglect, along with knowledge of predictors; however, the consequences are grave and self-neglect is positively associated with increased risk of death, even when controlling for factors such as age, depression, cognitive function and physical function (Dong, Simon, Mendes de Leon et al., 2009; Lachs et al., 1998).

Self-neglect is complex and exerts a negative influence on the health status of individuals who self-neglect, on the environmental safety of individuals who self-neglect and those in close proximity, on economics in terms of the costs of increased health care treatment for conditions that could have been treated or controlled, and on resources in terms of man hours spent following up on reports to housing or APS officials. Developing an approach to manage self-neglect effectively will require in depth research using multiple approaches to develop a full understanding, a consensus definition, and a trajectory of this phenomenon. Without these initial steps, interventions for self-neglect will continue to be fragmented, focused only on individual behaviors, and thus, inefficient and possibly ineffective.

## Healthcare Perspectives on Elder Self-Neglect

Previous research on self-neglect has failed to provide clarity for this intricate phenomenon, although it has provided foundational knowledge that informs the science of self-neglect. The study of this phenomenon has yielded descriptions rather than explanations for self-neglect, a testimony to the complexity of the phenomenon. The lack of clarity culminates in a dilemma for healthcare professionals regarding effective interventions for and management of self-neglect. Additionally, state statute definitions differ in the United States (Daly & Jogerst, 2003; Stiegel & Klem, 2007). For example, only 12 of the 50 states in America currently have statutes that address self-neglect and within those statutes, the definitions for self-neglect vary (Stiegel & Klem, 2007). Alaska's statute speaks to acts of omission committed by *vulnerable adults* [emphasis added], where New Hampshire's statute speaks to acts of omission committed by *incapacitated adults* [emphasis added]. Colorado and Utah statutes include mention of lifestyle choice as falling outside of the definition of self-neglect, while the statutes of the District of Columbia and Louisiana exclude individuals who seek healing through prayer. Washington's statute lists the types of agencies that an individual may be receiving care from, but notes that the neglect is not from actions of these caregivers (Stiegel & Klem, 2007). Improving consistency between states would improve professional understanding and provide the basis for national policy guidelines. Without a consistent definition or guiding legislation for self-neglect, professionals who encounter these individuals have no guidelines or basis for intervening and are instead forced to make professional decisions based on individual judgment. Additionally, the use of divergent definitions for

self-neglect render researchers unable to compare study findings in a meaningful way (Daly & Jogerst, 2003). National legislation addressing elder mistreatment was enacted with the Elder Justice Act of 2009 that addresses abuse, neglect, and exploitation (Falk et al., 2012). This act became a component of the Affordable Care Act (2010) when it became law in 2010 and provides funding for resources to ensure fair treatment for elderly Americans. Self-neglect is not specifically delineated in this legislation, but is mentioned under neglect with a definition provided as "...behavior of an elderly person that threatens his/her own health or safety" (Affordable Care Act, 2010; Falk et al., 2012, p.7). While there is now national legislation that earmarks money for protecting elders from abuse, neglect, and exploitation, there remains no evidence that all states have now adopted a consensus definition for self-neglect, nor that the problem of self-neglect has been lessened since this legislation was enacted. It has been proposed that a lack of consensus between states will continue, although the adoption of a common definition for elder mistreatment such as self-neglect would provide a framework for "researchers, practitioners, and for future policy changes" (Daly & Jogerst, 2003, p. 54).

Successful intervention for self-neglect may take the combined efforts of nurses, physicians, physical and occupational therapists, dentists and dental assistants, social workers, adult protective services personnel, housing professionals, tradesmen, and legal services personnel to address the physical, psychosocial, environmental, and legal needs of these clients. At present, there is fragmented communication between these disciplines (Lauder et al., 2005b), just as there is division in state laws regarding self-neglect. Each professional discipline has a different focus and therefore, a different approach to



problem solving. If the various disciplines worked in concert, this diversity in focus could be a strength that would facilitate positive outcomes for elders who self-neglect. A collaborative approach would ensure each discipline's valuable knowledge on a particular aspect of the client's care would be considered. Given the complexity of self-neglect, a multidisciplinary approach to intervention should result in positive outcomes (Braye et al., 2011; Ernst & Smith, 2012; Lauder et al., 2005b).

With so little information known about self-neglect, many professionals may find intervening with self-neglecting clients frustrating and challenging (Lauder et al., 2005a). Health professionals in general, including nurses, are often not aware of elder mistreatment including self-neglect nor of the steps to take when it is suspected (Falk, Baigism & Kopac, 2012). Often, intervening in self-neglect is so complex that many agencies that are based in the community "either refuse to get involved, or do so only briefly, then turn to APS [Adult Protective Services] for help" (Otto, 2002, p. 3). In turn, a greater strain is placed on Adult Protective Services (APS) agencies with limited governmental resources. Federal funding to address all types of elder abuse in the United States in 2009 totaled only 11.9 million (United States Governmental Accounting Office [GAO], 2011). Only a fraction of that federal funding available through social services block grants (\$206,171,540) was assigned to Adult Protective Service agencies (GAO, 2011), although all of the reporting of elder mistreatment is assigned Adult Protective Services agencies. This may be partly due to the fact that individual states may choose not to use federal funding available for APS and instead to use state and local funding (GAO, 2011). The enactment of the Elder Justice Act of 2009 earmarked \$500 million

dollars for Adult Protective Services agencies nationally for a five-year period beginning 2010 (Falk et al., 2012), but currently there is no published evidence of the effectiveness of this sweeping legislation. The lack of resources has no doubt been a barrier to intervention for self-neglect.

Investigations into the reports of self-neglect have also been limited by a lack of tools to measure this phenomenon. Until the advent of the self-neglect severity scale (SSS) (Dyer, Kelly et al., 2006), no tools to measure the phenomenon of self-neglect existed, effectively leaving identification of self-neglect up to the individual investigating a report. The work done in development of the SSS was comprehensive, leading to a tool that may be useful in the identification of the severity of self-neglect. However, it is a fairly new tool, is not currently widely used, and although the scale has shown promise in measuring the severity of self-neglect, it is currently undergoing refinement (Kelly, Dyer et al., 2008). Thus, there are no published reports of the psychometric properties of the final instrument. Additionally, nurses must first be able to recognize and define self-neglect consistently to rate the severity of the specific cases. Practitioners may be conflicted with decisions for care of the elder who self-neglects and the absence of an assessment tool that is consistently used further increases the lack of clarity. When no obvious physical or mental disability is perceived, the exact decisions made may depend upon the professional discipline of the decision maker (Lauder, 1999a), and the exposure that the individual professional has had with those who self-neglect.

**Physicians.**

Physicians working primarily in an office, clinic, or hospital setting rarely visit patients in their homes. When a physician encounters a patient in the hospital, they have most often received at least preliminary care and may be bathed and dressed in a hospital gown. The elder who had been self-neglecting may look the same as the elder not affected by self-neglect, therefore not exhibiting clues to their condition. Additionally, investigating elder mistreatment such as self-neglect is complex and may require a large time investment to identify all the aspects of the problem. Physicians report having limited time with each client, likely as a result of the reimbursement structure for healthcare, and therefore may focus on what they identify as the priority problem during a specific client encounter (Schmeidel, Daly, Rosenbaum, Schmuck, & Jogerst, 2012). Additionally, physicians who do encounter elder mistreatment report preferring to refer investigation of those issues to social workers, and identify social workers as experts in dealing with this type of mistreatment (Schmeidel et al., 2012). This evidence suggests that physicians may not be the best discipline to identify self-neglect, although the physician is key to treatment of identified conditions.

**Social Workers.**

Social workers may have professional skills more adept at identification of neglect or abuse perpetrated by a caregiver (Ernst & Smith, 2012) as opposed to a discipline with a medical focus.

A historic and defining feature of social work is the profession's focus on individual well-being in a social context and the well-being of society. Fundamental to social work is attention to the environmental forces that create,

contribute to, and address problems in living. (National Association of Social Workers [NASW], 2008, p. 1).

With this emphasis on individuals within a social context, the education of social workers provides a concentration on factors that are external to the individual (Ernst & Smith, 2012) such as problems caused by social injustice or problems inherent in the living environment of the individual. Therefore, financial exploitation and abuse by others may be more easily identified by social workers as well. The code of ethics for social workers emphasizes the need of social workers to address social problems, social injustice, and to recognize and respect the value and importance of human relationships (NASW, 2008). Although the education of a social worker may provide more knowledge on investigating social issues compared to nursing education, there is currently no evidence that self-neglect is caused by or leads to a social issue. Additionally, social workers report feeling restricted in what they can do for these clients due to unclear statutes for intervention and scarce resources (Schmeidel et al., 2012). Consequently, some social workers have reported feeling like they have failed these individuals (Lauder et al., 2005b). Subsequently, the problems of self-neglect continue. Investigations into these cases by social workers may not result in identification of an environmental or social trigger for the behaviors that may ultimately be deemed personal choice. The code of ethics for social workers speaks to respecting the self-determination of clients (NASW, 2008) and without clear environmental or social issues contributing to self-neglect the behaviors may go unaddressed and allowed to continue.

**Nurses.**

While social workers focus on issues external to the client (Ernst & Smith, 2012), nurses focus on health status and changes in that status using an approach that emphasizes internal factors (Ernst & Smith, 2012) such as depression, diet or the sequelae of a particular disease process. Additionally, while current nursing education includes a focus on interdisciplinary communication (American Association of Colleges of Nursing [AACN], 2009), nurses may be less prepared to identify the various disciplines needed to address the complex needs of a self-neglecting elder.

Much of nursing education revolves around acute care rather than community settings that include aspects of primary care, public health, and long-term care. Nursing education frequently does not incorporate the intricacies of care coordination and transitions. Nor does it promote the skills needed to negotiate with the health care team, navigate the regulatory and access stipulations that determine patients' eligibility for enrollment in health and social service programs, or understand how these programs and health policies affect patients and health outcomes. (Institute of Medicine of the National Academies [IOM], 2010, p. 2).

Given professional nursing education's focus on internal factors compared with a social worker's focus on environmental issues, nurses may be better prepared to identify self-neglect than social workers; however, there is currently not enough information to determine this. A multifocal and multidisciplinary approach may be needed to effectively identify and address the complex problems resulting from self-neglect, although this approach would be more costly. In fact, there is currently a dearth of information regarding the use of a multidisciplinary approach to identifying and intervening with elder self-neglect. Thus, the costs of these approaches may outweigh the

benefits (Ernst & Smith, 2012). Additionally, while self-neglect has been described, it has not been studied thoroughly enough to provide pragmatic guidance for practice (Reed & Leonard, 1989). With nursing education focusing on functioning in an acute care setting rather than in a community setting, nurses in general may be ill prepared for the in depth care coordination that may be required to effectively address problems for individuals who self-neglect. While nurses may recognize self-neglect as a problem, the manner in which nurses are educated may actually contribute to fragmented professional communication and collaborative care for elders who self-neglect, contributing to the subsequent problems remaining unresolved.

Effective abilities to coordinate the complex care needs of an elder who self-neglects will require a broad scope of knowledge on interdisciplinary collaboration, interventions for self-neglect, and reporting mandates. Intervention for elder mistreatment, including self-neglect is not generally taught in nursing education in this country, except for the cursory mandatory reporting information (Lauder et al., 2006). In a 2006 study of factors that affect nursing judgments in self-neglect, 10 widely used textbooks for nursing education were reviewed and found to be lacking information on self-neglect (Lauder et al., 2006). For validation of that finding, this researcher reviewed 21 texts on nursing fundamentals, medical-surgical nursing, nursing assessment, and psychiatric nursing. Consistent with Lauder and colleagues (2006) findings, only three of the 21 texts included any information on self-neglect, and the little information found included only a cursory mention of what self-neglect might look like and a mention of reporting. In spite of the inclusion of reporting issues in nursing education many nurses

are not sure of who they should report suspicions of self-neglect to or what they should report (Schmeidel et al., 2012). Nurses are more focused on and practiced at assessment of and intervention for individuals with health issues (Ernst & Smith, 2012).

In summary, both physicians and nurses report preferring to have social workers investigate the complex issue of elder mistreatment, yet social workers are also restricted by scarce resources and unclear definitions and laws. The code of ethics for both social work and nursing practice dictate the need to attend to the needs of the individual and to be mindful of keeping the value and worth of the individual central in those efforts (ANA, 2001; NASW, 2008). While estimating the costs of addressing self-neglect in regard to resources may be concerning, the human cost of doing nothing is much more compelling. In spite of the immense sums of money invested into healthcare and the public cries for improved quality of care, the current system for addressing eldercare in this country continues to utilize a fragmented approach to care that is woefully ineffective. It is imperative that the science of self-neglect include the perspectives of different professionals who contribute to the care of elder self-neglecters to identify effective interventions and preventative measures so that the problems evident with self-neglect do not continue. Addressing self-neglect with multiple professional perspectives may result in effective interventions for health care, as well as effective measures to address the ongoing fragmentation in professional communication and interaction.

### **Home Health Nurses**

When self-neglect results in environmental clutter and hoarding, the presentation is shocking and easily recognized. Home health nurses who encounter self-neglect know

it as a problem (Adams & Johnson, 1998). Yet, current research does not delineate whether home health nurses have an understanding of what constitutes self-neglect or specific interventions to institute in the event that it is suspected (Ernst & Smith, 2012; Lauder et al., 2006). Nurses in general, more than other disciplines are less knowledgeable about the laws that govern reporting and care of elder abuse (Schmeidel et al., 2012) which may contribute to nurses not taking steps to report behaviors that may indicate self-neglect. The education and scope of practice of a nurse may lead the nurse to describe the signs of elder self-neglect, report their findings, and leave the determination of assigning a name for this phenomenon to the physician (Schmeidel et al., 2012). Sadly, the current environment of managed care and Medicare reimbursement may have influenced both nurses who work in physician offices and home health nurses to be more focused on gaining information to ensure reimbursement is obtained for services (Schmeidel et al., 2012).

The home health nurse must be keenly aware not only of the nursing care for clients, but also of the factors that impact reimbursement that must be included in the assessment data that are transmitted to Medicare. The home health nurse is often the professional who admits the client to home health services, and sets the plan of care to include the number of and schedule for the visits made to the home (Department of Health and Human Services Centers for Medicare and Medicaid Services, 2012). Nurses in hospitals are not involved in individual patient reimbursement issues. Instead, those are the purview of the business office. The Institute of Medicine's (2010) report on nursing challenged nurse educators to redesign nursing education so that nurses enter the



workforce better prepared to address the needs of the complex health care consumer of today. As generalists, home health nurses may feel more comfortable dealing with assessment of issues that have been previously identified or encountered rather than assessing elder mistreatment issues for which they have little to no previous experience or education, preferring instead to make referrals to social workers or physicians for mistreatment suspicions (Schmeidel et al., 2012). Additionally, home health nurses may not have a strong background in making judgments on the need for interventions such as mandatory placement in nursing homes or hospitals (Lauder et al., 2006). Home health nurses provide care for individuals in their homes and subsequently are not surrounded by colleagues with whom they can discuss questions regarding care. Home health nurses provide care for individuals with a diverse array of conditions and problems, making the presence of standing orders and protocols virtually impossible. Thus, home health nursing relies strongly on collaborative practice with the physician. Conversely, home health nurses are better able to see the context where self-neglect exists and hence, the evidence for self-neglect. Without nursing education specifically targeting elder self-neglect nurses may be unclear on what they are seeing in the home.

The lack of a gold standard in caring for clients who self-neglect may lead home health nurses who encounter these clients to rely on their individual nursing judgment and previous knowledge which may not be sufficient for decisions regarding the care of these clients. Self-neglect research is virtually void of the voice of nurses, which further complicates defining standards of nursing care for self-neglecters.

## **Nursing Research and Self-Neglect**

Adams and Johnson (1998) noted the lack of nursing voices in the science of self-neglect and developed a study to identify whether nurses recognized self-neglect when they encountered it and what characteristics were indicative of self-neglect. That effort to understand nurse's perceptions of self-neglect included interviewing hospital nurses (n=18) and community health nurses (n=10), but the research report did not divulge whether these community health nurses made home visits. All of the nurses interviewed were able to identify attributes of the self-neglector that mainly focused on an overall lack of attention to providing for health, nutrition, hygiene and social needs. The overwhelming majority of nurses (n=23) indicated poor hygiene as a characteristic of the self-neglector, with poor nutrition also identified by many (n=21). Interestingly, several of the nurse participants expressed feeling that self-neglect was an area that needed further exploration. Yet, no further studies that included nurses were found until Lauder and colleagues (2006) published a study measuring whether the nurse who encountered self-neglect judged the client competent to make decisions regarding their health care, and whether the nurse thought the client needed statutory intervention. Vignettes were used for that factorial survey. The study utilizing Ohio nurses (N=40) found that the nurses used judgments on mental health to determine whether the client was capable of making their health care decisions. Self-neglect is associated with various mental health disorders (Abrams et al., 2002; Braye et al., 2011; Dyer et al., 2007; NCPEA, 2008). Conversely, mental health disorders are not always associated with self-neglect. Thus, significant questions arise related to the judgment of competency in individuals who self-

neglect based on Lauder and colleagues study (2006). Additionally, Lauder and colleagues (2006) found that nurses varied widely in their decisions on statutory intervention, attributing these variations to "...lack of expertise . . ." (p. 285), decisions on statutory intervention are usually "...outside (the) usual scope of nursing practice . . ." (p. 285)", and even "... greater inherent uncertainty in this type of judgment" (p. 285). While this study also provided a basis for further studies of nurses as they care for elder self-neglecters, there were no studies found that replicated Lauder and colleagues' work (2006).

Ernst and Smith (2012) compared care for clients referred to Adult Protective Services and explored the differences in care between clients who were seen by a nurse and a social worker to those clients seen by a social worker alone. Their study was a secondary analysis of data from two counties in Maryland. Client cases were rated for risk based on "...physical abuse, neglect by self or others, exploitation, physical environment and social environment" (p. 28). Risks were categorized as low medium or high and those cases in the low risk category were excluded from the study. The study findings suggested that risk reduction was greater in clients seen by a nurse and the social worker as compared to those seen only by a social worker. Interestingly, only one of the counties in the study used multidisciplinary teams while the other used social workers alone. The county that used only social workers had clients with lower risk profiles at the onset of the study. Achievement of greater risk reduction in clients seen by nurses and social workers may have been due to higher levels of risk initially that were more responsive to intervention. Ernst and Smith (2012) noted that higher risk profiles may

reflect crisis situations while lower risk profiles may “reflect chronic circumstances” (p. 34) which are more difficult to change. Thus, this study did not provide conclusive evidence that the reduction in risk was a direct result of the discipline of the care providers. Additionally, Ernst and Smith (2012) concluded that the costs associated with the multidisciplinary team were higher and that the evidence of this study did not specifically support the benefits to the client justifying the additional costs. Again, this was a valuable study with the potential to yield needed results in the care of those who self-neglect. Just as with the previous studies, no replication of this study was found, although this was a more recent study.

From these three studies of nurses, it is reasonable to conclude that nurses may be able to identify salient features of self-neglect such as poor hygiene and nutrition, yet they may use mental health status as the determining factor for deciding on the need for further intervention. Multidisciplinary teams that include both a social worker and a nurse may be of benefit to the elderly client who self-neglects, although the cost of that team may outweigh the benefit to these clients (Ernst & Smith, 2012). These three studies utilizing nurses have provided the perspective of only 77 nurses over a span of 14 years, and these were the only studies of self-neglect with nurses. Of these three studies, two were performed in the northeastern area of the United States (Ernst & Smith, 2012; Lauder et al., 2006) and one in the United Kingdom (Adams & Johnson, 1998). While these studies have provided a basis for further work, they provide appallingly little information on nurses’ perceptions on self-neglect.

### **Barriers and Facilitators to Self-Neglect Intervention**

Just as little is known about self-neglect, the same is true for barriers and facilitators to self-neglect interventions. The barriers to a complete understanding of self-neglect also prevent effective interventions with this phenomenon. The most compelling barrier to intervention is the incomplete understanding of the phenomenon that continues despite the longevity of self-neglect research. Defining and identifying a concept precede intervening, so the absence of a well defined interpretation for self-neglect is the likely reason that no effective interventions for this phenomenon have been established. Overall, there is a significant lack of knowledge of self-neglect.

The general public is not fully aware of this phenomenon or the risks associated with it (NCPEA, 2008). Unless an individual has personally encountered self-neglect, they may never have heard of the phenomenon. Unfortunately, healthcare personnel also have a significant lack of knowledge of self-neglect (Halphen, Varas & Sadowsky, 2009) and may differ on their opinions of whether an individual is exhibiting self-neglect. Dissension of opinions on self-neglect greatly hamper nurses' reporting and intervention efforts.

In cases where elder self-neglect may seem evident, the nurse may have ethical questions that arise regarding whether to protect the client's autonomy or take steps to intervene to protect the client. The difference in state statutes (Daly & Jogerst, 2003; Stiegel & Klem, 2007) and lack of knowledge of the laws surrounding elder mistreatment (Schmeidel et al., 2012) only add to this confusion. The court system is ultimately responsible for making decisions about the competence of an individual (Halphen et al.,

2009; Mauk, 2011), and clinicians may worry that intervening with these cases may be an unwelcome intrusion (Halphen et al., 2009). Additionally, making judgments regarding competency do not fall within the scope of practice for nurses (Lauder et al., 2006; Mauk, 2011), and therefore, nurses may be more hesitant to intervene when the client does not have obvious physical, cognitive or emotional issues that negate the ability to care for self. The lack of a clearly detected interference for self-care may lead the nurse to deduce that self-neglect behaviors are a conscious choice of the individual.

Nursing is also a trusted profession (ANA, 2012), and home health nurses especially develop a rapport with their clients as a single nurse is assigned to manage the client throughout their home health admission. The nurse may feel hesitant to report and intervene for fear of damaging the trusting relationship that is key to effective care provision. Further, nurses are taught in the beginning semesters of nursing education to protect the client's autonomy (Mauk, 2011) and to ensure personal values do not play into judgments about clients and their care. Inclusion of core ethical principles is part of any nursing education and nurses who encounter self-neglect often struggle with questions of autonomy versus beneficence. The lack of understanding of self-neglect may serve as validation of their questions regarding intervening.

Facilitators for intervening with self-neglect are inherent in the code of ethics for nurses. Provision three of the Nurses' Code of Ethics compels the nurse to be the advocate for their client and to protect the health and safety of the client along with protecting client rights (ANA, 2001). Protection of the client's right to privacy has been

identified as one concept that may interfere with a more collaborative approach (Snowdon & Halliday, 2009).

Nurses are educated to perform comprehensive client assessments (Ignatavicius & Workman, 2013; Jarvis, 2008; Lewis, Dirksen, Heitkemper, Bucher & Camera, 2011; Potter & Perry, 2011; Potter, Perry, 2013). For nurses employed in the home health arena this includes assessing home safety and the presence of adequate resources. Nurses are also adept at using screening tools such as the Mini Mental State Exam (Ashford, 2006) and the Geriatric Depression Scale (Kurlowicz & Greenberg, 2007) to detect changes in a client's mental or cognitive status that may indicate impending problems. The use of screening tools, such as the SSS (Kelly, Dyer et al., 2008) may also facilitate the process of assessment and intervention for self-neglect. Educating healthcare personnel, especially nurses who work in home health may be a great facilitator for intervening in self-neglect. Unfortunately, not enough is currently known about nurses' perspectives of self-neglect to develop education focused on self-neglect.

### **Importance of Nursing Research- Significance to Nursing**

Nurses constitute the largest group of healthcare personnel and serve a front line position in assessment of self-neglect where it is most evident, in the home. In spite of this, nurses' voices are virtually silent in the science of self-neglect as they have been relatively excluded in self-neglect research. In almost 60 years of research on self-neglect, only three studies have included nurses (Adams & Johnson, 1998; Ernst & Smith, 2012; Lauder et al., 2006). Those studies have yielded valuable information, but there remains an inexcusable and perplexing dearth of information regarding nurses and

self-neglect. Including nurses in developing the body of knowledge for this intricate and alarming phenomenon should strengthen the ability to understand the phenomenon, inform public policy decisions, and ultimately improve the care for those impacted by self-neglect. Growing numbers of elderly coupled with the significant consequences of self-neglect and increasing costs of healthcare make this research imperative at this juncture.

### **Theoretical Views on Self-Neglect**

Levine's Conservation Model (Figure 1.1) provided the guiding framework for exploring nursing perceptions of self-neglect and understanding the data that were revealed. This conceptual model of nursing care is comprised of four principles that together function to ensure wholeness in an individual. Use of this model was expected to be of great value in understanding self-neglect which is a process, or set of symptoms that threatens the ability of the individual to maintain his or her integrity, as well as the individual's ability to function as a whole being. For the purposes of this study, wholeness is used synonymously with physical, psychological and social well-being. As Levine (1966) proposed, nurses must intervene on behalf of individuals unable to maintain their integrity or wholeness; therefore, this researcher proposed that understanding the perspectives of nurses who care for clients who experience alterations in their wholeness such as with self-neglect is important. The principles of this model include the conservation of energy, structural integrity, personal integrity, and social integrity.



Conservation of energy is important to nursing and to the study of self-neglect as it is through expenditure of energy that an individual conducts the activities necessary to provide for their personal needs and safety. Consuming adequate food and drink is important for the synthesis of energy to expend on activities to appropriately care for self. Energy conservation is a balance of intake and expenditure. Without this balance the individual will not be whole and an unequal distribution will occur, which may be the case in clients who self-neglect. While nutritional deficits have been identified in individuals who self-neglect (Adams & Johnson, 1998; Aung et al., 2006; Bray et al., 2011; Ernst & Smith, 2011) it is unclear at this time whether the nutritional deficits lead to the lack of self-care or whether individuals who self-neglect do not consume adequate calories and nutritional value to meet their energy expenditure; therefore nutritional deficits occur.

The second principle in the model of conservation is the principle of structural integrity. Structural integrity was described by Levine (1973) as the “process of healing” (p. 15), with healing being necessary for adequate physiological function. Conservation of energy must be intact for healing to occur. Levine (1973) stated that humans learn from an early age to have faith and trust in their ability to heal. Individuals who self-neglect have reported having a sense of abandonment and betrayal that leads to a sense of mistrust (Bozinovski, 2000). This researcher questions whether this sense of mistrust could equate to a lack of faith in the individual for healing that may result in a downward spiral of apathy, depression, and a lack of attention to personal needs. However, there is no research on self-neglect to date framed with Levine’s model and consequently, not

enough knowledge to make that assumption. Impairment in structural integrity has however been found in individuals who self-neglect. Types of impairment in structural integrity found in individuals who self-neglect have included poor cardiovascular health (Ernst & Smith, 2011), cardiovascular degeneration (Macmillan & Shaw, 1966), gangrene (Macmillan & Shaw, 1966), tooth decay and the associated pain from that decay (Choi et al., 2009), and even increased risk of death (Dong, Simon, Beck et al., 2010; Dong, Simon, Mendes de Leon, Fulmer et al., 2009). There is no evidence that these impairments in structural integrity are resultant from self-neglect, only that they are correlated with self-neglect. With severe impairment of structural integrity that is associated with self-neglect, individuals are at risk of impaired personal integrity as well.

The third principle of conservation is that of personal integrity. Levine (1973) described personal integrity as the sense of self that each individual develops, the self-identity of an individual. Self-identity evolves over a lifetime as the individual adapts to changing life circumstances and strives to maintain continuity in their life and a sense of individualism (Bozinovski, 2000). Personal integrity entails how an individual views him or herself. Levine (1973) described how an individual's self-identity is challenged when illness occurs, especially if this illness is severe enough to lead to dependency on others for meeting needs that would normally be met independently. An interesting concept in this principle is that of protection of privacy for the individual. However, nurses have most often interpreted protection of the individual's privacy as the protection of their physical person and not protection of the individual's self-concept, which may be more important. Bozinovski's (2000) grounded theory research on self-neglect found

that one of the most important factors to individuals who self-neglect was “preserving and protecting identity and maintaining the style and type of control with which they are comfortable” (p. 52). The principle of personal integrity may be of great importance to an individual who self-neglects and who may view professional intervention as a threat to their ability to maintain that personal integrity or self-identity.

The final principle in the conservation model is that of social integrity. Levine (1973) assigned such high priority to social integrity that she proposed “individual life has meaning only in the context of social life” (p. 17). Additionally, Levine (1973) offered that wholeness is only recognized when compared within a social context of relationships. Social integrity could be viewed as an extension of the individual’s personal integrity (identity) and integrally tied to a sense of self. Those who self-neglect often live alone (Burnett, Regev et al., 2006; Culberson et al., 2011; MacMillan & Shaw, 1966; Payne & Gainey, 2005), or withdraw socially (Burnett, Coverdale et al., 2006; Burnett, Regev et al., 2006). Addressing the individual’s role as a social being is important for nurses to assist the self-neglector with social integrity, which is an essential component of the individual’s identity.

The conservation model was not tested with this study or used to explain the perspectives nurses have of self-neglect, but instead provided the lens through which the data were explored and the results of the study were understood. Principles of conservation are intuitive in nursing care as the nurse assists the client to balance their energy (energy conservation) through adequate nutritional intake and energy expenditure back to a state of health (structural integrity), focused on the individual’s sense of self

(personal integrity). The nurse recognizes that individuals exist in a social context and that healthy aging includes the ability to interact socially (social integrity). Nurses are intertwined with the individual who is the recipient of nursing care as the nurse must develop a relationship with his or her client in order to identify needed interventions, maximize the impact of nursing interventions, and be able to effectively evaluate nursing interventions. Using this holistic approach will protect the client's personal integrity.

Wholeness may be viewed as the antithesis of self-neglect. Wholeness is complex and involves ensuring the four conservation principles. Protection of the four conservation principles should allow the nurse to assist the client in achieving or maintaining the delicate sense of balance that is considered wholeness and therefore a state of physical and psychological health and independence.

As a nursing model, Levine's conservation model provided an appropriate model to explore self-neglect and to understand perceptions of nurses who care for clients with self-neglect.

### **Summary**

“There is a lack of consistency in how elder abuse is defined, used, valued, and applied both within the field of adult protective services (APS) and between APS and health care professions” (Daly & Jogerst, 2003, p. 40) and the same may be true for self-neglect. Home health nurses are the sector of health care most likely to encounter self-neglect as it is most evident in the home. However, evidence of how nurses define and identify self-neglect and how they apply that information in the care of clients that self-neglect is currently unknown.

Developing self-neglect knowledge is important to provide comprehensive care for the fastest growing segment of the United States (U.S.) population that is most often affected by self-neglect, the older adult. The healthcare community must be aware of the risks that self-neglect pose and seek to understand this phenomenon in order to intervene. Yet, it is important to be prudent in the assessment of the features of self-neglect in order to protect the individual's personal rights to privacy and autonomy. Just as compelling, is the need to develop a trajectory for self-neglect so that intervening prior to the occurrence of negative health consequences becomes possible. Because the risks of self-neglect are severe, research focusing on this phenomenon is paramount.

It is important to differentiate between individuals who are unable to take the steps needed to care for self and those that seem able but yet unwilling. This study focused on those individuals perceived as unwilling rather than unable to take the steps needed to provide for their personal needs. Therefore, nurses' perceptions of self-neglect in individuals unable to meet their basic needs, such as those with an acute injury or a mental diagnosis such as psychosis was not the focus of this study. Instead, using Levine's conservation model, specifically the four principles of energy conservation, structural integrity, personal integrity and social integrity, the focus of this study was on the perceptions of nurses who encounter home health patients with the attributes that have been described as indicative of self-neglect.

## CHAPTER III

### METHODS

#### **Introduction**

This chapter focuses on the methodology for this study of nurses' perceptions of elder self-neglect. The research design is discussed, along with the sampling process and steps taken to ensure protection of the study participants. The data analysis plan is discussed as well as steps to ensure the rigor of the research and credibility of the findings. The purpose of this study was to obtain a better understanding of elder self-neglect from the perspective of the nurse who encounters self-neglect in its natural setting, the home of the elder individual.

#### **Research Design**

This qualitative study utilized a naturalistic, descriptive design to gain an understanding of the perspectives of home health nurses who report having encountered self-neglect. Descriptive research is needed when little is known about a phenomenon (Nieswiadomy, 2012). Self-neglect has been discussed in professional literature for several decades; however, little attention has been given to the perspectives of nurses, specifically home health nurses who most often are the individuals who directly encounter self-neglect in their practice environments. Opportunities to describe a phenomenon and to gain meaning from the perspective of participants who experience

that phenomenon are important in knowledge development. With so little known about the perceptions that nurses have of elder self-neglect, a descriptive study was warranted.

Self-neglect does not result in the exact same experience or outcome for each individual affected. It is a complex phenomenon and best identified in the natural environment of the individual. In naturalistic inquiry design, the context is important (Lincoln & Guba, 1985). The same is true for self-neglect, as the phenomenon may not be evident outside of the individual's natural environment. Just as each individual with self-neglect may have different self-neglect experiences, it is important to recognize that each nurse who encounters self-neglect may view it differently. Self-neglect may carry a different "truth" for each individual or caregiver, and the nurse's reaction to self-neglect may be dependent upon the context of the situation. Understanding these different views is important to further develop the science of self-neglect.

Lincoln and Guba (1985) proposed that a problem goes beyond questions in that a problem leads to: (a) confusion in those who encounter it, (b) unwelcome outcomes for those who experience it, and (c) questions of how to respond to it. Self-neglect meets all three of those criteria and presents an area ripe for nursing research. Constructing knowledge on this poorly understood phenomenon requires an approach that extends beyond simply asking a question, logging an answer, and quantifying the types of behaviors seen. In spite of what is known about self-neglect, it continues to confuse those who encounter it and beget questions of ethical uncertainty in professionals charged with resolving the issues resulting from self-neglect. Thus, self-neglect lacks conception, a clear action for resolution, and may ethically affect those who encounter it. To develop

an understanding of this perplexing phenomenon, researchers must seek to understand self-neglect as experienced by various individuals, including healthcare providers who directly encounter self-neglect: nurses.

Qualitative researchers use an approach to find meaning in data rather than cause and effect to predict or control (Denzin & Lincoln, 1994; Lincoln & Guba, 1985). This qualitative study relied on a constructivist paradigm to develop knowledge of self-neglect through the lens of the nurse who directly encounters this phenomenon. Currently, nursing perspectives of self-neglect constitutes a gap in the science of self-neglect. Developing this knowledge should add depth and breadth to the science of self-neglect. A naturalistic approach to inquiry using in-depth interviews provided the vehicle to gain access to the nurses' emic view of self-neglect. With the naturalistic approach, the researcher is an important part of the research process and the findings. Interpretation of the data and construction of knowledge from those data are the purview of the researcher and based on an in-depth interaction between the researcher and the participant. With naturalistic inquiry, the researcher becomes the research instrument (Lincoln & Guba, 1985) by gathering data and seeking meaning in those data from the participant's perspective. Interviews are often used in the collection of qualitative data as they provide opportunities to gain rich information from the research participant regarding his or her particular experiences. Qualitative researchers must be keenly aware of the research process and recognize when to allow the study participant to openly share his or her experiences, when to interject to seek clarification, and when to ask for elaboration on areas of particular interest. The research process becomes an intricate interplay of the



researcher, who seeks meaning in the information, and the participant, who shares his or her experiences from their personal vantage point. Naturalistic inquiry was appropriate for this study of nurses' perceptions of elder self-neglect because the phenomenon is most evident in its natural context, the home environment. Additionally, with so little known about the phenomenon from the nurses' perspective an approach that allowed the participants' experiences to emerge through the recalling of these encounters was well suited.

### **Research Sample**

A purposive snowball sampling design was utilized for this study. This non-probability sampling method was chosen for the study because it is appropriate for exploring phenomenon that affects specific groups (Nieswiadomy, 2012). This sampling technique allowed for choosing only those nurses who had encountered elder self-neglect in their home health practice. The reality of elder self-neglect for nurses who have first hand experiences with these clients is important to the study of this phenomenon and important in developing a comprehensive understanding of the phenomenon.

Several health care agencies including hospitals, home health, and hospice agencies were contacted as well as professional organizations for home health nurses. Agencies that agreed to send information to their nursing staff provided letters of support for this present study (See Appendix A) The principal investigator (PI) informed the nurse supervisors of the study and requested that information on the study be shared with the nursing staff in their agency via electronic mail and/or by posting the study flyer that included possible signs of elder-self-neglect. The sample for this study was from a mid-

Atlantic state that is primarily rural. The PI's name and telephone number along with electronic mail address was provided to the initial contact for the agencies. Inclusion criteria were registered nurses who: (a) were licensed to practice in the study region, (b) self-identified as having at least two years of experience in home health nursing, and (c) self-reported having directly encountered elder clients who they considered as self-neglecting. Exclusion criteria consisted of disciplines other than registered nurses, and those nurses without home health experience.

The sample participants for this study (n=16) contacted the researcher directly via electronic mail or by telephone. All participants were chosen for the study based on meeting the inclusion criteria and their willingness to provide their experiences. The small sample size allowed the PI to explore the rich information from the participants' experiences. With qualitative research sample size is not as important as reaching data saturation. Data saturation is described as the point in the study that data become redundant, with repetitive data revealed (Denzin & Lincoln, 1994; Lincoln & Guba, 1985; Nieswiadomy, 2012). When data become repetitive, it can be viewed as validation of the data that were previously collected (Denzin & Lincoln, 1994).

### **Data Collection Procedure**

Semi-structured interviews were employed for data collection. Using a semi-structured interview format is important in gaining meaning. A more structured interview would help the PI to identify specific information. In this case, however, little was known about home health nurses' perceptions of self-neglect, and therefore the

participant was relied upon to provide information that gave meaning to their experiences (Lincoln & Guba, 1985).

Use of self as the research instrument is required in qualitative research (Lincoln & Guba, 1985; Munhall, 2007). Credibility of the study results can be altered however, if the researcher does not reflect on his or her own experiences and biases (Munhall, 2007), as well as their relative closeness to the research participants and data (Sandelowski, 1986). Qualitative interviewers who have particular experiences involving the phenomenon of study may benefit from reflecting on their personal experiences to “adopt a perspective of unknowing” . . . “to the extent possible” (Munhall, 2007, p. 170) to be better prepared to discriminate the experiences of the participant from the researcher’s own experiences (Munhall, 2007). This was the case with this PI. As a former home health nurse, the PI had encountered cases of elder self-neglect, although the phenomenon was not identified by name due to lack of knowledge of the phenomenon. In this study, vigilance was used in searching for meaning in the participant’s data rather than drawing correlations between the participant’s experiences and the PI’s. Clarifying questions were asked during the interviews when the participant’s ideas were unclear, or when elaboration on an idea was desired.

Qualitative research is based on the axiom that there are multiple realities (Denzin & Lincoln, 1994; Lincoln & Guba, 1985). Yet, to maintain some consistency in the research process, specific open-ended questions were included in the interview, allowing each participant to answer the questions based on his or her reality. Interviews were prefaced with an initial global statement or grand tour question: “(Can you) Tell me

about a time that you went into a patient's home to deliver care and felt like the client was self-neglecting." Each participant was then be encouraged to share information about him or herself in the role of the home health nurse and to articulate what they envision when they hear the term self-neglect. Each participant was advised they were chosen for the study because they identified themselves as someone who had encountered elder self-neglect. Additionally, they were informed that little is known about the perspectives that nurses have of self-neglect, and because home health nurses are often the ones who see self-neglect, their personal perspectives were important. Further, the PI communicated to the participants that their perspectives were needed to develop the science of this misunderstood phenomenon.

An important step in collecting data is setting the tone for the interview as a relaxed atmosphere to facilitate sharing of information. The semi-structured interview for this naturalistic, descriptive study framed the role of the PI and participant as peers (Lincoln & Guba, 1985). Once the tone was set for the interview, and the global question had been asked, probe questions or statements were employed to gain more specific information (See Appendix B). Interview questions asked of all participants included:

Q1: How do you define self-neglect?

Q2: Describe for me what a typical picture of self-neglect looks like.

Q3: Tell me about the factors that contribute to you deciding on a nursing intervention for self-neglect?

Q4: What are the facilitators and barriers to nursing intervention for self-neglect?

Interviews were audio-recorded with two digital recorders and transcribed into a Microsoft Word format. Additionally, field notes of the interviewer's personal feelings regarding the data shared and thoughts that might have influenced the interviewer's analyses of the data (Morse & Field, 1995) were taken. In addition to interview data, a demographic form was completed on each research participant. This form was developed by the PI for this study on nurses' perceptions of self-neglect (see Appendix C) and assisted in describing the participants by age, years of nursing experience, and type of nursing degree.

### **Issues of Data Quality**

Just as rigor is respected in quantitative research, it is also important to assure rigor in qualitative data collection. Because naturalistic inquiry focuses on constructing the truth of phenomenon as experienced by the participant, ensuring that the meaning of qualitative research is reflective of the true experience of the participant rather than the researcher becomes important in establishing rigor (Krefting, 1991; Lincoln & Guba, 1985) and thus, the credibility of the research. Additionally, qualitative research provides information about phenomena that is not possible through quantitative inquiry.

Developing the science of a phenomenon requires establishing depth and breadth in knowledge of a phenomenon making the use of qualitative inquiry equally as important as a quantitative approach. Establishing rigor in qualitative research is different than in quantitative, but equally as important to the credibility of the research.

Concepts used to decide the credibility of quantitative research cannot be directly applied to qualitative studies due to the different design of qualitative research.

Quantitative methods focus on control, manipulation, and prediction while qualitative methods focus on identifying meaning in data (Sandelowski, 1986). Concepts used to determine the worth of quantitative research target whether adequate controls are in place to trust the findings of the study and whether the findings of the study can be used to make predictions about other groups (Lincoln & Guba, 1985). Qualitative researchers are also concerned with establishing rigor for research (Lincoln & Guba, 1985), but rather than looking specifically at reliability and validity as used with quantitative research, the constructivist approach to knowledge development uses concepts of trustworthiness, transferability, dependability, confirmability, and authenticity (Denzin & Lincoln, 1994).

Trustworthiness serves as an overall term used to describe the worth or merit of naturalistic inquiry as a body and also the merit of the research findings (Lincoln & Guba, 1985). Establishing trustworthiness can be discussed in terms of truth value which is also known as credibility. Other measures of merit for naturalistic inquiry are applicability, consistency and neutrality (Lincoln & Guba, 1985).

Credibility refers to whether the truth or reality of a research participant is accurately reflected in the findings of the research as opposed to the researcher's idea of that reality (Lincoln & Guba, 1985; Sandelowski, 1986). Credibility is protected when the researcher establishes steps to ensure he or she has reflected on his or her own personal feelings and biases regarding the study topic and ensures that the participant's voice is the voice that is heard in the research findings, rather than a skewed form of the participant's voice that has been modified by the researcher. Credibility has been described as present when the research participants recognize their experiences in the

research findings or when individuals who have had the same experiences recognize the experience upon reading the research article (Sandelowski, 1986).

Applicability is also known as transferability and is another concept used to denote rigor in narrative inquiry. Applicability is similar to generalizability and is the ability of the researcher to have confidence that the research findings would apply to another group of individuals or to individuals in a different context (Lincoln & Guba, 1985). Because context is important in naturalistic inquiry, the ability to apply or transfer research findings to another group would require that the context be very similar if not the same.

Another check of rigor in naturalistic inquiry is consistency, and this concept is similar to reliability in quantitative studies. Consistency refers to the ability of a researcher to replicate the study with either the same participants in the same context or with very similar participants in a similar context (Lincoln & Guba, 1985). However, with naturalistic inquiry and with qualitative study in general, focus is given to the multiple realities in the human experience rather than replication (Morse & Field, 1995).

Finally, neutrality is the naturalist inquirer's form of objectivity (Lincoln & Guba, 1985). It is important to note that objectivity is value free and is therefore applicable to quantitative study rather than qualitative. Naturalistic inquiry on the other hand is value laden or value bound (Lincoln & Guba, 1985), and as such, objectivity is not plausible. Neutrality is more concerned with the degree that the findings of naturalistic inquiry are the actual voices of the participants in the context of study rather than a representation of

the bias' or values of the researcher (Lincoln & Guba, 1985); it is then the degree that the research process as well as the research findings are free from bias (Sandelowski, 1986).

### **Data Analyses and Synthesis**

Glaser and Strauss developed the constant comparison method in 1967 as a method for grounded theory research (Lincoln & Guba, 1985). The purpose of this proposed research was not to develop a theory for self-neglect; however, the constant comparison method as described by Lincoln and Guba (1985) proved to be an effective tool for analyzing data revealed in this study.

Once the data were collected and transcribed into an electronic format they were explored for incidents. An incident is described as the smallest unit of data or information that has some meaning or provides an understanding (Lincoln & Guba, 1985). Once the transcripts were divided into incidents, the incidents were then explored for placement into broad, general categories. It is important for the researcher to ensure that the category assigned, or meaning of the incidents in a category is consistent, and this is constantly checked through comparison. During this process the PI compared the incidents for similarities in categories assigned and meanings and differences. When there were differences then either categories or meanings were refined. This process is labeled constant comparison and is germane to qualitative data analysis. As incidents were assigned to a category they were compared with incidents previously placed in that category as well as with incidents placed in other categories for best fit or placement.

As the process of placing incidents into categories continued the properties of the categories begin to emerge, making rules for inclusion in the category more evident and



lending unique meaning to each category. This was the second phase of the constant comparison method of analysis. Through continued constant comparison some incidents were moved to other categories that seemed to be a better fit. In this second phase of analysis relationships among the incidents became more evident, and a clearer understanding of the data emerged, thus beginning construction of meaning from previously distinct incidents (Lincoln & Guba, 1985).

The third phase of data analysis using constant comparison continued the construction of meaning as the researcher began to identify relationships between categories. As relationships became apparent categories were moved into overall themes. Parsimony becomes important for a comprehensive understanding to be revealed (Lincoln & Guba, 1985) and incident placement into the appropriate category is vital for parsimony. This third phase quickly segued into the final phase of identifying the constructed meaning of the collected data and translating that into the research findings.

Use of the constant comparison method provided a useful method of data analysis for nurses' perceptions of self-neglect. Through this method the data collected were constantly explored and compared with other data for similarities and differences. Because so little is currently known about nurses' perceptions of self-neglect and their responses to this phenomenon, identifying meaning in these data provides a voice for the nursing profession that heretofore has been virtually silent in the science of self-neglect. Identifying nurse perceptions of elder self-neglect should provide a foundation on which to build future studies and enhance nursing education on this topic.

### **Protection of Human Subjects**

Steps were taken to ensure protection for the participants of this study. Approval for this research was obtained through the Institutional Review Board of The University of North Carolina at Greensboro before any data collection occurred. The agency contacts and the nurses were assured that no information would be sought that would violate the principles set forth in the Health Insurance Portability and Accountability Act (HIPAA).

Voluntary consent to participate in the study was obtained from each participant following explanation of the study and prior to any data collection (See Appendix D). Efforts to protect the confidentiality of participants included applying a code for each participant to identify their individual data, applying only the identifying code to the data collection documents, and keeping the list of participants and their associated numerical code in a separate locked location. Data collected were audio-recorded and any pertinent notes during interviews were also digitally recorded and transcribed, or recorded as written notes and transcribed. All data were transcribed into a Microsoft Word document and maintained in a password-protected environment. Transcribed data are identified by code only. Audio files and initial field notes are maintained in a locked file cabinet separate from the transcribed notes and separate from the coding key.

Participants were informed of the minimal risks of the study during provision of informed consent to participate. It was anticipated that a possible risk of participation in this study might be a sense of anxiety in recalling experiences with elder self-neglect. The right to withdraw from the study was provided at all times during the study.

## **Limitations**

Potential limitations of this study are inherent in the sample plan. Utilizing a purposive sample allowed the PI to choose participants that had the experience with self-neglect that was key to this study. However, utilizing non-probability sampling designs does not provide for rigor in the sampling method, and may result in an underrepresentation of some element of nurses' perspectives of self-neglect (Nieswiadomy, 2012). Additionally, because these data were collected in a circumscribed area, it is conceivable that nurses in different geographical locations or settings may have different ideas or *truth* [emphasis added] regarding elder self-neglect. However, this is one of the first studies of nurse perspectives of self-neglect in the elderly and should provide foundational knowledge of what nurses currently know about elder self-neglect, how nurses make care decisions for these clients and what barriers nurses encounter in providing further care for these elders who self-neglect.

## **Summary**

This chapter provided a review of the methods that were employed for this study. A discussion of the naturalistic, descriptive method that was utilized was provided. Data collection methods were detailed in this chapter along with the sampling plan. Steps to ensure the quality of the study data were delineated, as well as plans for the protection of human subjects. A detailed description of the constant comparison method of data analysis as it was utilized was also discussed. Finally, possible limitations of the study were discussed in this chapter.

## CHAPTER IV

### RESEARCH FINDINGS

#### **Introduction**

Home health nurses often encounter elderly clients who neglect even their most basic needs. Yet, these nurses are challenged to develop an effective plan of care for these clients because there is no common understanding of this phenomenon, no known cause or treatment for elder self-neglect, and little to no specific educational offerings on this topic for nurses who may encounter these situations in professional practice. Additionally, very little is known about how nurses perceive these cases or currently intervene to help these clients. Therefore, the purpose of this study was to explore the perceptions experienced home health nurses have of elder self-neglect. Additionally, the study was designed to determine what steps home health nurses take to intervene with self-neglect. Five research questions were used to elicit this information with appropriate probe questions to illicit raw data to answer the research questions.

1. What are home health nurse's perceptions on self-neglect?
2. How do home health nurses identify self-neglect?
3. What actions do home health nurses employ to intervene with self-neglect?
4. What are the facilitators and barriers to identifying self-neglect for home health nurses?

5. What are the facilitators and barriers to intervening with self-neglect for home health nurses?

This chapter will describe the findings of the study. A description of the sample is also provided. Interview data and emerging themes will be presented as they relate to the research questions.

### **Sample Characteristics**

Seventeen potential participants contacted the principal investigator (PI) for further information regarding the study after seeing the study flyer or receiving correspondence from their employer or professional organization. Sixteen participants were interviewed between July 11, 2013 and August 6, 2013. One potential participant did not arrive at the pre-arranged time and location of the planned interview and did not contact the PI further. Six additional potential participants contacted the PI after data saturation was reached and no further interviews were necessary for this study.

Interviews were conducted face-to-face and/or through telephone correspondence. The interviews ranged from 27.22 minutes to 57.37 minutes with a mean interview time of 39.94 minutes. Each participant was provided a \$20.00 gift card incentive. The interviews were digitally recorded and transcribed verbatim. The PI compared all transcripts to the digital recordings to confirm accuracy, and corrections were made as necessary. To protect the participant's confidentiality, pseudonyms were assigned alphabetically in order of the sequence of the interview. Each participant's pseudonym was used for reporting purposes.

A demographic form was designed by the PI for this study and used to collect information to describe this sample (See Table 1).

Table 1

## Demographic Characteristics of the Sample (N=16)

Variable	<i>M (SD)</i>	Median	Frequency	Percentage (%)
Age	45.9 (7.54)	45.0		
31-40			5	31.25
41-50			8	50.00
51-60			2	12.50
61+			1	6.25
Race/Ethnicity				
African-			1	6.25
American			14	87.50
Caucasian			1	6.25
Other				
Nursing Education				
Diploma			3	18.75
Associate degree			7	43.75
Bachelor of Science			6	37.50
Years as RN	20.3 (8.41)	18.5		
2-10			2	12.50
11-20			7	43.75
21-30			6	37.50
31-40			0	0.00
42-50			1	6.25

*M* = Mean; *SD* = Standard Deviation

The average age of nurses in this study was 46 years, consistent with the mean age of registered nurses currently reported at 45 years by the United States Department of Labor

[USDL] Bureau of Labor Statistics (2013). Nurse participants were experienced registered nurses (RN's) with an average of 20.28 years of professional nursing experience (range = 5 - 41 years). The median time in nursing practice for these study participants was 18.5 years. Almost half of the nurses ( $n=7$ ) were educated at the associate degree level, while another six held baccalaureate degrees in nursing. Three of the participants were diploma graduates. Interestingly, the only participant to report that self-neglect was taught in their educational program, and that this education included signs and symptoms of self-neglect, and guidance on when to contact adult protective services was a diploma graduate. This was a homogenous sample that was predominately Caucasian ( $n=14$ ), with one participant self-reporting as African-American and one participant self-reporting Caribbean and Thai descent.

Participants of this study were experienced home health nurses (see Table 2) with a mean (with standard deviation in parentheses) of 11.43 (6.71) years of experience in home health nursing (range = 2 - 23 years). Each participant reported at least one year of nursing experience prior to entering home health nursing, with mean years of practice prior to beginning home health nursing of 9.09 ( $SD = 5.68$ ) years. The median number of years in home health practice was nine years. The majority of this sample (93.75%) held full-time positions in home health nursing and over half (56.25%) practiced in rural areas.

Most nurses in this study (75%) reported that elder self-neglect was not taught in their nursing education programs. Four participants reported that self-neglect was taught during their nursing education. However, only one nurse reported that she was taught

signs and symptoms used to identify self-neglect and that reporting to adult protective services might be needed.

Table 2

## Home Health Practice Demographics

Variable	<i>M (SD)</i>	Median	Frequency	Percentage (%)
Employment status in Home Health				
Full-time			15	93.75
Part-time			1	6.25
Area of Practice				
Rural			9	56.25
Urban			4	25.00
Combination			3	18.75
Years as Home Health Nurse				
	11.43 (6.71)	9.0		
1-10			9	56.25
11-20			4	25.00
21-30			3	18.75
Years of Nursing Experience Before Home Health				
	9.09 (5.68)	18.5		
1-10			9	56.25
11-20			7	43.75
21-30			0	0.00

*M* = Mean; *SD* = Standard Deviation



Another nurse reported that her nursing education included only very basic information on self-neglect, while two other participants reported self-neglect was taught as non-compliance or a symptom associated with mental health disorders such as dementia or depression. None of the participants could identify any past continuing education opportunities for learning about elder self-neglect. Fifteen of the 16 participants reported they had never heard of a workshop focused on elder self-neglect. One nurse reported that she could not remember whether she had heard of a workshop for learning specifically about elder self-neglect.

The majority of these nurse participants (81.25%) reported using screening tools for home health assessments such as the Geriatric Depression scale and the Medicare Outcome and Assessment Information Set (OASIS). All of these nurses had encountered elder self-neglect in practice as a home health nurse, but none reported having used a screening tool for self-neglect. Additionally, 12 of the 16 participants reported there was no protocol for identifying or intervening with elder self-neglect at their home health agencies. Of the four participants who did report protocols, the steps taken for self-neglect included: a) notifying the director of the home health agency and adult protective services as needed, b) notifying the social worker of the agency and adult protective services as needed, c) holding a high risk conference call with the agency social worker along with other disciplines and agencies as needed, and d) screening clients on admission to the agency for depression or mental status compromise.

### **Reason for Home Health Referrals**

Most often, home health services are ordered for clients when they are discharged from the hospital following an acute episode by the physician in charge of the client's medical care. Study participants related clients being referred for services following acute episodes or exacerbations of heart failure and diabetes. Other clients were referred for medication management and many of them for wound care or teaching about wound care. Nurses also reported patients being referred for reasons more obscure such as generalized weakness, assessment of home health needs, or post hospitalization teaching. None of the study participants reported clients being referred for home health services due to self-neglect, or even a diagnosis of self-neglect to accompany physician orders for other reasons. Instead, self-neglect was identified by home health nurses after entering the home and observing the client in their regular home environment.

### **Content Analysis**

Home health nurses' perceptions became evident through the rich experiences recounted during the interviews. Initially, content analyses of the interview transcripts were conducted. This process consisted of reading and rereading each transcript to identify specific terms used by the participants to describe both their thoughts on elder self-neglect and their experiences as nurses caring for these clients. Raw data from each transcript were thoroughly examined multiple times for these key statements. The PI made notes on these key statements in order to identify possible data units from the "natural language" (Lincoln & Guba, 1985), of the participants. Each transcript was marked to highlight significant statements made by each participant. As each interview

was analyzed individually for content, similar terms used across the interviews became evident. These similar terms were used to develop the self-neglect codebook definitions (see Appendix E). Codebook definitions were developed to ensure consistency with content analysis for the PI as well as for checking coding accuracy between coders. Once the codebook was developed, both the PI and the PI's faculty advisor analyzed the first three interviews for content, and to check the accuracy of the codebook. This was accomplished by marking each sheet of the transcript for significant statements exemplifying the definitions identified in the self-neglect codebook. The outcome of the content analyses conducted by the PI and the faculty advisor were compared. Any differences were discussed, and the codebook was subsequently refined. This process continued until 100% agreement was reached between the two coders.

Significant statements were placed into broad categories based on similarities and differences in the statements. Participants' statements were placed into categories on a tool designed by the PI for data management (See Appendix F). Microsoft Excel was used to design the data management tool. These broad categories were distinct topics and became the initial codes used for further content analysis and constant comparison. These initial codes included: a) how the nurse participants described individuals who self-neglected, b) descriptions of the environment of the self-neglector, c) behaviors demonstrated by the clients who self-neglect, and d) problems that brought the clients into the healthcare system and ultimately into the home health process. Additionally, nurses' responses to encountering and interacting with the client who self-neglects was another initial code along with actions taken by the nurses to validate what they were

seeing, to make decisions for the care of the self-neglecting client and to mobilize the resources needed for that care. Finally, facilitators and barriers to self-neglect intervention were other codes evident during the content analysis process. With the initial codes identified, specific definitions were designed based on the participants' words and expressed thoughts. To ensure credibility of the data, the PI was careful to bracket her own perceptions during analysis to ensure the information from the published literature and the PI's own experiences with elder self-neglect would not contaminate the data from this study. The PI took specific steps to thoroughly examine and reexamine interview data to determine whether the topics and codes identified were evident from the interview data. It was important to ensure the codes were a reflection of the expressed ideas and articulated experiences of the research participants rather than any preconceived ideas based on past evidence (Morse & Field, 1995) or the PI's own experiences. Once content analysis was completed for all interviews, the constant comparison method was employed to identify emerging categories and themes.

### **Constant Comparison**

With the interview data deconstructed through the process of content analysis, constant comparison was employed to identify major categories present in these interviews. During this process, the PI became immersed in these data, comparing concepts evident in significant statements made. Comparisons were made within the interviews and across interviews. Raw interview data in each category were compared and further explored resulting in integrating and renaming categories as similarities and differences of the raw data were explored. Statements were also reallocated to other

categories for better fit when applicable. Thus, perceptions of self-neglect held by these home health nurses were constructed through an inductive process with constant comparison of the raw data and data categories.

Themes emerged from categories identified from the statements made by these home health nurses regarding elder self-neglect. Five major themes emerged for home health nurse perceptions of self-neglect; a) armor, b) psychological derivation, c) seclusion, d) nonconformity with self-care conventions, and e) nurses' responses (see Table 3). Raw data were moved to other categories when indicated through constant comparison. Additionally, themes, categories and raw data were compared both within the interviews and across the interviews.

In addition to the themes that emerged from the data, actions taken by home health nurses to intervene with clients who self-neglect, as well as barriers and facilitators to interventions for self-neglect were evident. Comparisons were made of these data as well and similarities across participants were evident.

### **Theme One- Armor**

All nurses interviewed were able to express characteristics used to identify clients who self-neglect. Evident in the interviews was a perception held by nurses that individuals who self-neglect exhibit thought patterns and actions that serve to "shield" the self-neglector: a type of armor to protect that individual. Three categories were identified for armor: a) it's my normal, b) control of territory, and c) emotion.

Table 3

Themes

<b>Themes</b>	<b>Categories</b>	<b>Raw Data</b>
Armor	It's my normal	Has become their normal Just a normal state of being
	Control of territory	Territorial Viewed us as an invasion
	Emotion	Belligerent Withdrawn
Psychological derivation	Undiagnosed mental illness	No diagnosis of mental illness Emotionally walling off
	Depression	Hopeless They don't care
	Dementia	Demented states Sometimes it's dementia
Seclusion	Isolation by choice	They push people away They shut folks out
	Isolation by others	Children have alienated them Got excommunicated
	Isolation by circumstances	Family moved away No support system
Nonconformity with Self-Care Conventions	Medication	No concerns for her medication Refusing to take their medication
	Hygiene	Unkempt and dirty Very disheveled, very unkempt
	Nutrition	Poor nutrition They are not eating
	Environment	House is absolutely filthy Hugely cluttered
Nurses' responses	Emotional responses	Feel like I left them in a lurch Go home feeling guilty
	Action responses	Take stuff out of my own cupboard Adult protective service referral

**It's my normal.**

One of the significant statements that reoccurred throughout the interviews related to self-neglect becoming a normal way of life for the individual. Nurses related perceiving that individuals who self-neglect conduct themselves as if their behaviors and the state of their surroundings are normally accepted practices, and thus, do not give any indication that what is observed by others may seem out of the ordinary. Statements supported this category. For example, some nurses noted how long this behavior had occurred. Beth stated, "Well, I think after someone lives like that for so long it becomes their normal. And they just don't see it as being odd, or out of the ordinary." Ella related the same experience, "They've just done things their way so long." Other nurses noted how their patients acted as if this behavior was normal for them. For example, Fran stated, "And that is perfectly normal for them. For those people it's just a normal state of being." Jan recalled a situation where the situation she observed in the home was not anything that she would consider even close to normal, yet the client gave no indication they believed otherwise.

And then sometimes you'll go in and you can tell right off the bat that because they got roaches everywhere and they got feces of their dogs and urine and everything everywhere, that they don't care. That's their life, that's how they live, and that's what's normal to them.

These articulated experiences clearly support "it's my normal" as a strong category.

### **Control of territory.**

Another behavioral component identified by home health nurses was that individuals who self-neglect perceive controlling their territory as part of their armor. This was evident in significant statements heard across many interviews, and suggests that nurses recognize control is important to these individuals. For example, Ella stated, “They just, I think maybe viewed us as an invasion into their home, their privacy, their independence. It was you know, control, independence and control [that these individuals valued].” Hal also believed control was important to these clients stating, “I mean, I could see maybe control issues.” This was echoed in Ila’s words as well, “I think of some of my patients where it’s a control issue. [The patients state] I’m in my right mind and I’m going to do what I want to do. It is a control issue.”

One way these individuals control their territory is by using anger. This was evident to home health nurses in the manner that these clients interacted with them and with others. For example, Ann stated, “She would cuss me out every time I came in there.” Ila’s recalled a client who would react to her family members with anger, “The son came in and tried to clean out the house and she became very angry and upset.” Jan stated sometimes clients demonstrate a lack of tolerance to others who do not agree with them, and react angrily. Jan recalled a patient who stated, “You know, you might not like the way I live here, but I have lived here for 40 years. This is me. This is my home, if you don’t like it you can just get out.” Other nurses just viewed the client’s behaviors as a means of control. Those clients demonstrated [a need for] control by sending either a



verbal or non-verbal message indicating they didn't want others intruding into their domain. One nurse recalled a client who would not allow her access to the entire home. Dora stated, "There's just enough for a path to get from the living room to the, well she doesn't really let me get past the living room." Other nurses stated that some clients didn't want nurses coming to visit. Nina recalled, "They just don't want anybody in there." Pam recalled that clients may choose to allow some individuals in their home and not others; "...even if they allow me to come in there they may not allow someone else to come in because they start to feel like they are intruding on them."

### **Emotion.**

Home health nurses identified diverse emotional responses noted in elders who self-neglect. These emotional responses in individuals ranged from withdrawn or dispassionate, to irate and belligerent. Some nurses shared experiences where the clients seemed "disconnected." For example, Beth stated, "Some of them really just seem to be indifferent." Kay also related having the same experiences. She stated, "Sure, yeah, withdrawn would be the best global word for that. And folks often have reactions like well, you know very blasé, like slow and drawn out, like well I don't mind it here." Another nurse participant remembered going into client homes that she felt were in shambles, and yet the client reacted as if nothing was amiss. Nina stated, "They act like everything is fine. They act like life is going on as usual. And clearly you can tell everything's coming apart at the seams. And you know things are kind of falling apart around them." Still other nurses recalled more hostile reactions from clients. Ann stated "Well, and amazingly, sometimes even the patients are very belligerent.... It's their home

and they do not want to leave there. She would cuss me out every time I came in there.” Ella had experiences similar to Ann’s, recalling, “So, he became very belligerent with her [another nurse] and it was almost like he, he didn’t realize that he had a right to refuse our services.... We hate that, but that is their right.” Clients maintaining their routines was heard consistently across the interviews. Nurses related perceiving that some clients may have been in a pattern of this behavior for so long that it had become who they were, while others nurses used the term “control” and identified behaviors such as anger these clients use to maintain this control. These behaviors and the presentation of these clients and their environments served to “shield” the client, making armor an important theme in this study.

### **Theme Two- Psychological Derivation**

The second major theme was psychological derivation. Fourteen out of the sixteen nurse participants related pathological states as attempts to understand the behaviors exhibited by clients who self-neglect. By viewing the behaviors noted in elders who self-neglect in the context of psychological or cognitive challenges, the nurses could attempt to understand steps they needed to take to intervene. Three main categories for this theme emerged from the interviews: a) undiagnosed mental illness, b) depression, and c) dementia.

#### **Undiagnosed mental illness.**

Undiagnosed or unidentified mental illness was a significant construct identified by nurses in these interviews. Undiagnosed mental illness was evident in statements made by study participants. The vast majority believed self-neglect was related to

undiagnosed mental illness. Ann shared experiences with clients she felt might have had some psychiatric illness.

Some of these patients I do believe had some mental illness background as well, and that was one reason for their self-care deficit. When we had him, he was there for medical reasons, and he did not have any diagnoses that I knew of mental illness, but it was odd....I mean he, he wasn't completely there.

Other nurses also believed the origin of these self-neglecting behavior was based on the client's mental health. Beth stated, "I think for a lot of them there is a psychological element that is undiagnosed that hasn't been addressed by physicians or the patient." Some hinted at mental health issues without specifically using the term "illness." For example, Dora stated, "But, there's probably a lot of deep rooted issues that she has never dealt with." Others specifically stated they believe the client had some mental illness not yet diagnosed. For example, Ella stated, "And in his case, I have no doubt that he may be dealing with some undiagnosed mental illness. I think we see that a whole lot, whether it's diagnosed or not." Kay also related, "We believe that there's probably some kind of psych issue to be discovered." Many of the nurses in this study spoke to undiagnosed mental illness. Therefore, study data clearly supported undiagnosed mental illness as a strong category in this theme.

### **Depression.**

Clients with depression often fail to attend to their personal needs such as hygiene and nutrition. Home health nurses in this study were adept at identifying signs of depression, and it was evident that nurses connect self-neglecting behaviors to depression. This connection was manifested in their statements. For example, Carol

stated, “That’s where...you know some of them I really believe it’s from depression and maybe their primary doctor is not addressing that, and I address it with them.” Others related signs and symptoms of depression, without using the actual term. Ella stated, “I could lump most of them into the category of being hopeless, or depressed....I don’t think they are helpless, but they view themselves or I view them as hopeless.” Nina also shared her observances of behaviors she felt were indicative of depression. She stated, “They just are kind of shut, they seem almost like they’re shutting down. Emotionally, they’re just kind of walling off.” Others speculated at depression based on what they observed. For example, Ila stated “She just has no, it’s as if she has no interest in life. So I think it’s more of a depression, but I’m not sure.” Jan also speculated about depression stating, “Or maybe they’ve got something going on depression wise.”

None of the study participants related that their clients actually had a diagnosis of depression, but it was clear that these nurses are familiar with depression and the signs and symptoms of this. Nurse participants clearly identified a perception that self-neglect could stem from depression, making depression a key category in this theme.

### **Dementia.**

Similar to depression, clients with dementia may fail to attend to their fundamental needs. Nurse participants identified dementia as a possible context for self-neglect. For example, Ann stated “I’m really not sure...he hadn’t been diagnosed at that time with anything but he probably had some, some cognitive problems.” Carol also indicated a perceptions that dementia could be associated with self-neglect. Carol stated “A lot of these clients are you know what I would call in the beginning stages, or some of

them are in the beginning stages of Alzheimer's and the family just doesn't see that or they're in denial." Others speculated that self-neglect behaviors could occur in clients with dementia. Fran stated, "The...other one that I'm thinking about recently...it could be dementia." Still others spoke to clients having the ability to appropriate answer screening questions by adult protective services even if they have dementia, speculating memorization of needed information. Lea stated, "They have dementia but they can still answer those [referring to the screening questions from adult protective services]. They're the same questions that people ask all the time. It's almost like they have them memorized."

Like depression, nurses did not identify clients specifically with diagnoses of dementia, yet they related self-neglect and dementia. The mention of dementia was heard across many of these interviews making this a strong category for this theme.

### **Theme Three- Seclusion**

The third major theme was seclusion. Seclusion was a phenomenon identified in clients who self-neglect by these home health nurses who provide care for them. Study participants readily offered information on the antecedents to seclusion noted in these clients. It was clear in the interviews that these nurses sometimes attributed seclusion to client's choices. Nurses want to honor client choice, however, may experience questions of whether choices made by clients are sound. Thus, study participants reported experiencing a sense that intervention was needed even though the client may have made a seemingly conscious choice to seclude him or herself. The rationale for the seclusion

varied, and included a) isolation by choice, b) isolation by others, and c) isolation by circumstances.

### **Isolation by choice.**

Home health nurse participants reported sensing that clients who self-neglect isolate themselves by choice. Some nurses identified elder self-neglecters as “hermits.” For example, Ann stated “It was his choice to live there....He didn’t want to go anywhere....He seemed to be more of a hermit type....It’s their home and they do not want to leave there.” Others noted that these individuals may have had some element of isolation behavior for years. This was evident to Carol who stated, “I see that more if they are loners or have been loners most of their life.” Still others identified actions by these self-neglecters that served to isolate them. Ella shared, “No, generally speaking the kind of patients that I had to deal with, they shut lots of folks out.” Gail stated, “He still continues to refuse to leave his home.” Other’s identified steps taken by the clients to conceal their actual status to others in the effort to isolate themselves. Lea recalled a specific client and stated, “She so much wanted to be by herself that she denied that she could take care of herself.” Study data clearly supported isolation by choice as a key category in this theme.

### **Isolation by others.**

Isolation may not be a volitional action of the self-neglector and instead, may occur as a result of the individual being abandoned by others. Home health nurses also reported situations where this was perceived. It may seem that nurses would identify this category as elder neglect, however none of the nurses in this study used that term, and

instead focused on behaviors noted in elder self-neglecters. For example, Dora stated, “The husband stays in the back room, and will fix her something if she asks. But he’s kind of in and out.” Ella also identified a case of isolation by others, and yet, did not name it as neglect. Ella stated, “I can think of one patient within the last 2 years that we had...and her son was her caregiver. He was not really involved in her care...for whatever reason their children may have isolated them or alienated them.” Others noted times when they have seen the client have visits from their adult children who are not involved in the client’s care. Hal recalled, “And the times that I’ve seen the adult children come to visit its always with their sense of disgust and they need to get out of there and there’s not, you know, there’s not a good relationship.” Still others perceived the responsibility for being isolated by others may lie with the client him or herself. Jan stated, “Either because they got...excommunicated from their family because they’ve been so mean to their family and friends that nobody wants anything to do with them.” Isolation by others was a key construct identified in the study data lending credence for this as a significant category for the theme of seclusion.

#### **Isolation by circumstances.**

Finally, isolation may also occur due to life circumstances rather than volitional choices of individuals or the willful actions of others. Specific life situations were noted by home health nurses and associated with isolation of an elder. One such life situation is family moving away, or the client not living in close proximity to the family. Carol shared an example of this: “It’s really, their children have moved out of the home and they are living alone.” Hal also shared an instance and stated, “I find that there is family

and the family has usually moved away....And their adult children have all moved out of state.” Others recalled clients that have no family to be involved in their care. For example, Dora stated “And, she doesn’t have children, he doesn’t have children, so they really don’t have anybody to check on them on a regular basis or to say I care. I don’t think they have anybody.” Some participants identified the absence of a support system as problematic. Ella shared, “So, it’s not like they would have a strong church support system or even a network of friends and I see them as being alone.” Another example of a situation that serves to isolated was the death of caregivers. Ila shared a case where this was the issue.

Then you find out that his brother recently died, who was the one that primarily helped him....I think a lot...probably for the biggest majority of these patients, not all, but the biggest majority have very little family support, or no family support.

#### **Theme Four- Nonconformity with Self-Care Conventions**

Perhaps the most striking component of self-neglect for the home health nurse centers on the individual’s lack of conformity with socially accepted self-care conventions. These are the actions or behaviors taken by the individual to ensure his or her own health, comfort and even survival and include a) taking medications prescribed, b) attending to personal hygiene needs, c) consuming an adequate amount of calories for normal life functions, and d) attending to the living environment.



**Medication.**

Home health nurses identified volitional actions by individuals surrounding failure to take prescribed medications. Some of the medications were prescribed for chronic or even life threatening conditions. For example, Ella stated, “She would not do the fundamental things like be compliant with medications. She wouldn’t do her part in her care although the resources had been made available to her.” Home health nurses verbalized assessing medication management. The ability to manage medications independently is a key behavior in preventing re-hospitalization, and an important element in home health nursing assessments. Many study participants identified instances where clients neglected their medications. One example was noted by Beth who stated, “I see a lot of them too that...will run out of the medication and have a refill available. They just don’t bother to call it in even when they have a pharmacy that will deliver and it’s so convenient. Dora related information that highlighted medication assessment as important in home health nursing.

The first thing that clued me wasn’t necessarily the filthiness of the house, it was just that she had no concern for where her medicines were or if she was supposed to be taking them even though she had a terminal diagnosis. I mean you would think...even if they’re in remission right now that they would want to take their medications to stay that way.

Some nurses related cases where the client was taking medications but decided to discontinue that behavior. Gail shared her experiences with clients who stop taking their medication.

And...he says he doesn't need medicine....But then, he decided he didn't want to take his medicine, period. So he stopped taking it altogether. And you cannot convince him to start taking it again. He just says he doesn't need it.

Jan shared a similar experience recalling, "And like I said, one environment I walked into, they just quit taking the medicine. The wife's not necessarily helping him with the medicine either because he's saying he doesn't want to take it...."

Nurses are educated from the beginning of their nursing education about the importance of medication in the treatment and prevention of disease. Nurse perceptions of medication neglect was evident in these study data supporting this as a category for this theme.

### **Hygiene.**

Failure to attend to personal hygiene is well supported in previous studies on elder self-neglect (Adams & Johnson, 1998; Clark, Mankikar & Gray, 1975; Dyer, Kelly et al., 2006; Dyer et al., 2007; Kelly, Dyer, Pavlik, Doody & Jogerst, 2008; Lauder, 2001; Macmillan & Shaw, 1966; McDermott, 2008; NCEA, 1998; Poythress et al., 2006; Tierney et al., 2004). Consistent with earlier research, study participants reported making visits to elders who were not maintaining their personal hygiene. The lack of attention to personal cleanliness observed was so extreme that study participants described clients as filthy with a strong smell of body odor, and with no attention to teeth, hair or nails. The retelling of these experiences during interviews brought about feelings of shock and disbelief for participants who observed client's extreme inattention to the most basic of personal care needs. In addition to the failure of the client to provide for their hygiene needs, the nurses reported their own uneasiness that the clients demonstrate a lack of

concern regarding the state of their hygiene. Home health nurses' perceptions regarding lack of personal hygiene were evident in these study data. For example, Ann stated, "She was very disheveled, very unkempt and did not take care of her personal hygiene at all." Others spoke specifically to bathing as being neglected. Beth stated, "They live alone and they might get a bath when somebody tells them they have to have a bath because they smell bad." Carol also noted clients not bathing, and recalled, "They don't wash, they don't bathe....But you know, he was filthy, and it smelled." Other participants spoke to specific areas of hygiene neglected by clients. Dora shared,

Hair was unkempt, dirty. Nails were outgrown with dirt underneath. Some were broken half off. You know just not well cared for. She had no motivation getting a bath. I could tell by her teeth that she hadn't maintained herself even as far as daily brushing.

One nurse spoke to men neglecting shaving. Hal stated "And again, the men wouldn't be shaven, they would all have beards, and certain things, hygiene issues....But it was like fingernails...dirt in the fingernails, beards, unwashed, it would be an odor." Kay spoke to the degree of neglect of hygiene stating, "Particularly with the people that I'm thinking of, hygiene was you know nothing, zero in some cases." Others recalled clients who have incontinence and still neglect their hygiene. For example, Nina stated, "And sometimes they don't bathe, they don't."

If they have incontinence episodes sometimes they don't clean themselves up completely, or sometimes they don't clean themselves up at all." Hygiene neglect was evident in all of the interviews, supporting the importance of this as a category in this theme.

### **Nutrition.**

In addition to failing to care for their own personal hygiene and take medications to treat sometimes chronic or even terminal illnesses, the nurse participants reported that clients who self-neglect also neglect their own nutrition as well. Nutrition is a component of the overall assessment of home health patients. It was evident to study participants on client assessment that self-neglect could also involve neglect of hygiene needs. For example, Ann stated, "He neglected his hygiene, his nutrition, but he really wanted to live there." Ella stated, "So, poor nutrition, poor self-care." Other's spoke to specific behaviors and why the nurse perceives the client is neglecting his or her nutrition. Hal stated, "A lot of them ... do have poor nutrition. But a lot of times nutritionally they're challenged because they just don't eat enough, they don't eat the right things, and they just don't have the appetite." Nina stated, "They'll just nibble a little bit here and there and I don't even know that they know they are not eating. It just doesn't occur to them that they haven't eaten." Nutrition is an important element to self-care and the study data clearly support this as a category for the theme of nonconformity to self-care conventions.

### **Environment.**

Home health nurses report one of the most striking components of self-neglect is the state of the home environment of the individual. Home health nurses reported the

overall living environment of these individuals as cluttered, filthy, infested with bugs and rodents, and even structural problems that were left unattended. Nurse participants verbalized a sense of disbelief in the living environment of elder self-neglecters. For example, Ann described in great detail a client's home she had visited years earlier. Ann described this client as "a hoarder."

And I drove down the road and there was a shack down there that was heated by a wood stove. When I went into the building to see the patient, the floors were dirt. There was no floor except in a kitchen area and a bathroom area, but the bathroom area had a hole in the floor....The electricity was hung from the rafters by extension cords....there was no running hot water, there was only water. And this was not the first time that I saw a place that did not have running hot water. His kitchen was filthy and you know, of course there were bugs....The clothes are in piles filthy everywhere. I mean you go in the kitchen, there's nothing to eat and then you go in there and if there's anything in there the dishes are filthy. There's dried food left in there and it looks like they've been piled up there for days and nothing's been touched....This person was a hoarder. There was stuff stacked everywhere in this home.

Carol recalled a similar experience with a client who was hoarding. Carol's experience highlighted structural disrepair of the home and the appliances.

He lived in a home and the insulin was in the refrigerator. First of all the kitchen floor where the refrigerator was, was on the same side of the wall as the sink, and the whole wall was falling in. So the refrigerator was falling through the floor. And the... refrigerator door, every time you would open it would fall off onto your feet because the hinges were broken. And you would have to prop it back up to keep the insulin cool....You know you go in those hoarder houses and they've chosen to live like that their whole life so you can't do anything about it....But, the roaches would fly at you. And I was like oh my God! And I was so happy when I would go see this guy and he was sitting out on the porch.

Dora also described the home of a self-neglector who had pets in the home. Safety was a concern for Dora.

It's, it's cluttered, filthy, dog feces and urine all over the place. Very unsafe, there's literally trash and empty beer cans and liquor bottles and that type of thing all over the floor. There's just enough for a path to get from the living room to the, well she doesn't really let me get past the living room. So, it's nasty.

Fran described another home where the client had pet cats in the home. The home was also infested with roaches.

Yes...she had cat feces all over the house and holes in the floor, and roaches you know, you couldn't lay anything down. You only take what you can take into the house in your pockets....One case I can remember in particular there was just roaches everywhere and the man had had his scalp literally like lifted away. I think that the incision was like 32 centimeters long. And then when you peeled the scalp back he had roaches on there. And you know his wife picked up that medicine box and went over there and slammed it on the counter and the roaches went running everywhere. And then she brought me the medicine....Yea, I would be flipping out if I saw a roach at my house. But a roach crawling on them is not a big deal.

Gail's experience included a description of the yard, and rodent infestation.

But you know you drive up into the driveway there's grass up to your knees, so first sign you know there's nobody taking care of the yard. You walk into the house, it's very dirty, nothing has been done. Actually when I had been he had no running water. The house is absolutely filthy, every place you look at, and rat droppings everywhere....And...you know dust that's been there for years and years and years....The bathroom was filthy, filthy, filthy.

Ila's experience was consistent with other participants, and she described the client's home like a movie set, highlighting the surreal atmosphere of this home.

The floor is dirty. There's dishes in the sink, dust on everywhere, odor of urine in the home. The home itself, the actual building is rather run down....And the smell in the home is one of stale animal urine....She was a hoarder, totally a hoarder. There was a dog in a cage. There was dog poop everywhere. I could

not walk on a clean part of the floor. There were papers. There were cobwebs that was like out of a movie hanging down everywhere.

Lea also described a patient encounter where rodent infestation was a problem, and a problem virtually ignored by the client.

And I walked in this trailer and it all seemed like it might have been OK, but then when I looked at the couch and started to sit down and there was just rat pellets everywhere. And then looked at the chair and they were there too. And then I thought well, I'll go over here...and put my bag down on the kitchen counter. And they were all over the kitchen counter. And...it was just awful.

Study data clearly support environmental neglect as a strong category in this theme.

### **Theme Five- Nurses' Responses to Self-Neglect**

The final theme evident in these data was nurses' responses. Study participants related both their emotional responses to elder-self-neglect and the action responses or steps they take to intervene with clients who self-neglect.

#### **Nurses' emotional responses to self-neglect.**

Nurses in this study shared their emotional reactions as feeling shocked, saddened, and even guilty about their inability to effectively intervene with these clients. Others noted feeling helpless. Statements made by these nurses reflect their emotional reaction to elder self-neglect. For example, Ann stated,

I just have certain clients that stick out in my mind that I can remember their environment that they were living in that I found horrific. She stopped...eating correctly, she stopped taking her insulin the way she should, she stopped doing her finger sticks and she ended up in ICU...she ended up dying. And that just broke my heart. That just tore me up.

Other nurses expressed frustration with trying to care for these clients. Beth stated, “It is, it is very frustrating.” Carol perceived a sense of ineffectiveness and stated, “I try to help when I can but I can’t save the whole world. I can only do my part.” Carol relayed this same sense of ineffectiveness and frustration in her statements.

And I’m sometimes even overwhelmed even as a nurse going to a home and you see these situations and you feel you know that you almost take on the responsibility in that, I’ve got to fix this and I’ve got to fix that, and not always knowing what to do.

Still, others related feeling that same sense of responsibility to the client, followed by a sense of guilt when unable to make a difference. Jan stated, “And I mean...but then you feel like if you don’t do something you go home feeling guilty....I feel like I left them in a lurch. “ Others articulated their responsibility to the client and recurring problems with these clients returning to their care. Mia stated,

So it was like a never ending home health nightmare because you know you’re obligated to take care of these people and you want to take care of them, and you would do this great job healing them. And then, she was there again [in the home health system].

Pam articulated the perception of caring for clients with self-neglect very eloquently stating, “But sometimes like a train wreck, you’re just watching it, you’re waiting on it to happen. And you can’t do anything about it.”



### **Nurses' action responses to self-neglect.**

Nurses reported utilizing independent nursing actions such as establishing a rapport or trusting relationship and taking a nonjudgmental approach to establish connections with the client. Nurse's also reported drawing on their nursing education to prioritize and educate these self-neglecting clients. Nurses even took steps to take clients food from their own cupboards or to stop at fast food restaurants to purchase food for clients they identified as having nutritional challenges. Some of these nurses described utilizing independent nursing actions. For example, Ann stated, "When you are talking with the patient you have to build a trusting relationship with the patient." Ann also stated, "But, I mean I would take stuff out of my own cupboard and take it over there if I needed to." Others described how they approached the client in order to make a connection with them. Dora stated, "And I make that apparent as I walk in the door that I'm not judgmental and I try to use the body language and right tone of voice. And show more action more so than saying." Kay also related, "I have learned not to rush in asking 512 questions at the beginning." Mia recalled a specific client case and her approach; "And I would talk to her very openly and very honestly. I think you owe that to any patient that you are helping." Others related how they would prioritize the care of these clients. Pam stated, "...if I can get them at least medically stable and doing OK, then I can start working on the surroundings."

In addition to independent nursing actions the nurses also reported collaborating within the field of nursing with their fellow home health nurses and with hospital case managers to advocate for these clients. Nurses also reported reaching outside of nursing

both within the home health agency and to outside agencies as well. Many of the nurses reported that their agencies had medical social workers on staff. Nurses would make referrals to these social workers when further resources such as transportation may be needed or when safety issues were identified. Nurses also referred to home health aide services when possible or to Personal Care Services (PCS) and Community Alternatives Programs (CAP) when personal care was needed. Many of these nurses also reported referring clients to Meals on Wheels for nutritional assistance. When safety threats were identified, the nurses referred clients to the department of social services in their area or to adult protective services agencies.

Even though these nurses reported being well versed in resources available to them, they were able to identify both facilitators and barriers to intervening with self-neglect. None of the nurses reported any barriers to identifying elder self-neglect and could readily describe elder self-neglect for this study. There were however barriers to intervening reported and none of the nurses reported a single case of successful interventions for elder self-neglect that resulted in the client no longer neglecting their own needs.

### **Facilitators to Intervening with Self-Neglect**

Nurses in this study readily identified collaboration with family members, other nurses, the interdisciplinary team and in particular, the medical social workers as facilitating intervention for self-neglect. The nurses also reported collaborating with outside agencies as stated earlier, but did not name adult protective services or the

department of social services as facilitators, but instead as barriers based on current laws and policies for intervening.

Law and policy were also named as facilitators, but instead of being current facilitators, they were actually discussed by the nurse participants as current barriers and possible future facilitators. Specifically, nurses wanted changes in the reimbursement structure for home health services to allow for nurse practitioners, physicians and physician assistants to go out to the patient homes. Additionally nurses stated paraprofessional staff, such as home health aides, were needed and that these services should also be incorporated into the payment structure for home health services. Other potential facilitators named were mental health and counseling services.

### **Barriers to Self-Neglect Intervention**

Multiple barriers to intervening were identified by the study participants. These included resources, regulation and reimbursement, interdisciplinary access, and the ethics of patient autonomy and choice (See Appendix G). Nurses in this study expressed frustration at the resources that are limited for the elderly and for elderly clients who self-neglect. For example, Beth expressed frustration at the limited resources and the waiting period for those limited resources.

You know, out here with the people that I am seeing...the resources are so limited. And what we do have is such a long waiting list. We have a Pace Program [all inclusive care for the elderly]....And there is a year long waiting list. And I see a lot of these folks that would qualify for that kind of a program....We do still make referrals to the program. But all too often by the time their name comes up to the top of the list, they're already in an assisted living, or in a skilled nursing facility, or in a hospital or dead. It's so unfortunate.

Fran articulated problems with resources based on the client's geographic location; "In a rural setting, you're very limited on what your resources are." Participants stated that many of these clients do not qualify for Medicaid, and therefore do not qualify for services such as PCS and CAP that would help them maintain their personal hygiene and living environment. For example, Beth spoke to the rules and regulations regarding qualifying income limits for these elderly clients.

To qualify for a PCS worker there is such a fine line with the income. One dollar disqualifies them. You know if their income goes one dollar over the limit then they can't get PCS. And they don't qualify for Medicaid so they can't get PCS or CAP workers.

Carol expressed frustration with the bureaucracy of the system formalities required to get elderly clients qualified for payer services such as Medicaid.

[If we could get them signed up for] Medicaid and get some long term PCS care in their home, or ...CAP care in their home. But they now have such waiting lists that we can get a patient qualified but they usually die before they get care.

Additionally, a huge resource missing for these elderly self-neglecters is having social resources such as someone to come by to check on them from time to time. Many of these clients do not have caregivers or even a social network of support. Nurses related trying to arrange for someone to check on these clients in those cases. Beth provided an example of this.

You know but we try to get them with meals on wheels which really doesn't provide them with any, um any foods that are better. But at least they would have a regular meal and somebody coming by and knocking on the door on a regular basis and you know at least seeing inside and making sure that person is OK.

Resources for mental health services were identified by study participants as limited and needed. Kay identified the lack of providers is a huge barrier to mental health care access.

So, we have, if you can imagine two counties where the populations are probably 10,000 to 15,000 a piece, and there are two psychiatrists. Who can even serve like that? You know, poor doctors. You know you can't take any new patients. So I would say that I wish there were more medical providers.

Finally, more education on self-neglect for those caring for these individuals was identified as a limited or missing resource. Ella articulated this very poignantly.

What are the best practices to care for clients you feel are neglecting themselves? You know, we really fly by the seat of our pants, and not know. You go in [and] you do the very best you can at that moment in time. And you try to navigate that situation and you know I think that we maybe just need more education as an industry and a profession.

Regulation and the reimbursement structures for home health were key barriers for these study participants. Decreased reimbursement, fewer home health visits authorized, and services for the elderly being cut were common complaints of study participants. For example, Gail spoke to problems with services for the elderly being cut.

And then the services for elderly are getting cut; I mean I can just give you an example right now. Medicaid as of July 1<sup>st</sup>. We see patients and fill up their insulin syringes and their pillbox and it helps keep them compliant. And, I have two patients that I've been seeing on a weekly basis. But it's not just about filling up their pillbox and their insulin syringes, I'm doing a physical assessment and I'm talking to them and sometimes as I'm seeing these things that are wrong, you know you don't even have to tell me. But now, as of July 1 Medicaid has cut our visits back and we can only go in twice a month now instead of every week like I've been seeing them. And that's just one example that I can see where people can fall between the cracks.

Additionally, adult protective services was identified as the outside agency to contact in cases of self-neglect. However, a common refrain across these interviews was that adult protective services would go out for the visits and almost invariably come back with the report that the patient was “in their right mind”, “making conscious choices to live as they do”, and “the clients have the right to make choices for their lives”.

Interdisciplinary access was another barrier identified by this study. This is defined as a barrier both within and outside of nursing and was evident in the nurses stating they did not have direct access to the physicians. These nurses voiced frustration at not being able to connect directly with the physician. Instead, when they call to give a report to the physician, they either have to leave a lengthy message or speak to a clerical person or medical assistant. Beth expressed that she felt lucky if she was actually able to speak with a nurse. “And honestly, I don’t have many conversations with the doctors themselves. It’s all done through the CMA’s [certified medical assistants] and the office person. If I’m really lucky I actually speak with the nurse.” Nurses stated that they were unsure whether the message that they wanted to convey actually arrived at the physician as intended.

So it depends on whether or not we can get the doctor to really understand and get the picture of what’s really going on in the home. I mean I try to paint the picture as well as I can, but you don’t always get to talk to the doctor. You know, you’re talking to a triage nurse who just relays to the doctor that the nurse called and the patient’s having a problem....I don’t know what the doctor hears. You know...you go through the channels to get to the doctor and I’m not sure that the message always gets through and then they get long and lengthy...and they may not read them....Because you don’t talk directly to a doctor. I mean you’re calling his office and you know most doctors they don’t pick up the phone and talk to you, you’re talking to you know a triage nurse and they are very busy.

Additionally, some nurses recalled practices in their agencies of having to communicate with other disciplines through electronic mail, and interdisciplinary notes, and written communication methods which may not convey the same message as the nurse could transmit if the communication were conducted verbally. Beth related some concern with the lack of face-to-face collaboration.

All too often, it's just sad to say, that we just don't have the time to have a phone conversation unless we think there's something that's really urgent. So we communicate through email or we just go back and forth and read each other's notes and kind of keep track of what their plan is and what their goals are.

Ethical treatment of clients is at the heart of healthcare and is a core value of nursing; yet, these nurses also identified protection of patient autonomy and choice as a major barrier in intervening with self-neglect. These patients generally do not want to leave their homes and as competent adults, they have the right to live as they choose. Study participants voiced feeling an ethical dilemma in the care of these clients. Home health nurses want to honor the rights of the individuals, but struggle with not being able to intervene to improve the lives of their clients. For example, Ann recalled safety issues.

And then you are like oh my gosh, there is a real safety issue there. But when the patient is choosing to...stay at home. And they're, exhausting everything they can to be able to stay at home you know, you feel like it's not your choice to make that decision for them.

Beth articulated the same conundrum.

I've even considered APS referrals on a few occasions, but that one is really, really tricky for me...because I don't know the family dynamics and how the family is. Sometimes you just say this is the way this person chooses to live and

they are competent, they are able to make these decisions for themselves, so this isn't really an appropriate APS call.

Dora also voiced concerns over protecting the client's right to choose.

There's really nothing we can do if they're in their right frame of mind. I struggled all the way home yesterday trying to decide...maybe this is how she wants to live, maybe this is the way she wants to die, maybe this is her choice.

Ella echoed the concerns of other participants. "There's times that I feel very conflicted.

Do I want to help a patient? Yes. Do I think they have the right to refuse me and my services? Yes." Kay related wanting the client to "want" to make changes in their life, recognizing the choices the client were making were their own.

It feels like they just don't realize where they are, how awful this is, what the alternatives are. You know, it's kind of like do you know that like a lot of people do not live like this? Do you know there is clean water out there in the world? Do you know this is an option for you?

Pam struggled with when nurses could have a sense of solace with the decisions that the clients make, especially when the nurse knows the client is making choices that will not result in optimum outcomes. "Well, when do we get to this point of saying OK I understand that she's making this choice. But, is this a good choice that she's making for herself. And is it safe? It's, it's difficult."

## **Summary**

Sixteen experienced home health nurses who had provided care for elders who self-neglect were interviewed for this study to determine nurse perceptions of elder self-neglect. This chapter provides a description of the study sample. Data were collected



from these participants in face-to-face interviews or through telephone correspondence when the nurses were physically located remotely from the PI. Interview data were transcribed verbatim and used to identify significant statements regarding nurse perceptions of elder self-neglect. Content analysis was conducted on these data and provided the broad categories for analysis through constant comparison. Five themes were identified that reflect the nurses' perceptions of elder self-neglect. Additionally, nurses' emotional responses to elder self-neglect and the action responses taken to intervene with self-neglect were constructed from these data. Both facilitators and barriers to self-neglect interventions were also identified.

## CHAPTER V

### DISCUSSION

The purpose of this study was to determine how experienced home health nurses perceive self-neglect. An additional purpose of the study was to explore steps these nurses employ to intervene when self-neglect is suspected. This chapter provides interpretation of the study findings and a discussion of the study's relevance to the science of self-neglect. Implications for nursing education, nursing practice, healthcare, and public policy will be discussed. Recommendations for further research will also be provided.

Self-neglect presents challenging situations for healthcare professionals and lacks a consensus approach for addressing this complex phenomenon (Braye et al., 2011; National Committee for the Prevention of Elder Abuse [NCPEA], 2008). Each of the nurses in this study provided their individual definition for elder self-neglect (See Appendix H), and some provided attributions for self-neglect, such as cognitive and physical challenges, willful behaviors, or lack of resources. Definitions offered by study participants were similar in that they described the phenomenon, but differed in that not all the characteristics of the phenomenon were consistently included. For example some excluded certain aspects of care such as medications. Others noted resources were adequate and the client continued to not utilize the resources. However, all participants identified the failure of the client to provide what was needed for their health, safety or

comfort. The diversity in self-neglect definitions revealed with this study is consistent with the current literature on self-neglect that also lacks a shared definition for this phenomenon (Braye et al., 2011; NCPEA, 2008). Despite the diversity in definitions offered by these nurse participants, they were all keenly aware of behaviors and observations made that reflected self-neglect. Also consistent with Lauder (2001), this study revealed that nurses identify self-neglect based on a constellation of features rather than a single defining attribute.

Many studies on self-neglect have focused on describing the manifestations of self-neglect (Adams & Johnson, 1998; Clark, Mankikar & Gray, 1975; Dong, Simon, Beck et al., 2010; Dyer, Kelly et al., 2006; Dyer et al., 2007; Kelly, Dyer, Pavlik, Doody & Jogerst, 2008; Lauder, 2001; Lauder et al., 2005a; Macmillan & Shaw, 1966; McDermott, 2008; NCEA, 1998; Poythress et al., 2006; Tierney et al., 2004). Several researchers (Bozonovski, 2000; Clark, et al., 1975; Dyer et al., 2007; Gibbons et al., 2006; Pavlou & Lachs, 2006) have offered definitions for self-neglect. However, to date, diversity in defining self-neglect and in the understanding of self-neglect continue. Because environmental neglect is a cardinal feature of elder self-neglect, the home may be the best place to identify it. Home health nurses often encounter these individuals, but may experience confusion, in their attempts to understand the behaviors seen, and frustration, in their attempts intervene to improve the lives of these self-neglecting individuals. The current science of self-neglect fails to provide a clear working definition for the concept or intervention guidelines needed to inform nursing practice. This study represents the first study of self-neglect focused solely on the perspectives of home health

nurses and therefore, provides information from the perspective of the healthcare professionals who may be most likely to identify elder self-neglect. Five themes were revealed in this study and included: a) armor, b) psychological derivation, c) seclusion, d) nonconformity with self-care conventions, and e) nurses' responses.

### **Theme One- Armor**

The first theme noted in statements made by these home health nurse participants reflected the perception that elders who self-neglect have patterns of thinking and behaving that result in effectively "shielding" them from others. This "armor" protects the self-neglector, but may also serve to further insulate them. The armor may compound the effects of self-neglect because the individual is shielded from others, and therefore less likely to be identified.

Individuals who self-neglect conduct themselves as if their lifestyle practice of failing to meet their basic human needs is standard behavior that is commonly accepted. In fact, this was so strongly present in these study data that one of the categories that emerged was that of "it's my normal." This finding is supported by Bozinovski's (2000) grounded theory work which determined that "maintaining customary control" (p. 43) was important to the self-neglector and that striving for this control compels individuals to exhibit "attitudes and behaviors they hold most comfortable and usual for them" (p. 44). Bozinovski's (2000) grounded theory was constructed through interviews with elder self-neglecters and the Adult Protective Service (APS) personnel who were assigned to them. This study extends that work in that study findings show home health nurses also identified that control is important to elders who self-neglect.

Nurses in the present study shared the perception that these individuals have lived this way so long that it becomes what they think of as their normal. Nurses related that they would not consider the living situations of these individuals as even minimally acceptable. Yet, these self-neglecters did not give any indication that they felt their lives were inconsistent with how others might live. That behavior could indicate a psychological coping mechanism that allows the self-neglector to maintain a sense of normalcy, or quality of life. Previous studies have revealed this perspective in individuals with chronic disease who continue to report a high quality of life, when others may perceive that individuals have a lower quality of life (Kring, 2008).

Individuals with chronic illnesses and disabilities must develop adaptation strategies to cope with the changes from these illnesses or disabilities. When faced with life altering events such as chronic illness or disability, the individual may fear a change in regular routines due to reduced capability and possible dependence on others (Daker-White, Donovan, & Campbell, 2013). It must be considered that self-neglecters may also have these types of fears due to some event that they have perceived as a threat to their ability to remain independent, and that they develop coping strategies to address these anxiety provoking fears. It has also been proposed that adapting to chronic disease may not be fully understood, and the differences between an individual functioning well within the newly defined boundaries of chronic disease and just accepting their fate are unclear (Daker-White et al., 2013). It appears that self-neglecters may be accepting their fate, but more information is needed to determine this. Additionally, coping abilities may be skewed in individuals who have lower social support (Zucca, Boyes, Lecathelinais, &

Girgis, 2010). Since many self-neglecters are social isolated, their ability to adapt to stressors without outside intervention may be ineffective. However, currently, not enough is known about the trajectory of self-neglect, what self-neglecters perceive as threats, or the adaptation strategies of these individuals to identify whether shielding themselves is a protective coping mechanism, the inability to adapt to some perceived threat, or a component of some yet unidentified pathology. Further study in this area is needed to identify adaptation strategies of self-neglecters, factors associated with their ability to adapt, and how nurses can intervene to help promote healthy adaptation in these individuals.

A second category in this theme was emotion and included a wide range of emotions exhibited by these clients who self-neglect. The nurses noted that emotions displayed by self-neglecters seemed labile and incongruent within the context of the situations where they were observed. Study participants stated client's emotions were evident in behaviors that ranged from dispassionate and withdrawn, to irate and belligerent. These types of behavioral responses are also noted in clients with pathologies such as dementia, depression, or even some mental disorders.

The Institute of Medicine [IOM] (2012) estimated that approximately one fifth of elderly individuals are affected by mental health issues such as depression, dementia or substance abuse. However, no prevalence data were offered with the IOM report of these findings. Some pathologies, such as various types of dementias (Tanev, Sablosky, Vento, & O'Hanlon, 2012) can also result in labile and situation disparate emotions (Alzheimer's Association, 2014). Not only do clients with Alzheimer's disease and other

dementias exhibit emotions similar to those of self-neglecters, these emotional reactions can occur suddenly (Alzheimer's Association, 2014). Similarly, nurses in this study also reported sudden outbursts of emotion from self-neglecters. The ability to have meaningful social interaction hinges on the ability to cognitively process emotional messages (Kumfor & Piquet, 2012). Some clients with dementia, such as those with frontotemporal degeneration (FTD) may lack that ability (Kipps, Mioshi, & Hodges, 2009). The resulting behaviors may be perceived as rude or insensitive (Mendez et al., 2013), and may demonstrate what is perceived as a total lack of empathy (Kipps et al., 2009), similar to the reactions seen in self-neglecters. Individuals with FTD and the dementia that results lose the ability to recognize emotions in others. This affects their reciprocal responses. These individuals may respond with emotions that seem out of context (Kipps et al., 2009), and others may perceive them as apathetic and aloof (Kipps et al., 2009; Mendez et al., 2013), which mimics the emotional responses seen with self-neglecters. However, of importance is that none of the self-neglecting clients cared for by these study participants had diagnoses of dementia.

Depression is another comorbidity that must be considered in cases of self-neglect. Poorer health (St. John, Blandford & Strain, 2006) and advanced age (Institute of Medicine [IOM], 2012) are associated with depression. Abrams and colleagues (2002) found depression was an independent risk factor for self-neglect. Depression in the elderly can be displayed in emotional reactions such as apathetic withdrawal or the opposite emotional reaction of anger and lashing out (Townsend, 2012; Vickers, 1992). Emotions are usually modified by the use of defense mechanisms to decrease anxiety

(Townsend, 2012), yet in cases of cognitive impairment, this may not be possible (Vickers, 1992). When use of normal human defense mechanisms fail or when the individual is very depressed, that individual may retreat from others (Townsend, 2012). There are many similarities in depression and in the emotional reactions seen in individuals who self-neglect. Thus, screening for depression may be useful in identifying depression that may respond to medication or counseling. Only three nurses out of the sixteen in this study indicated they had no experience using screening tools such as geriatric depression scales, yet none of them reported having used these tools with these self-neglecting clients. Additionally, clients cared for by these nurses did not have diagnoses of depression. Thus, the impact of depression on self-neglect is not fully understood.

Emotions displayed by clients of nurses in this study were perceived as having the effect of “shielding” the individual. Nurses reported that self-neglecters either emotionally disconnect from others and conduct themselves as indifferent to the thoughts and actions of others, or they react so violently to others that future contact is avoided. After experiencing self-neglecters’ intense reactions to suggestions for changes or actions to intervene, other individuals such as their family and friends often evade further contact with these individuals, thus effectively insulating the self-neglector from further interaction. In the end, the outcome is the same, and the self-neglecting individual is left in seclusion to continue to conduct their lives as they choose. Emotions exhibited by self-neglecting clients are at times similar to those displayed by individuals with Alzheimer’s disease, dementia, and depression. However, self-neglecters may not have



these disorders, and do not appear to be getting screened for these conditions. A lingering question is whether these clients display these emotions due to self-neglect, or whether these individuals are experiencing cognitive decline, depression or some other pathology that is leading to their emotional responses. Inclusion of depression and cognitive screening on admission to home health services and on discharge may yield further information on client status to help guide future practice decisions. Additionally, further data on client attributes such as socioeconomic status, the impact of comorbidities on emotional status, and client resources for care may provide valuable insight into these elder's behaviors.

In this study, nurse participants described elders who self-neglect as withdrawn, blasé, guarded, mean and nasty, and belligerent. Macmillan and Shaw's (1966) seminal work on self-neglect revealed these same expressions of emotion by self-neglecters. "The pattern which emerged again and again was that of a domineering, quarrelsome, and independent individual. Typical of the adjectives applied to them were independent, unfriendly, stubborn, obstinate, aloof, aggressive, suspicious, secretive and quarrelsome" (p. 1034). So, almost 50 years later, nurses continue to describe these individuals in the same manner, yet still have no formal direction on identifying self-neglect or guidelines to effectively intervene with these individuals.

The final category that comprised the self-neglecters' armor was that of control of territory. It was evident that home health nurses perceive these self-neglecting clients as fiercely protective of their environment and their way of life. Home health nurses expressed that self-neglecters do not like others intruding into their privacy and that these

self-neglecters react to intrusions with indifference or with emotional outbursts. In fact, many nurses related stories of individuals who stated to them that this was the way that they lived and that they liked it, adding that if the nurse did not like it she could leave. Nurses in this study related that these individuals do not want to leave their homes and as awful as nurses may think the client's living situations are, the clients wanted to stay there and took steps in attempts to ensure this. Similar behaviors are seen in some cases of schizophrenia. Having a sense of territory may be part of the normal human instinct (Townsend, 2012), however, some individuals have a skewed sense of territory and may actually retreat back into what they consider their territory. This has been termed "restrictive territoriality" and is noted when individuals seclude themselves, do not allow others into their territory such as their home, and display aggression when others invade that space (Singh, Kay & Pitman, 1981). This type of interaction is seen in some cases of illegal drug use, such as with methamphetamines (Brecht & Herbeck, 2013) but was also reported in self-neglecters by nurses in this study. While the behavior of protecting territory is similar in self-neglecters, some schizophrenics, and some illegal drug users, the self-neglecters in this study did not have known diagnoses of mental illness or any known illegal drug use. Perhaps individuals strive to control their territory as a protective adaptation, or perhaps this is a maladaptive response to anxiety utilized by self-neglecters, schizophrenics and individuals who use illegal drugs. More research is needed in this area to identify the basis of this behavior.

Study data supported a perception held by home health nurses that elder self-neglecters want to be left undisturbed, and that these elders take steps to shield

themselves from the intrusion of outsiders. Functional components of the self-neglecters' armor included: a) conducting themselves as if the lifestyle of self-neglect is common to all (indifference), b) using emotion to keep others at bay, and c) fierce control of their territory. The armor serves to segregate and protect the individual. This theme of armor is consistent with the grounded theory work of Susanna Bozinovski (2000) who found that the quest to maintain continuity was the explanation for many of the behaviors that individuals who self-neglect exhibit. Continuity according to Bozinovski "refers to the perception of maintaining a coherence of one's inner psychic and external environmental and interactional activities" (p. 42). Bozinovski (2000) proposed "older self-neglecters engage in various self-preserving and self-protecting behaviors" (p. 42). This study, described some of those behaviors as perceived by the home health nurses that are assigned to care for those clients. Future studies should focus on investigating approaches to adaptation in self-neglecters, exploring whether more effective adaptation strategies would ameliorate the symptoms of self-neglect, and how nurses can assist with this process.

### **Theme Two- Psychological Derivation**

The second theme evident in these data was psychological derivation. This theme focused on home health nurses attributing self-neglect behaviors to mental health issues. Categories noted in this theme included undiagnosed mental illness, depression and dementia. Challenges and behaviors that accompany mental health issues are taught in nursing education and seem to intuitively make sense to nurses who care for clients with these issues. It is logical to nurses that clients who are cognitively challenged may lack

decision-making abilities, and therefore, not make the best choices for themselves. However, when study participant's clients were referred for determinations of competence, they were not deemed incompetent. This parallels research by Ernst and Smith (2011) who stated that the majority of elders who self-neglect "are legally competent" (p. 290). Nurse participants expressed frustration with these findings of competence, citing issues of safety arising from the decisions these clients were making for themselves. However, there is no continuum of competence and individuals are either legally competent to make decisions for their lives or they are not (Dong & Gorbien, 2005). The dilemma for nurses seems to be derived from instances when individuals are making decisions in specific situations that nurses suspect will result in poor outcomes. Questions of competence and safety can occur when individuals have cognitive impairments (Paveza, VandeWeerd, & Laumann, 2008) such as dementia (O'Brien, Thibault, Turner, & Laird-Flick, 2000), or delirium (Page, Kowlowitz, & Rhodes, 2010), are suffering from depression (Abrams et al., 2002; Adams & Johnson, 1998; Burnette, Coverdale et al., 2006; Burnett, Regev et al., 2006; Choi et al., 2009; Culberson, 2011; Dyer, Goodwin et al., 2007), or have diagnoses of mental illness such as schizophrenia (Singh, Kay & Pitman, 1981). However, clients of these study participants were not diagnosed with any of those conditions. Although nurses in this study felt that these clients lacked adequate decision making abilities, there was no legal support for that, and selectively limiting decisional capacity for legally competent individuals is an infringement on their rights. When clients were deemed competent, nurses were left with

more questions regarding the basis of these self-neglecting behaviors and the steps needed to address them.

Interestingly, the salient features of self-neglect are failure to attend to basic human needs such as personal care, the living environment, maintaining adequate nutrition, and attending to medical needs. These same behaviors may be seen in some cases of clients with mental illness, but clients in this study were not diagnosed with mental illness. Likewise, previous studies have failed to identify mental illness as an etiology for self-neglect, and yet nurses in this study and in research conducted by Lauder and colleagues (2006) attributed self-neglect behaviors to issues of mental illness. According to adult learning theory, adults bring their rich life experiences to bear in new experiences (Culatta, 2013) and use these past experiences to problem solve when they encounter new experiences. Nurses are well versed in caring for clients exhibiting challenges in caring for themselves when cognitive deficits or mental illness is present. Thus, this may be a plausible reason for nurses associating self-neglecting behaviors with mental illness. Depression and dementia were specifically named by many of the nurses in this study as conditions that could result in self-neglect. Lauder and colleagues (2006) also found that nurses caring for self-neglect may “resort to tried and tested cognitive schemata” (p. 285) which intuitively makes sense to them. Lauder and colleagues (2006) stated that nurses may assume that clients who need help with their “activities of daily living (ADL’s) have de facto impaired decision-making capacity” (p. 285). However, this is a biased view in that decreased abilities to perform ADL’s can occur when clients have physical dysfunction or even pain (Pickens et al., 2006).

Depression was one of the mental conditions identified by nurses in this study as a possible reason for clients to neglect their own care. This was consistent with previous studies (Abrams, 2002; Adams & Johnson, 1998; Burnett, Coverdale et al., 2006; Burnett, Regev et al., 2006; Choi et al., 2009; Culberson et al., 2011; Dyer, Goodwin et al., 2007) that found depression was associated with self-neglect. Clients with depression may not have the mental or physical energy to attend to their personal care needs sufficiently (“Major depressive”, 2014; Townsend, 2012), but again, none of the clients discussed by participants in this study were diagnosed with any psychiatric comorbid conditions. Additionally, while an association has been found between depression and self-neglect, the actual impact that depression exerts on self-neglect is not fully understood.

Findings from this study echo the work of Lauder and colleagues (2006) who used vignettes to study factors exerting an influence on nurses’ decisions regarding clients who self-neglect. Lauder and colleagues’ (2006) study found “mental health status was the strongest predictor of judgments ... of decision making capacity” (p. 285), and that this was problematic given that an individuals’ mental illness or depressive episodes may have either little or no impact on their ability to make decisions for their self-care. Many individuals with mental illness, depression or dementia have very mild forms or beginning stages of these conditions. Thus, the individual’s ability to problem solve or care for self may be unaffected (Townsend, 2012). Additionally, many self-neglecters may not have any mental health deficits (Lauder et al., 2006). Thus, nurses

may be applying labels to these self-neglecters based on their previous nursing experiences rather than accurately identifying patient specific data.

Attributing self-neglecting behaviors to the state of the clients' mental health was a key theme in this study although no clients cared for by nurses in this study were referred for home health services due to mental health problems. This may represent "confirmation bias", which is the tendency of individuals to "... seek, perceive, interpret, and create new evidence in ways that verify their preexisting beliefs" (Kassin, Dror, & Kukucka, 2013, p. 44). Confirmation bias includes not only relying on tried and true heuristics, but also integrating new information in ways that are familiar (Charman, 2013; Cook and Smallman, 2008; Kassin et al., 2013). This can result in flawed clinical decisions if the nurse fails to objectively assess all aspects of the client's symptoms and the context in which those symptoms are present, or to fully integrate all client data to determine what is occurring. For example, nurses who believe that clients who present with symptoms of self-neglect must have some underlying mental deficit will look for signs and symptoms of that deficit to identify what is driving the client's behaviors and confirm their suspicions. While nurses may be accustomed to caring for clients who fail to attend to self-care when they have depression, care needed for the client who is failing to care for self in the absence of a diagnosis of depression may be very different. Therefore, when a nurse assumes clients who self-neglect do so as a result of a disorder that the nurse is familiar with, it may result in ineffective approaches to treat the exact issues that the nurse is trying to intervene with. Education on confirmation bias is needed

in nursing so that nurses will be aware that this could play a role in their assessment and care planning.

### **Theme Three- Seclusion**

The third theme evident in this study was that of seclusion and was operationalized as actions that socially isolate individuals. Previous studies on self-neglect have established social isolation as associated with individuals who self-neglect (Burnett, Coverdale et al., 2006; Burnett, Regev et al., 2006; Culberson et al., 2011; Dong, Simon & Evans, 2010; Dyer, Goodwin et al., 2007; Kutame, 2007; Macmillan & Shaw, 1966; Mauk, 2011; Payne & Gainey, 2005). Some researchers have offered possible reasons for the social isolation, but no definitive link has been delineated. Likely the source is multifocal. Socioemotional selectivity theory holds that as individuals age, they tend to focus their time and energy on relationships and activities that bring them enjoyment rather than engaging in the many relationships and activities that was part of their earlier lives (Lockenhoff & Carstensen, 2004). Further study is needed to determine whether elders choice to seclude is a healthy part of the aging process or whether this is part of a more problematic issue.

This study revealed that home health nurses perceived seclusion was present in their self-neglecting clients, and that there were three distinct reasons for that seclusion: a) isolation by choice, b) isolation by others, and c) isolation by circumstances. In addition to isolation by choice that was previously discussed as part of the armor of the self-neglector, a category evident from this study was isolation by others. It is interesting to consider that many individuals who self-neglect may be of the baby boomer



generation. Anetzberger and Teaster (2010) suggested that the children of baby boomers may not feel compelled to provide care for their aging parents as baby boomers did for their parents. This was attributed to the fact that many baby boomers left their children with others to care for them as they went to work (Anetzberger & Teaster, 2010).

Isolation by others was apparent in home health nurses' recollections of cases where the client actually had families who appeared to have "turned their backs" on these individuals who self-neglect, which may be influenced by generational differences.

While baby boomers have been described as craving success and focused more on career than on child care, their children have been described as focused on their lifestyle and less loyal (Anetzberger & Teaster, 2010). Children of baby boomers may have no reservations regarding moving away from their elderly parents and this could contribute to the elder's seclusion.

Some nurse participants revealed family members who actually lived in the homes of these self-neglecting individuals, yet remained in different rooms or distanced themselves emotionally and interactively from the self-neglecting elder. Other nurses related stories of family members that would visit the elder self-neglector but did not spend much time with their family member, were visibly uncomfortable with being in the home, and wanted to leave as soon as possible. Still others related stories of the self-neglecting individual treating their family members so badly, the family excommunicated them. Seclusion from others may result from the armor of the self-neglector who uses that armor as a protective device. Other self-neglecters may have been isolated by life circumstances.

Circumstances that served to isolate individuals were evident in cases where the self-neglector had a primary caregiver who was no longer available because of death or a physical move to a distant location. In some of the cases there was no obvious decision by the individual to be secluded, nor were they secluded based on the actions of others; however, the elder self-neglector lacked a significant individual in their life, and had no network of friends or support system otherwise. This can be especially prevalent in the elderly who may have outlived their spouses, friends and family members (IOM, 2012).

Seclusion of the self-neglector may compound self-neglect. First, the elder has no one to interact with and therefore, eccentricities may become more ingrained than they would if the individual were socially active. This could occur because self-neglecting behaviors go unnoticed and not addressed in the absence of a caregiver or someone to interact with (Paveza et al., 2008), or just because the individual may not see an urgent need to wash their hair, or change their clothes if no one else is around, as was reported by participants in this study. Social interaction may also improve cognitive function (Glass, 2006; Ristau, 2011), and thus, the lack of social interaction may have the opposite effect. Glass and colleagues (2006) found that social engagement had an inverse relationship with depression. This same relationship was reflected in statements from nurse participants in this study who stated that they rarely saw self-neglect in cases where the elder had a caregiver who was actively involved in their care.

In describing the need human beings have for social interaction, Myra Levine (1967) specified, “the essence of his humanity is the result of his dynamic relationship with other human beings” (p. 56). Given the human being’s strong need for social

interaction, those individuals who lack this important component may be lacking an essential component for healthy psychological functioning, and this may be the core of self-neglecting behaviors (Levine, 1967). This is supported in a study by Crooks, Lubben, Petitti, Little and Chiu (2008) who found that elder women with stronger social networks have decreased cognitive problems. Also, Chen and colleagues (2014) found that elders who have little social support may be at risk of functional decline. Thus, the self-neglecting individual who is secluded from others may have more cognitive as well as physical problems, although this is currently unknown. When left to his or her own devices, the self-neglector may fall into a pattern of poor choices for himself or herself. The longer the seclusion lasts, the more indelible these bad choices and problematic behaviors may become. Further research is needed to explore the relationship of seclusion to cognition.

While clients cared for by nurses in this study had no diagnoses of depression or cognitive disorders, correlating social engagement with self-neglecting behaviors is an area ripe for research. There is support for the benefit of social interaction. What is not known is whether self-neglecting behaviors occur as a result of social isolation, whether self-neglectors withdraw from others intentionally, or whether others choose not to interact with these individuals because of their self-neglecting behaviors and surroundings. What is clear from this study is that nurses perceived social isolation as a possible mechanism to shield the individual from others, and this seclusion only compounds self-neglect as it may go unnoticed and unreported.

Unfortunately, health care regulations such as the Health Information Portability and Accountability Act (HIPAA) may serve to perpetuate social isolation in some cases. Study data revealed nurses are well aware of the privacy laws that permeate nursing practice. It should at least be considered that elders who choose to isolate themselves might be intentionally excluding family and friends from their lives. If that individual chooses not to allow nurses to inform family and friends, then HIPAA laws prevent nurses from involving others in the client's care, further isolating the individual. Therefore, healthcare personnel inadvertently become part of the isolation.

Healthcare reimbursement for services may also serve to further isolate elder self-neglecters. In June of 2013 the Centers for Medicare and Medicaid Services (CMS) issued a rule to change the payment structure for home health services. This rule will effectively reduce Medicare payment for home health visits by 220 million dollars in 2014 (CMS, 2014). Frustration with this rule was heard throughout many of the interviews for this study, with nurses citing this as a key reason that elderly client's needs will go unmet. Current costs per home health visit average approximately \$130.00 each (Abt Associates, 2013). Reducing costs by 220 million dollars this year will equate to 1,692,307.7 fewer visits this year to home health patients, many who are elderly and may already be isolated. This reduction in costs can only result in further isolation of self-neglecters who do not seek out medical care on their own. In this study, these self-neglecting individuals were referred for home health services following hospitalizations for exacerbations of chronic conditions such as diabetes and chronic wounds. It seems

reasonable that fewer home health visits may allow chronic conditions to worsen without nursing intervention.

#### **Theme Four- Nonconformity with Self-Care Conventions**

Nonconformity with self-care conventions led to strong emotional reactions from nurses. For the purposes of this study, this theme was defined as willfully failing to attend to self-care. Failing to provide for basic needs is the salient feature of self-neglect, and this aspect has been widely discussed in previous research (Adams & Johnson, 1998; Clark, Mankikar & Gray, 1975; Dyer, Kelly et al., 2006; Dyer et al., 2007; Kelly, Dyer, Pavlik, Doody & Jogerst, 2008; Lauder, 2001; Macmillan & Shaw, 1966; McDermott, 2008; NCEA, 1998; Poythress et al., 2006; Tierney et al., 2004). Self-care conventions are culturally defined and exist on a continuum. Gibbons (2007) proposed that self-neglect behaviors that concern hygiene or cleanliness of the home might well be personal choices or “personal norms” (p. 38) of the individual and as such, require tolerance rather than intervention from healthcare personnel. Gibbon’s stance on hygienic issues echoed Lauder (1999b) who argued for a postmodernist approach to understanding self-neglect that included attention to context, individual choice, and values of the individual (Rodgers, 2005).

Self-neglecting individuals fail to conform with any usual manner of attending to self-care, and this failure to conform usually extends over various aspects of the individual’s self-care. In the present study, that included failure to conform to accepted practices in the areas of (a) medication, (b) hygiene, (c) nutrition, and (d) environment. Nurse participants noted that even though they had questions regarding the competence

of these clients, self-neglecters did not react as if there were any differences in the way that they attended to their needs as compared to others. Again, this indifference could be a component of the armor of these individuals.

Older individuals who self-neglect often fail to take their medications as prescribed, even when the medications may be prescribed to treat chronic or even terminal illnesses (Adams & Johnson, 1998; Dyer, Kelly et al., 2006; Tierney et al., 2004). For the purpose of this study, individuals who lacked the financial resources to procure their medication were not the focus. Many of these nurse participants reported that while these clients are not taking these medications, it was not because they lacked the resources to obtain the medications, but instead, it was a behavior choice. Home health nurses reported struggling with attempts to convince these clients to take their medications as prescribed. Education by the nurse regarding the value of the medication in treating their health conditions and the consequences of not taking the medications as prescribed went unheeded.

The detrimental effects of failing to take medication as prescribed are well known, however, the medical community has not determined how to correct this behavior nor has the behavior stopped (DiMatteo, Haskard & Williams, 2007). Medication non-adherence is associated with poor control of health conditions and poor outcomes, including hospitalization, increased visits to the emergency room and even premature death (Choudhry, & Winkelmayr, 2008; Heisler et al., 2010; Malik, 2006; Munger, Van Tassell, LaFleur, 2007; Sokol, McGuigan, Verbrugge & Epstein, 2005; Vik et al., 2006).

Failing to take medications is not exclusive to self-neglecters as many elderly clients fail to take their medications as prescribed (Henriques, Costa, & Cabrita, 2012; Gentil, Vasiliadis, Preville, Bosse, & Berbiche, 2012; Berry et al., 2010). Nurses are aware that many clients fail to adhere to prescribed medications. What is unknown is whether or how failing to adhere in self-neglect is different from other individuals who do not adhere. Adherence to medication is just one part of the constellation of self-neglect behaviors. When nurses focus on medication as a single entity, they may fail to identify how medication is just one part of the full constellation of behaviors of self-neglect. Thus, nurses may miss key assessment data for this population.

Self-neglecters may neglect only one aspect of their care, but generally, the neglect is found in more than one area of self-care, such as hygiene, nutrition, or their living environment. Failure of the self-neglector to conform to hygiene conventions presents a picture that these nurses report “never forgetting”. Study participants described these self-neglecters as disheveled, dirty, unkempt, odiferous, and filthy. Yet, nurses reported their attempts to rectify the hygiene issues were often rejected by the self-neglector. Nurse participants reported these clients as either having no motivation regarding care of their hygiene, or that these clients refused to allow nurses to arrange for someone to help with the obvious issues of poor hygiene. These findings are consistent with previous research on self-neglect (Adams & Johnson, 1998; Clark, Mankikar & Gray, 1975; Dyer, Kelly et al., 2006; Dyer et al., 2007; Kelly, Dyer, Pavlik, Doody & Jogerst, 2008; Lauder, 2001; Macmillan & Shaw, 1966; McDermott, 2008; NCEA, 1998; Poythress et al., 2006; Tierney et al., 2004). Nurses in this study tended to concern

themselves with how to change the hygiene state of these individuals through intervention from others such as home health aides rather than determining how to correct self-neglect behaviors as a whole. Perhaps the nurses viewed client hygiene as something the nurse could impact immediately while reporting client behaviors to the physician, social workers, or even adult protective services for further intervention of the overall situation. Nurses may be overwhelmed by the totality of self-neglect due to the complexity of the issues and the lack of education on this topic. Thus, nurses may focus on what they have experience with, knowing they had positive results with what may seem to be similar situations.

Nurses are accustomed to encountering clients who may fail to attend to personal hygiene. This may occur in cases of dementia or depression (“Major depressive’, 2014; Townsend, 2012), delirium (Townsend, 2012), or even in personality disorders (Townsend, 2012). However, just as with medications, failure to attend to personal hygiene is only one component of self-neglect that might be addressed with assistance from personal care assistants if these clients would allow. Assistance with personal hygiene would however not correct the totality of self-neglect. In fact, it might actually mask self-neglect, as these clients would not exhibit a key feature of the phenomenon.

Coupled with the failure of individuals to attend to their personal hygiene is the failure to attend to the living environment. Study participants also reported this as a striking feature of self-neglect, and one that they could never forget. Terms used by study participants to describe these homes included horrific, shack, stark, falling apart, run down, unsafe, cluttered, smelly, infested and filthy. Although nurses who cared for



these clients described the homes of these individuals with strong terms that indicated their distress at the state of the living environment, nurses described their clients' reactions to living in these homes as appearing indifferent to their surroundings. This supports Bozinovski's (2000) finding. "Older persons who fail to clean their homes for seven years, or who hoard piles of debris six feet high throughout their houses, do not interpret their behavior as self-neglectful" (p. 54). It also lends support for the theme of "it's my normal." Participants of this study reported feeling alarmed at the conditions in these homes. One participant's reaction to the environmental state of the client was particularly poignant. She stated, "How is that possible, that someone isn't you know sad, or crying, or scared, or freaked out or whatever about...the nurse you know slipping on dog feces in front of you...or bugs in your wound. How is that not weird to someone?" Yet, these clients do not react as though anything is askew in the way they live, the choices they make, or the state of their surroundings. Their indifferent reactions led nurses in this study to identify the self-neglecting behaviors as the clients' normal. These indifferent reactions by clients also left these nurses trying to determine the origin of the behavior, and they tended to attribute the behaviors to psychiatric issues, consistent with the same finding by Lauder and colleagues (2006). Searching the literature for other conditions or examples of failing to care for personal and environmental hygiene did not reveal any pathological states where this might occur in the absence of physical or cognitive ability. Certainly, disorganized schizophrenic or psychotic states would lead to neglect of these areas of care (Townsend, 2012), however, studies of these disorders focus on the etiology and the symptoms that result from the disorder such as thought and

speech patterns rather than self-care. The combination of failing to attend to needs in several aspects such as nutrition, safety and comfort is readily found readily in the literature on self-neglect (Ballard, 2010; Bozinovski, 2000; Braye et al., 2011; Burnett, Regev et al., 2006; Lauder et al., 2006).

The question of autonomy and patient choice based on chosen lifestyle and cultural values must be considered. The medical community honors the choices of competent adults. This can be seen in cases of refusal of blood products based on religious beliefs (Woolley, 2005) or in cases where clients refuse invasive treatment modalities such as chemotherapy (Olsen, 2007). Is the state of the self-neglecters personal and environmental hygiene a personal choice? Could it be that medical professionals do not understand it, do not value it, and therefore want to label it as some type of pathology so that we can correct it? Lauder (1999b) stated,

Self-neglect should not be regarded as an abstraction that is amenable to capture in a single theory, nor can it be defined by some operational definition. Self-neglect is a human experience, understood within a particular historical context that has its own cultural values and interpersonal practices. (p.62).

It would be prudent for nurses to thoroughly explore client rationales for choices to determine whether culture or healthcare beliefs may be impacting patient choices.

Nutrition was another area where self-neglecters fail to conform to self-care conventions. Self-neglecting elders often disregard their nutritional needs. Study participants reported self-neglecting clients not only do not eat healthy foods, but that they do not eat enough food or may sometimes go days without eating. When home health nurses questioned the clients about their nutrition, clients would provide vague

answers. It is possible that these self-neglecting clients may be aware that nurses might disapprove of the answer, and therefore the client is trying to avoid that conflict. That leads to questions of whether these clients are fully aware of their choices. Study participants also reported the answers they receive may be different based on the phrasing of the question. For example, a study participant articulated asking a client about their appetite, and the client replied “pretty good.” When the nurse proceeded to ask the client to tell them what they had eaten that day, the client may have eaten very little or nothing at all. This highlights the importance of communication skills, health histories and comprehensive nursing assessments. Although these are skills and activities used daily in nursing practice, nurses must become aware of the possible influence that confirmation bias can have on these activities.

Elder clients often fail to attend to their nutritional needs, but often these issues with nutrition can be traced back to problems with ill-fitting dentures (Lee, Yang, Ho & Lee, 2014; Watson, Leslie & Hankey, 2006), dry mouth (Watson et al., 2006), having no enjoyment in eating because the social aspect of eating with others is not possible (Watson et al., 2006); or even depression and dementia (Townsend, 2012). However, in cases of self-neglect clients’ nutritional neglect is a component of the issue rather than an isolated issue to be addressed. Nutritional neglect in clients who self-neglect appears to be different than it is with other populations, but further inquiry is needed in this area.

Nonconformity with self-care conventions is often the area that nurses identify most compelling as the need to intervene. Perhaps this is because the presentation of these symptoms is different from ideas of cleanliness and hygienic care that nurses tend

to value. Culture must be considered as the driving force for the clients' choices in self-care. However, when self-neglecters' decisions place them at risk of harm, nurses are compelled to intervene. Nurses may view each area of nonconformity with self-care as a separate entity to be addressed. However, it is the totality of the constellation of self-neglectful behaviors that must be studied in order to develop the science of self-neglect, an understanding of the phenomenon, and steps for intervening.

### **Theme Five- Nursing Responses**

Both emotional responses and action responses were evident in these study data. Home health nurses expressed shock at what they saw in these homes, and reported feeling saddened by many aspects of the lives of these individuals, and saddened at the deaths of these individuals when they occurred. Nurse participants reported feeling helpless to do anything effective for these individuals because they felt helpless to impact the choices that these individuals were making. Caring is the core of nursing (National League for Nursing, 2013), and nurses have chosen a professional career as caregivers. When nurses are impotent to provide that care, strong emotional responses result. The National League for Nursing (2013) characterized caring as:

A culture of caring, as a fundamental part of the nursing profession, characterizes our concern and consideration for the whole person, our commitment to the common good, and our outreach to those who are vulnerable. All organizational activities are managed in a participative and person-centered way, demonstrating an ability to understand the needs of others and a commitment to act always in the best interests of all stakeholders.

Caring was evident in the nurse's responses to self-neglect. Action responses in the study data included both independent nursing actions and interdisciplinary actions. Prior to

involving others, nurses employed efforts to “make a connection” with the client and establish a “presence” with that client. Nursing presence is a central process that nurses may implement regardless of whether they know the term. This study used Finfgeld-Connett’s (2008) definition of nursing presence.

Presence is an interpersonal process that is characterized by sensitivity, holism, intimacy, vulnerability and adaptation to unique circumstances. Presence results in enhanced well-being for nurses and patients and improved physical well-being for patients. In keeping with the nature of a process, the consequences of presence go on to influence its enactment in the future. (p. 527)

Connecting with these self-neglecting clients was key for the nurses to develop a relationship with them. One effort used to establish that presence was using therapeutic communication techniques. While all registered nurses are educated in these techniques, some nurses may view therapeutic communication as the purview of the mental health nurse. Not practicing these techniques may result in a loss of effective use of these communication techniques, which would be a detriment for home health nurses who encounter self-neglect in their professional role. Other efforts nurses used to establish a presence with self-neglecting clients included approaching the client with a nonjudgmental attitude (Townsend, 2012), and establishing a rapport with the client (Townsend, 2012) prior to suggesting changes in their routines.

Once nurses felt they had developed a rapport with the clients, they would develop teaching plans for clients to educate them on the value of changing their actions, such as with the prescribed medications. However, nurses in this study reported no success in these teaching efforts. Finally, prioritizing was evident in the independent

nursing actions as home health nurses reported identifying the most compelling needs to address first. Many of these nurses prioritized medication management, but again reported no success with convincing these clients to take their medications as prescribed. Medication non-adherence is a common concept in nursing. Many times clients refuse medications because of the undesirable side effects. However, in this study nurses reported the self-neglecters did not cite reasons for non-adherence other than choice. Thus, medication non-adherence in self-neglect may be different. More research is needed in this area.

Home health nurses in this study reported relying heavily on interdisciplinary resources. This is consistent with other research (Ernst & Smith, 2012; Schmeidel et al., 2012). Nurses attempted to employ services for assisting the client with their personal care and reported searching for services from the community, such as meals on wheels, to help with nutritional issues, and help from community groups for assistance with donation of blankets or other resources. Nurses noted that if they could just get these types of services in the home then at least someone would be stopping by to check on the patient on a regular basis, thus, decreasing social isolation. Nurses also reported relying heavily on their agency social workers. These nurses related that the social workers were very aware of community resources and could perhaps even mobilize family members when the nurses were unable to engage the family. This was supported in the literature (Ernst & Smith, 2012; NASW, 2008; Schmeidel et al., 2012). If safety issues were identified, nurses would refer to the department of social services or to adult protective services. However, nurses were quick to identify many barriers to these interventions.

Nurse participants reported their responses to elder self-neglect. Initially, nurses reported experiencing strong emotional responses like shock. Then, nurses employed independent nursing actions to make connections with their clients and to prioritize the clients' care. Finally, nurses employed interdisciplinary actions by collaborating with other disciplines and agencies to impact client situations and what nurses perceived as client needs. Although nurses reported using a systematic approach to address client needs, no successful interventions for self-neglect were reported by nursing in this study.

### **Relevance of Levine's Conceptual Model of Wholeness**

The intent of this study was not to test Levine's (1967) model, but instead to use the model to understand the findings from the study. This model is centered on conservation (wholeness) and is comprised of the four principles of conservation which include energy conservation, structural integrity, personal integrity and social integrity. It was clear from this study that individuals who self-neglect are not "whole" as they lack physical, perhaps psychological, and certainly social well being. Levine (1966) proposed that nurses must intervene in these cases, yet there are no evidence-based interventions for elder self-neglect. Additionally, nurses did not report effective intervention for any of their clients that resulted in correction of any of the self-neglect behaviors.

Initially, Levine's model of conservation (1967) seemed to be a good fit for the study of self-neglect, as self-neglect involved the principles of this model. Indeed, study participants identified deficits in each of the areas of the model for clients who self-neglect. However, the present study was focused on nurses' perspectives rather than the actual individuals who self-neglect. Thus, a model centered on nurses' understanding of

complex phenomenon or nurses' decision-making may have been more appropriate for this study.

Levine's model provided a good starting point for exploration of this poorly understood topic that is addressed by nursing. However, the principal investigator (PI) found the model lacking in applicability for this study. For example, this model was intended to explain the basis for application of nursing knowledge rather than knowledge development (Fawcett, 2005). Self-neglect is a topic that is not fully conceptualized. Therefore, a model more suited to development of nursing knowledge would have been a better fit for this inquiry. Additionally, Levine (1989) stated that "patients must be accepted as they are - for what they are -with dignity and honesty" (p. 6). Of course, it is inherent in nursing to treat patients with dignity and honesty; however, accepting these patient "as they are - for what they are" (p.6) may result in nurses failing to advocate for these vulnerable clients, placing the client at risk for further compromise. Levine stated that she felt the conservation model brought "coherence to nursing problems" (Fawcett, 2005), however this model did not improve the understanding of self-neglect with this study.

Previous uses of this model in research were studies of well-known nursing concepts such as skin care (Burd et al., 1992; Burd et al, 1994), pressure ulcers (Hanson, Langemo, Olson, Hunter, & Burd, 1994; Hanson et al., 1991), and conserving energy (Higgins, 1998; Schaefer, 1995). A model that focused more of developing understanding of an obscure topic, with a focus on the psychosocial aspects of the human experience may have been a better fit.



### **Facilitators and Barriers**

It is important to note the sampling method may have been both a facilitator and a barrier to obtaining home health nurses' perceptions of self-neglect. This method was a facilitator in that the flyer provided characteristics that may indicate self-neglect and the nurses who volunteered to participate all indicated providing care to clients with those characteristics. Thus, this purposive sample garnered nurses with perspectives of clients that may have fit these characteristics. However, this method may have also served as a barrier. Self-neglect may be a progressive phenomenon that culminates in the overt characteristics listed on the flyer, or there may be levels of self-neglect. Thus, nurses who may have had other perspectives of self-neglect may not have volunteered for this study.

All nurses in the current study were able to identify self-neglect, in fact they were very adept at identification of self-neglect. There were no specific facilitators for *identifying* [emphasis added] self-neglect noted by these study participants. In fact, only one of the study participants stated self-neglect was taught in her nursing education, and that the education she received included signs and symptoms that constitute self-neglect. None of the nurses stated they had every received any specific education on elder self-neglect in their professional practice, with 15 of the 16 participants stating they had never heard of a workshop on self-neglect. With the numbers of self-neglect clients being reported (National Committee for the Prevention of Elder Abuse [NCPEA], 2008; Pickens et al., 2007) coupled with the growing elderly population (IOM, 2012), it is

imperative to educate the nursing profession on this phenomenon to ensure nursing practice is based on evidence for the care of these clients.

Many nurses identified facilitators for *intervening* [emphasis added] with self-neglect, although no effective interventions were reported. Facilitators identified by study participants were expressed in independent and interdisciplinary nurses' responses. Nurses in the present study lauded social workers as the "experts" in identifying and mobilizing community resources. This provided support for previous research with similar findings (Ernst & Smith, 2012; Schmeidel, 2012).

Nurse participants readily identified barriers to self-neglect intervention, but none for identifying self-neglect. For this study, barriers to self-neglect intervention were operationalized as anything that prevented the ability of the nurse to act or intervene, or anything that prolonged self-neglecting behaviors. Barriers that prolonged self-neglect behaviors included the lack of resources for both the clients and the home health nurses. Missing or limited resources such as transportation and caregivers were key to prolonging self-neglect. Nurses identified governmental rules and regulation as a barrier. For example, Medicaid income limits are so high that many elderly clients do not qualify for services. Although, regulation barriers were offered as a general perspective rather than associated specifically with clients who self-neglect. In North Carolina the income limit to qualify for Medicaid is \$16,104.00 annually (Healthcare.gov, 2014). This could be problematic for self-neglecting elders because Medicaid covers services that provide assistance with personal care where Medicare does not. However, it was unclear whether these elderly self-neglecters would accept assistance with their personal care if those

resources were available to them. Additionally, the processing time for applications such as Medicaid was reported by nurses as being very slow, and thus, also identified as a barrier to self-neglect intervention. Some nurses reported a few communities that had great resources for elderly clients, although long waiting lists for those programs presented barriers to intervention.

Home health nurses also targeted the lack of health care practitioners to address issues such as self-neglect as a barrier. Studies by the IOM (2012) corroborated these complaints from nurses citing few professionals choosing geriatrics as a field, and many geriatric professional choosing to “let their credentials in geriatric specialties lapse” (p. 27). The IOM (2012) termed the growing elderly population a “Silver Tsunami” (p.1) and warned that the current healthcare workforce is not adequate to address the mental health needs of this population. Specific concerns of the IOM (2012) related to healthcare providers for geriatrics included:

For members of the general workforce, professional education provides little training related to the assessment and treatment of older adults and little exposure to geriatric populations. Whatever is provided tends to occur late in the sequence of educational experiences, minimizing its potential to influence interest in specialization. Factors cited as impediments to increasing training regarding geriatric care included the lack of faculty trained in geriatrics, the lack of funds, competition for time in program curricula, the stigma associated with older adults and their care, and financial disincentives to geriatric practice (p. 28).

Nurses in the present study echoed those findings of the IOM (2012) identifying the paucity of education on self-neglect for the healthcare industry in general, and specifically to nurses as barriers to self-neglect intervention.

Study participants also reported that law and policy present barriers to intervening with self-neglect. Specifically, the ability of adult protective services (APS) to intervene and remove a client from their home in unsafe situations was named by nurses as a barrier to intervention. Home health nurses stated a common response from APS personnel was “they are in their right mind” indicating a finding of legal competence. Although, it is important for nurses to identify and intervene when safety concerns are identified, it is also important for nurses to consider that hygiene practices, including home maintenance are culturally bound and that culture must be a consideration when caring for these clients (Gibbons, 2007; Lauder et al., 2006). Policy decisions regarding healthcare funding were also identified as barriers. Nurses reported home health and other services for the elderly were being reduced (CMS, 2014) at just the time that the elderly population is growing (IOM, 2012).

Interdisciplinary access was another barrier evident in this study, and extends findings from the United States Department of Health and Human Services, Agency for Healthcare Research and Quality [AHRQ] (2013) who cited “poor patient-provider communication” (p. 1). Nurses revealed problematic access between the disciplines that may communicate only through patient records. The ability to convey what the nurse perceives as the client’s reality through the written word may be muted. Thus, the problem as perceived by the nurse is not shared as intended with the other practitioner. This effectively prepares the other practitioner to enter the patient setting with a skewed picture a priori, and this misunderstanding may interfere with timely and/or effective intervention. In addition to communication barriers within the home health agency, nurse

participants identified barriers when communicating with the physician in charge of the client's care. Nurses reported rarely, if ever, getting to speak directly to the physician, and instead having to relay messages through a clerical person or a medical assistant. This was considered problematic by these nurses because messages relayed to the physician may not be received as intended. If the person taking the message has no experience with self-neglect, he or she may not receive the message as the nurse intended it. Additionally, most physicians do not make home visits and therefore, may not truly understand the situation of the home.

Although nursing practice is grounded in the ethical treatment of clients (American Nurses Association [ANA], 2001), nurses stated that these ethical principles sometimes present barriers to self-neglect intervention. The nursing profession is strongly supportive of patient autonomy (Mauk, 2011) although situations deemed as unsafe often caused nurses to question whether intervention should take priority over patient autonomy. Questions of autonomy and beneficence were distinct in these interviews. Nursing education at the pre-licensure level is grounded in the ethical principles of nursing (American Association of Colleges of Nursing, 2009), and nurses in the present study reported wanting to protect patient choice. However, these nurse participants also reported feeling the need to intervene to ensure safety for their self-neglecting clients. Questions of autonomy versus beneficence arose when nurse participants questioned whether they had the right to make choices for these clients when there was no obvious physical impairment, no diagnosed psychiatric or cognitive impairment, and a finding of legal competence by APS personnel. "Capacity is a term

that is often used interchangeably with competence” (Mauk, 2011, p. 63). Competence is an overall term used to identify whether an individual has the faculties to make decisions for self, regardless of whether others may think the decisions are not sound. Capacity on the other hand, is more of a more broad concept that relates to multiple abilities such as making decisions, providing for self-needs or protecting self (Maul, 2011; Naik, Pickens, Burnett, Lai, & Dyer, 2006). Nurses often determine whether clients have capacity. Competence is determined by the legal system.

Elder self-neglect presents a conundrum for nurses. In fact, this may extend to disciplines other than nursing as noted by the AHRQ (2013) who found that healthcare in America is sometimes delivered “without full consideration of a patient’s preferences or values” (p. 1). However, it is important for nurses to recognize the role of culture in patient choice (Gibbons, 2007; Lauder, 1999b) and to rigorously seek to protect client choice to every extent possible (Gibbons, 2007; Lauder, 1999b; Mauk, 2011). Future research is needed to explore the influence of culture on behaviors in elders who self-neglect.

Nurses also reported feeling that clients who self-neglect may not get adequate follow-up as needed. Ann poignantly stated,

So they’re not getting the follow up that they need. And those issues a lot of times are just shoved under the rug and everybody acts like it’s not there. And that’s very sad to me because any of us can reach that place.

Perhaps the perceived lack of follow up is due to a lack of understanding of the phenomenon of self-neglect. The AHRQ (2013) cited disparities in healthcare caused by

“differences in access to care, social determinants, provider biases, poor provider-patient communication, and poor health literacy” (p.1). Further research on barriers to self-neglect intervention must be undertaken.

Elder self-neglect has been proposed as a geriatric syndrome (Pavlou & Lachs, 2006). Indeed, self-neglect is complex and encompasses many behaviors. Lauder (1999) cautioned against labeling self-neglect as a medical syndrome because the salient features of self-neglect are failure to attend to personal “cleanliness and hygiene” (p. 63) and these are areas open to scrutiny based on cultural values. This study identified self-neglecters as perceiving their behaviors as “normal” which in itself implies a moral judgment of others that these behaviors are not normal. The diversity of constructions of self-neglect in the healthcare industry may contribute to the lack of understanding of this phenomenon.

### **Limitations**

This study offers relevant information on a poorly understood phenomenon from a novel perspective. Home health nurses have great potential to help build the science of self-neglect because they are the practitioners who work closely with these self-neglecting clients in their natural environments. However, it is important to recognize that limitations exist in research and exploring those can improve future studies. Limitations in this study included the purposive sampling that was employed to garner this group of home health nurses. While the sampling plan in this study may have lacked rigor, this approach to sampling was needed to gain participants with the experience needed for this study. Because this was a small, homogenous sample from one

southeastern state in the United States, the study findings cannot be generalized to other groups. This study included the perspectives of 16 home health nurses. Thus, there is no way to definitively state how many nurses' perspectives were not included in this study. Other home health nurses may have conflicting perspectives. Further research is needed to gain the perspectives of greater numbers of home health nurses as well as nurses in other practice areas. Additionally, interview methodologies provide self-reported data and as such these data cannot be independently verified (Lincoln & Guba, 1985). However, this study does provide meaningful information in the study of elder self-neglect, and provides the voices of nurses who are key stakeholders in the care of community-dwelling self-neglecters.

### **Relevance and Implications**

This is the first study of self-neglect focused solely on the perceptions of home health nurses. This is important because home health nurses are the individuals who identify self-neglect as they see these clients in their natural environment. Self-neglect may not be evident when these individuals are seen in the physician's office or the hospital. Data obtained from these 16 home health nurses provided rich descriptions of their experiences with self-neglect and the meaning of these experiences was constructed from the home health nurses' viewpoint. A full understanding self-neglect continues to elude the healthcare community. It is only through comprehensively approaching the study of a phenomenon that it can be fully explained. Because home health nurses interact with these clients in their natural environments, these nurses are key to the study of this phenomenon.



An accurate prevalence of elders who self-neglect is not currently available. Similarly, information on whether home health nurses can accurately identify elder self-neglect when it is demonstrated is also unknown. It could be that current perspectives of elder self-neglect represent only the overt characteristics of the phenomenon and that more subtle findings may be indicative of self-neglecting behaviors.

Results of this study indicated that home health clients are not consistently screened for depression or cognitive issues. This is concerning in that these screenings may indicate those at greatest risk for self-neglect. Hence, exploring the value of screening for possible antecedents such as depression and dementia is warranted.

Study participants identified a dearth of education on self-neglect for those who provide care for these individuals. Many home health nurses are associate degree nurses. Associate degree programs have historically not included a focus on community health, and thus, these nurses may lack education on the care of community dwelling individuals with healthcare needs. Self-neglect is not a topic generally covered in nursing education in schools of nursing, nor are there continuing education opportunities for nurses to learn about this phenomenon and how to intervene with it. Home health nurses who observe these clients are left to identify approaches to address the multiple consequences of self-neglect using techniques that may be ineffective to address such a complex phenomenon. Additionally, home health nurses are in fact generalists. Lauder and colleagues (2006) suggested that generalists may “rely on broader heuristics” (p. 286) that can be utilized to explain a wide variety of situations, but ineffective to make judgments on complex phenomenon such as elder self-neglect.

Healthcare is an industry, and one that consumes a great deal of the gross domestic product. A key concept to the effective function of any industry is providing the tools necessary to accomplish the work. However, nurses providing care for clients in the home are lacking the necessary tools to effectively intervene. Simultaneously, services and reimbursement are being reduced. Registered nurses are professionals who take their jobs very seriously and are dedicated to providing care for their clients. Yet, they are ill equipped to provide this care based on a lack of available information on self-neglect. The key to correcting this situation lies in more research on this poorly understood topic, more education for healthcare personnel, and more governmental attention to the care of these vulnerable elders. Several studies on self-neglect have been conducted; yet, the voices of home health nurses have remained silent in this research until now.

### **Recommendations for Future Research**

This study provides a good first step to developing knowledge that can inform nursing education and practice. These study findings must be compared with similar studies to develop the evidence of self-neglect from the home health nurses' perspective, therefore further studies on self-neglect from the home health nurses' perspective are needed. Studies on decision making in home health nurses may help to identify heuristics nurses use to determine steps to take in providing care for these complex clients. Additionally, more research on adaptive responses of individuals who self-neglect and the impact of culture on self-neglecting behaviors is needed. Comparing the perspectives of home health nurses to nurses with other practice areas may also reveal

important findings. For example, because clients are most often referred for home health services following an acute illness or exacerbation nurses in the emergency room may have been the professionals to encounter these individuals initially. Comparing the two perspectives for the same client may highlight differences in nurses perspectives based on practice area.

Exploring the possible roles that other conditions may play in self-neglecting behaviors is needed. Medical or psychiatric conditions such as diabetes or anxiety disorders may be significant comorbid conditions or they may be antecedents to self-neglect behaviors. Further studies of self-neglect focusing on comorbidities may provide important information for the trajectory of the phenomenon and treatment.

Further study is needed to develop evidence-based interventions for elder self-neglect, and nurses are pivotal stakeholders in helping to develop this science. Participants in this study perceived clients who self-neglect have a different perspective of their behaviors. Simultaneously exploring perspectives of self-neglect in home health nurses and their clients may provide additional insight to inform the science of self-neglect and the development of effective nursing interventions. Care of elderly clients who self-neglect is the reality of home health nursing. The resounding voice heard from this study is “who will advocate for these individuals?” Many of these self-neglecting elders are isolated, and nurses are constrained by reimbursement structures for payment of services and healthcare policy (CMS, 2014). Further studies on self-neglect screening and intervention need to be widespread using both qualitative and quantitative measures and multiple disciplines.

## **Policy Issues**

The United States has long taken a public stance on providing protection to vulnerable persons. However, provisions in laws and public policy lauded by politicians as providing protection sometimes seem to conflict with the overall sentiment shared in public. Guidelines such as reimbursement structures for Medicare and Medicaid as well as privacy laws are two examples of this. Study participants shared opinions about HIPAA preventing the nurse from contacting family of self-neglecters, and reimbursement criteria preventing personal care services from being provided for self-neglecters. Additionally, Medicare does not authorize home health agencies to care for clients in their homes on a long-term basis. Without caregivers, isolation can occur when home health nurses must discharge patients from services. Funding for services for the elderly including payment for home health services is being cut at the same time that the numbers of elderly individuals in this country are growing. This is effectively creating a “perfect storm” effect on the health of our elders. More resources and clearer guidelines for risk assessment are needed by nursing and social service agencies that provide care for these self-neglecting individuals.

The Affordable Care Act (Public Law 111-148, 2010) included a provision named the Elder Justice Act. The intent of this act was to provide resources to ensure just treatment of American elders, although the outcomes of this legislation are yet unclear. Alford (2011) contended that the act has a large focus on preventing abuse in long term care facilities. With self-neglect generally noted in the homes of individuals rather than in facilities, the Elder Justice Act may be inadequate to address the needs of individuals

who self-neglect. One of the provisions of the Elder Justice Act was more funding for APS agencies. More cases of self-neglect might be addressed if APS agencies had more resources, however the present study highlighted that APS screening of self-neglecting clients resulted in findings of legal competence. Consequently, no actions were available to intervene with these self-neglecters. Mixson (2010) proposed a different approach to care for these clients using a case management perspective. Of course, these efforts would require federal support through policy changes and funding due to the large numbers of personnel that may be needed. Mixson (2010) suggested elders identified as self-neglect could be referred to social service agencies that could provide these clients with "...financial assistance, long-term care case management, and mental health services..." (p.27). Long-term case management might serve the self-neglecting population well in that they would have someone assigned to follow them over time which should decrease their isolation. Additionally, the case manager would be able to identify changes that occur over time, which is currently missing in self-neglect research (Dong, 2013). Clients could also be referred for care such as mental health services when needs were identified. This approach might reduce fragmentation in services, result in cost savings through preventative treatment, and improve overall quality of life for these self-neglecting elders. More research would be needed to determine the benefits of long-term case-management.

Older adults often do not receive care for mental health conditions even though "mental health and substance abuse conditions were the eighth most costly type of health care conditions for older adults in the United States" (IOM, 2012, p. 39) in 2010. The

IOM (2012) identified conditions that are not listed in the Diagnostic and Statistical manual of Mental Disorders (DSM-IV-TR). Hoarding, severe domestic squalor, and severe self-neglect were included in that list. The revisions reflected in the most recent version of the manual (DSM-V) include the identification of hoarding as a mental disorder. Hoarding is only one component of the constellation of behaviors that may be noted with individuals who self-neglect. Nevertheless, the inclusion of hoarding in the newest version of the DSM may assist clinicians in identifying behaviors that may signal the larger, more complex issue of self-neglect. Although self-neglect has major implications for individuals who exhibit these behaviors, the fact that it is not identified as a “formal diagnosis” carries implications for education and funding, and signals a need for further research in this area.

### **Summary**

The present study has implications for nursing education and practice, as well as public policy. Self-neglect is poorly understood and it is complex. Home health nurses reported receiving no education on the phenomenon during their pre-licensure nursing programs, or through workshops after entering nursing practice. Thus, nursing care decisions for clients who self-neglect may be made with heuristics that the nurse is familiar with, yet not appropriate for decisions to address this complex phenomenon. Additionally, nurses may not identify subtle self-neglecting behaviors. Inclusion of self-neglect in nursing education for both pre-licensure and post-licensure nurses is vitally important for a coordinated response to identification and intervention.

When exploring data from this study, it was easy to identify common health conditions that demonstrated behaviors also identified in self-neglecters. Nutritional deficit is one example. Each of the behaviors in the self-neglect constellation could be identified in a known health condition, but no health condition could be identified that contained *all* [emphasis added] of the components in the constellation of self-neglect. This may contribute to nurses being confused by the phenomenon because they easily recognize symptoms that fit a familiar pathology, but are unable to identify a pathology that fits all of the symptoms demonstrated by a self-neglecter. In the present study this was complicated by the fact that none of the clients these home health nurses cared for were diagnosed with any of these familiar pathologies (i.e. depression, dementia).

To compound nurses' confusion, the perspectives of self-neglect are different depending on the individual experiences of those who either live it or encounter it. Home health nurses may practice within close proximity to their homes and thus, are a part of the community. As a result regional or cultural aspects of behaviors may not be obvious to the nurse living and working in the same community. Lauder (2001) stated that self-neglect is a constellation of behaviors and symptoms, and this study supports that perspective. Nurses may be adept at focusing on each behavior or symptom in this constellation independently because nurses are familiar with addressing concepts such as self-care or nutritional deficits in other patient populations. However, when nurses encounter all of these behaviors and symptoms together it presents a confusing picture for nurses, and one that nurses have no previous paradigm for. Therefore, nurses may feel helpless to intervene. The absence of evidence-based interventions for self-neglect

further complicates the ability of nurses to make care decisions. Developing interventions for self-neglect may be as complex and elusive as the phenomenon itself.

Assessing and intervening with self-neglect is an area where nurses can make a difference in the status of these self-neglecters. Many bedside or home health nurses are educationally prepared at the associate degree or baccalaureate level, and therefore not equipped to develop knowledge and evidence for practice changes. The current study represented the perspectives of 16 nurses, and the majority (n = 13) were prepared at the undergraduate level. Home health nurses are well versed in connecting with these clients, establishing a presence with the client, and intervening as possible. Yet, effective interventions for self-neglect have not been identified. Nursing research is needed to develop strategies that home health nurses can employ to address self-neglect. Additionally, identifying ways that different educational levels of nursing can contribute to knowledge development on self-neglect is crucial based on the ratio of associate and baccalaureate prepared nurses to advanced practice nurses. As advanced practice nurses, nurse practitioners have a broader scope of practice. Including nurse practitioners in the treatment plans for home health clients may provide improved opportunities for the identification and treatment of self-neglect. The present study provides beginning research on the perspectives of home health nurses who provide care for these individuals and highlights the wealth of knowledge of self-neglect held by these nurses.

Self-neglecters are individuals who either cannot or will not advocate for themselves. They often have no caregiver and thus, home health nurses may be their only advocates. However, nurses reported efforts to advocate for these individuals may



be prevented by the nurses' inability to effectively communicate with other professionals. The present study found communication issues occur within the discipline of nursing, between the nurse and other disciplines with the agency, and especially between the nurse and the physician. Elder self-neglect is a constellation of behaviors and symptoms that nurses can identify, yet feel helpless to intervene with. Many individuals who self-neglect are vulnerable, and many are socially isolated. Thus, these individuals have little to no voice. Home health nurses try to advocate for them, and yet current health policy is constraining contact between these individuals and home health nurses. Keeping elder self-neglecters silent only serves to further exacerbate the consequences of self-neglect, which will only compound this complex issue. Advocacy for these individuals may be the key to intervening and to developing the science of self-neglect. Changes are needed in the approach to care of elders who self-neglect and nurses at all levels should be involved in that change.

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## APPENDIX A

### LETTERS OF SUPPORT



10001 Executive Drive  
 Suite 204  
 Raleigh  
 North Carolina  
 27609  
 Phone: 910.848.2403  
 Fax: 910.848.2307  
 Cell: 910.848.2309  
 E-Mail: [membership@ahcnc.org](mailto:membership@ahcnc.org)  
[www.ahcnc.org](http://www.ahcnc.org)

June 21, 2013

Yvonne O. Johnson, MSN, RN  
 PO Box 549  
 Pilot Mountain, NC 27041  
 336-413-8457  
 Fax: 336-386-2695  
[yjojohnso@pilotnc.edu](mailto:yjojohnso@pilotnc.edu)

Dear Yvonne,

I fully support your research study of home health nurses, "Nurse Perceptions of Elder Self-Neglect." The Association for Home & Hospice Care of North Carolina, a 42-year old non-profit trade association, is one of the oldest and largest of its kind in the nation. We strive to be an excellent and important resource for home care providers and for those across the state who provide training and assistance on quality care for individuals in their homes. I believe the voices of home health nurses are important and can greatly enhance our knowledge of phenomenon seen in the care of elders in their home. Also, given the growing elderly population coupled with the constraints on reimbursement for healthcare services, there is a strong need for on-going research in identifying signals to future health problems that may be prevented with early detection and treatment.

I am pleased to serve as a partner to your recruitment for study participants on your nursing research. I will assist the project by: (1) sending out an inquiry for you through our membership of home health nurses; and (2) sharing information on any additional resources and recommendations that should become available.

Home health nurses are an important part of the healthcare team and have wonderful, rich experiences in the care of elders in their homes. This is important work and I think your research is right on the mark. Thanks for including me on this project.

Sincerely,

Sherry L. Thomas, BSN, MPH  
 Senior Vice President  
 Association for Home & Hospice Care of NC



Forsyth Medical Center  
3333 Silas Creek Parkway  
Winston-Salem, NC 27103

Yvonne O. Johnson, MSN, RN  
PO Box 549  
Pilot Mountain, NC 27041  
336-413-8457  
Fax: 336-386-3695  
[yjohnso@uncg.edu](mailto:yjohnso@uncg.edu)

July 1, 2013

Dear Yvonne,

I fully support your research study of home health nurses, "Nurse Perceptions of Elder Self-Neglect." Novant Health strives to be a leader in quality care for individuals, and we support improving care for elders in our community. I believe the voices of home health nurses are important and can greatly enhance our knowledge of phenomenon seen in the care of elders in their home. Also, given the growing elderly population coupled with the constraints on reimbursement for healthcare services, there is a strong need for on-going research in identifying signals to future health problems that may be prevented with early detection and treatment.

I am pleased to serve as a partner to your recruitment for study participants on your nursing research. I will assist the project by sharing your recruitment flyer and email with our nursing staff.

Home health nurses are an important part of the healthcare team and have wonderful, rich experiences in the care of elders in their homes. This is important work and I think your research is right on the mark. Thanks for including me on this project.

Sincerely,

A handwritten signature in cursive script that reads "Daria L. King".

Daria Kring, PhD, RN, NE-BC  
Director  
Department of Nursing Practice, Education & Research  
Novant Health Forsyth Medical Center  
Winston-Salem, NC  
Office 336-718-2120  
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## **APPENDIX B**

### **INTERVIEW GUIDE**

The purpose of this interview is to learn about your experiences with elder clients who self-neglect. I am interested in your thoughts and ideas about self-neglect and especially in hearing about your experiences as a home health nurse assigned to care for clients that you felt were neglecting their needs. There are no right or wrong answers for the questions that I will be asking you. Please think about your experiences with these clients, how you felt, and any possible questions or concerns that you may have had when you encountered these clients. As you are answering the questions feel free to add any other information about your experiences as well.

During the interview I will be tape recording our discussion, and I will also be making a few notes on paper just to keep my thoughts organized and keep myself on track. If at any time you want to tell me something that you do not want recorded feel free to turn the tape recorder off (demonstrate how to turn recorder off).

Do you have any questions? OK. Well, let's begin. How long have you been a home health nurse? In your \_\_\_\_\_ years/months as a home health nurse how many times have you encountered a client that you felt was self-neglecting?

#### Grand Tour Statement

Tell me about a time that you went into a client's home to deliver care and felt like the client was self-neglecting.

1. Tell me about an experience that you had with a client(s) who you felt was self-neglecting.
  - How would you describe their nutrition, environment, and hygiene?
  - Talk to me about their primary diagnosis and the purpose of your visit.
  - Describe any particular problems such as wounds, comorbidities, etc. that may have impacted this client's health.
  - Tell me how this client came to be referred for home health services.
  - Describe how you felt the client(s) viewed themselves.
  - Explain how this client(s) interacted with others.
  - Why did you identify what you saw as a problem?
  - How did you decide the steps to take in providing care for this client? (which resources were needed, who to contact etc.)

2. You have told me about these specific characteristics that you noted in a client who you felt was self-neglecting. Tell me how your experience with this client resulted in your feeling that this client was self-neglecting.
  - Describe for me what you think a typical picture of a client who self-neglects looks like.
  - How do you think these characteristics combine to form a picture of self-neglect?
  - You stated \_\_\_\_\_ first. Tell me why that particular characteristic came to your mind first.
  - Was there any particular characteristic or client behavior that concerned you more than others? Why?
  
3. After thinking more about this client that you have told me about, tell me what you used to help you make decisions about the care for this client?
  - Are there any services or resources you found particularly helpful?
  - Are there any services or resources you wish you had at that time?
  - Describe any workshops, seminars or formal education you may have had on self-neglect.
  - During the care of this client did you contact any other disciplines, or services? Why or why not?
  - If you contacted other disciplines or services for this client tell me about that conversation and the outcome.
  - Was there anything that you found especially helpful in making decisions regarding the care of this client?
  - Was there anything that you felt hindered your ability to make decisions or provide the care that this client needed?
  
4. You have told me your thoughts about the client's nutrition, their hygiene and their living environment. How did what you observed in regard to those things fit with how the client interacted with you?
  - Did the way the client carried on a conversation match what you initially thought when you observed the client and their surroundings? Why or why not?
  - Do any questions arise when you think about the conversations you had with this client given what you observed about this client?
  - Talk to me a bit about what you thought this client needed, and why.

- Some professionals have stated they felt conflicted with questions of autonomy (protecting the patient's wishes) and beneficence (doing what they felt was best for the client) when encountering clients who self-neglect because the client was able to carry on a meaningful conversation with them and was adamant that they could take care of themselves. Describe for me any conflicts that you may have felt in caring for this client.
5. Tell me about others who may have been involved with this client.
    - Did your client talk about relationships with others? Tell me a bit more about that.
    - What role(s) did these other individuals have with this client you have described?
    - Describe any social activities or group involvement that this client discussed with you.
    - Did you suggest any social activities for this client? If so, tell me about the client's reaction to that suggestion.
  6. What might have made a difference in your care decisions for this client?
  7. We all have a sense of who we are as a person, a personal identity. Some have stated that elders who self-neglect may be fearful and trying to keep others away from them, while others have stated that the elder who self-neglects is trying to maintain control of their life.
    - What do you think about what the self-image of the client you have described to me, and possible factors that led them to have the behaviors that you have shared?
    - How do you think the client's behaviors surrounding nutrition impacted their personal identity?
    - How do you think any disease processes or conditions impacted the client's sense of who they are?
    - Some have said that elders who self-neglect isolate themselves socially. Did you see this in the client you described for me and if so, can you describe for me how you think that impacted your client.
  8. Self-neglect has been described as a perplexing phenomenon, and one that presents a picture that you never forget. Now that you have encountered self-neglect in your practice as a nurse are there any changes in how you practice home health nursing, and can you describe that for me?

9. If I asked you to define elder self-neglect for me what would your response be?
10. Is there anything that you wish you had known about self-neglect before encountering a client exhibiting this phenomenon?
11. Now that you have some nursing experience with elder self-neglect can you describe for me anything you might do differently if you ever encounter another case of self-neglect.
12. If you were explaining elder self-neglect to a brand new home health nurse what would you tell them?

**APPENDIX C**  
**DEMOGRAPHIC FORM**

**Instructions: Please answer the following questions by drawing a circle around your answer or writing in your response.**

ID#: \_\_\_\_\_

Date: \_\_\_\_\_

1. Date of Birth: \_\_\_\_\_
2. Ethnicity/Race: \_\_\_\_\_
  - a. African-American/Black
  - b. American Indian
  - c. Asian
  - d. Caucasian/White
  - e. Hispanic
  - f. Asian/Pacific Islander
  - g. Other
3. Number of Years Worked as RN: \_\_\_\_\_
4. Number of Years Worked as Home Health RN: \_\_\_\_\_
5. Do you work Full-time or Part-time in Home Health? \_\_\_\_\_
6. How many hours per week do you work? \_\_\_\_\_
7. Nursing Education:
  - a. Diploma
  - b. Associate Degree
  - c. Bachelor of Science
  - d. Master of Science
  - e. Doctorate
8. General Area Worked:
  - a. Rural
  - b. Urban





**APPENDIX D**  
**CONSENT FORM**

**UNIVERSITY OF NORTH CAROLINA AT GREENSBORO**

**CONSENT TO ACT AS A HUMAN PARTICIPANT**

Project Title: Nurse Perceptions of Elder Self-Neglect

Project Director: Yvonne Johnson

Faculty Advisor: Dr. Patricia Crane

Participant's Name: \_\_\_\_\_

**What is the study about?**

This is a research project. Your participation is voluntary. This research study is being conducted to determine what home health nurses know and think about self-neglect in the elderly. The goals of this study are to determine how home health nurses identify self-neglect, define self-neglect, the steps nurses take in the event that self-neglect is suspected, and what home health nurses identify as facilitators and barriers to caring for a client with self-neglect.

**Why are you asking me?**

The reason for selecting the participant is that you are a home health nurse and have stated that you have encountered self-neglect in your professional role.

**What will you ask me to do if I agree to be in the study?**

You will be asked to describe client situations that you feel demonstrated self-neglect. I will be interviewing several home health nurses who report having these experiences and comparing the information to determine how nurses view self-neglect.

I will be asking you questions and recording your answers on an audio recorder so that I can play them back later and transcribe them into a written document. The interview may last for approximately an hour. You may experience anxiety in recalling these individual clients you have cared for. Please know that at any time during or following the interview you can ask that the interview stop and/or the information not be used for this study.

When I transcribe the data into a typed document, I may have questions. If you consent to a follow-up phone call, I may call you to clarify something in the interview that I may not understand.

**Is there any audio/video recording?**

The interview will be audio taped so that I can review the interview later to make sure I transcribe your information correctly. Because your voice will be potentially identifiable by anyone who hears the tape, your confidentiality for things you say on the tape cannot be guaranteed although the researcher will try to limit access to the tape as described below.

**What are the dangers to me?**

The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risk to participants. A potential risk is a sense of anxiety when recalling the client's behaviors and home living situations. You should not mention any particular client(s) by name or identify any client(s) in any way.

If you have questions, want more information or have suggestions, please contact Yvonne Johnson who may be reached at (336) 413-8457 or [johnsony@uncg.edu](mailto:johnsony@uncg.edu), or you may contact Dr. Patricia Crane (my professor) at 336-334-4896 or [patricia\\_crane@uncg.edu](mailto:patricia_crane@uncg.edu)

If you have any concerns about your rights, how you are being treated, concerns or complaints about this project or benefits or risks associated with being in this study please contact the Office of Research Integrity at UNCG toll-free at (855)-251-2351.

**Are there any benefits to society as a result of me taking part in this research?**

Potential benefits may include increasing what is known about self-neglect in the elderly. Improving our understanding of elder self-neglect may provide information on which to build interventions for self-neglect that could possibly allow for intervening with these clients before any negative consequences occur from self-neglect.

**Are there any benefits to *me* for taking part in this research study?**

There are no potential benefits from participating in this study.

**Will I get paid for being in the study? Will it cost me anything?**

There are no costs for participating in this study. Study participants will be awarded a \$20.00 gift card for their participation. Participants who choose to withdraw from the study after data collection has begun will receive the \$20.00 gift card.

**How will you keep my information confidential?**

The audio recordings will be kept in a locked file cabinet separate from the consent forms and transcribed data. All interview data will be transcribed onto an electronic file that will be maintained on a password protected computer. This consent form with your name will be kept in a locked file cabinet separate from the transcribed information. When the study is reported names of the study participants and their employers will not be shared. All information obtained in this study is strictly confidential unless disclosure is required by law. You will not be asked to provide any confidential information about clients that you have cared for that would be a violation of the Health Information Portability and Accountability Act (HIPAA). Your information will only be identified with a pseudonym (code associated with your name) rather than your actual name. The audio recordings will be destroyed in 3 years, and the study data will be destroyed in five years.

**What if I want to leave the study?**

You have the right to refuse to participate or to withdraw at any time, without penalty. If you do

withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data which has been collected be destroyed unless it is in a de-identifiable state.

**What about new information/changes in the study?**

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

**Voluntary Consent by Participant:**

By participating in the interview you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document and are openly willing consent to take part in this study. All of your questions concerning this study have been answered. By participating in the interview you are agreeing that you are 18 years of age or older and are agreeing to participate, or have the individual specified above as a participant participate, in this study described to you by Yvonne Johnson.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX E

### SELF-NEGLECT CODE BOOK DEFINITIONS

#### 1. **Definition**

##### a) **Definition as it relates to Personhood**

What the nurse identifies as the overall picture of the individual that indicates self-neglect.

##### b) **Definition as it relates to Environment**

What the nurse identifies in the physical environment that indicates self-neglect.

#### 2. **Problem**- Reasons for referral to home health services.

#### 3. **Action**- Steps nurses take to validate what they are seeing, make decisions, and mobilize the resources needed to impact the situation.

#### 4. **Behaviors**- Manner in which the self-neglecting individual interacts with other individuals.

#### 5. **Barriers**- Anything that prevents the ability of the nurse to act or intervene or anything that prolongs self-neglecting behaviors.

#### 6. **Facilitators**- Anything that speeds or makes easier the ability of the nurse to act or intervene.

#### 7. **Nurses Responses**

a) How nurses rationalize their actions

b) Nurses emotional response to Self-Neglect

## APPENDIX F

### THEMES

#### Themes for Nurse Perceptions of Elder Self Neglect

Global Categories	Clusters	Initial Raw Data
<b><u>Armor</u>: Perceived conduct used by self-neglecting individual to protect self</b>		
<b>ARMOR</b>	It's my normal	just don't see it as being odd or out of the ordinary It has become their normal just a normal state of being that is their normal normal life for them perfectly normal for them
	Control of territory	Territorial I do see control Viewed us as an invasion It is control, independence and control felt kind of territorial This is my home. If you don't like it you can just get out. Adamant that we not be in their home
	Emotion	Belligerent cuss me out very angry and upset Withdrawn Blasé act like life is going on as usual.
<b><u>Psychological Derivation (root)</u>: Psychological attributions for self-neglect behaviors</b>		
<b>PSYCHOLOGICAL DERIVATION (ROOT)</b>	Undiagnosed mental illness	No diagnosis of mental illness He wasn't completely there no doubt that he may be dealing with some undiagnosed mental illness Emotionally, they're just kind of walling off

Global Categories	Clusters	Initial Raw Data
<p style="text-align: center;"><b>PSYCHOLOGICAL DERIVATION (ROOT)</b></p>	Depression	view them as hopeless being hopeless They're so depressed they don't care something going on depression wise I think it's more of a depression maybe some depression has started
	Dementia	sometimes its dementia A lot of these clients... in the beginning stages of Alzheimer's Related to mental or demented states They have dementia but they can still answer those (questions from APS).
<b><u>Seclusion</u>: Actions that socially isolate clients who self-neglect</b>		
<p style="text-align: center;"><b>SECLUSION</b></p>	Isolation by choice	His choice to live there He didn't want to go anywhere Hermit type It's their home and they do not want to leave there They push people away They shut folks out Wanted so much to be by herself
	Isolation by others	Their children may have isolated or alienated them Son not involved Husband stays in the back room sense of disgust and (family) need to get out of there They've got excommunicated from family
	Isolation by circumstances	His brother recently died. lack of another significant individual family has usually moved away No ... support system No network of friends Lack of available caregiver

Global Categories	Clusters	Initial Raw Data
<b><u>Nonconformity with Self-Care Conventions: Willfully failing to attend to self-care</u></b>		
<b>NONCONFORMITY WITH SELF-CARE CONVENTIONS</b>	Medication	Don't care enough...to call in their meds No concerns for her medication would not...be compliant with her medication didn't want to take his medicine period stopped taking it altogether Refusing to take their medication
	Hygiene	very disheveled, very unkempt. Did not take care of her personal hygiene Don't care about bathing unkempt and dirty men wouldn't be shaven No motivation getting a bath
	Nutrition	Neglected nutrition don't eat regular meals Poor nutrition they are not eating
	Environment	Lived back in the woods in that shack Holes in the floor not even running water roaches ...everywhere Bugs in wounds Dried food ...piled up for days Dog feces and urine grass is up to your knees House is absolutely filthy cobwebs ... like out of a movie Hugely cluttered Hoarder bathtubs are filled with things

Global Categories	Clusters	Initial Raw Data
<b><u>Nursing Responses:</u> Nurses reactions to self-neglect. These include both emotional responses and action responses.</b>		
<b>NURSING RESPONSES</b>	Emotional Responses	Horrorific Really, really bad That just broke my heart That just tore me up Shocked If you don't do something you go home feeling guilty I felt like I left them in a lurch Like a train wreck, you're just watching it and waiting on it to happen
	Action Responses-Independent	Therapeutic communication Establish a trusting relationship Establish a rapport Try to connect with them with a conversation Important not to be judgmental Don't try to take over Take stuff out of my own cupboard and take it over Educate Give very specific instructions Prioritize
	Action Responses-Interdisciplinary	DSS referral APS referral Lifeline Social Worker referral Therapy evaluations for equipment needs



<b>Global Categories</b>	<b>Clusters</b>	<b>Initial Raw Data</b>
		Church groups that can deliver blankets Meals on wheels Talk to, with a family member PCS services CAP services Home Health Aide services

## APPENDIX G

### BARRIERS AND FACILITATORS TO SELF-NEGLECT INTERVENTION

#### Facilitators and Barriers to Self-Neglect Intervention

<b><u>Barriers:</u> Actions/Entities that interfere with the nurse's ability to intervene on behalf of the client who self-neglects</b>		
<b>BARRIERS</b>	Resources	<p>Lack of transportation</p> <p>No resources</p> <p>don't qualify for Medicaid</p> <p>Don't have anybody to check on them</p> <p>can't make somebody have running water</p> <p>very limited ... resources</p> <p>need more education as an industry and a profession</p> <p>Need more access to mental health</p> <p>Resources for psychiatric issues are at a loss out there</p>
	Regulation/ Reimbursement	<p>APS ... will say this patient is in their right mind, they are choosing to live like this, and they have every right</p> <p>APS... the law has their hands tied</p> <p>well they're in their right mind</p> <p>Cuts in funding/ Reimbursement is being cut</p> <p>Home health is short term intermittent service</p> <p>Services for the elderly are getting cut</p> <p>Fewer visits are authorized</p>
	Interdisciplinary Access	<p>I don't have many conversations with the doctors themselves.</p> <p>If I'm really lucky I actually speak with the nurse.</p> <p>You go through channels... not sure that the message always gets through</p>

<b>BARRIERS (continued)</b>	Interdisciplinary Access (continued)	<p>The doctor's ... aren't going to make a home visit.</p> <p>The doctor said if they don't do this, this, and this, then I refuse to see them</p> <p>We communicate through email or... read each other's notes</p> <p>they're not getting the follow up... needed those issues... are just shoved under the rug and everybody acts like it's not there.</p>
	Ethics of Patient autonomy Patient choice	<p>Patients want to stay at home</p> <p>Fully mentally competent, and when she was non-compliant it was her choice</p> <p>This is the way this person chooses to live and they are competent</p> <p>Sometimes it all comes down to personal choice</p> <p>They have the right to refuse</p>
<b><u>Facilitators:</u> Actions/Entities that helps nurses to intervene on behalf of clients who self-neglect</b>		
	Collaboration	<p>Family members that can attend to (safety needs)</p> <p>I try to sit down...(with) family members in front of the patient</p> <p>Having nurses to communicate with interdisciplinary notes in patient record</p> <p>Social workers know a lot of resources</p> <p>Social workers can get family members involved</p>

	Law/policy	Changes in reimbursement to allow funding for doctors, NP's and PA's to go into the home (are needed) If personal care could somehow be incorporated in Medicare Mental Health resources More counseling services
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## APPENDIX H

### PARTICIPANT DEFINITIONS FOR SELF-NEGLECT

Participant	Definition
Anna	Elder SN would be indicative of a patient that either does not cognitively have the ability to self-care for themselves or they do not have the will to self-care for themselves. And, or they do not have the resources to self-care for themselves meaning that they do not have the financial ability to buy detergent for their clothes, or have hot water, or have heat or have adequate food. They are either lacking in resources, the will, or the cognitive ability to take care of themselves.
Beth	For some people I think it's almost willful, you know they just don't do it on purpose. It goes back to their self-esteem or I feel like nobody else cares about me so why should I care.
Carol	Inability to care for themselves independently, or inability to care for themselves with assistance that the caregivers are lackluster people. Ad for caring for themselves means the whole physical, medical, mental, you know parameters. The whole thing, all of it.
Dora	Neglecting basic everyday necessities, but excluding medications. Not everyone believes in medications.
Ella	An elderly person that has the knowledge, has the resources, but chooses to not participate in health promoting or health maintaining behaviors.
Fran	When they're not doing the things with the healthcare system that you want them to do. (They are doing things) that are detrimental to their health. (Not following suggestions like the) physician ordered diet, not taking medications correctly. Usually it has something to do with their physical (health) and it has a negative outcome on their healthcare.
Gina	Yard not cared for, nasty house, refusing to leave the home that is inadequate, not taking meds or following medical advice.
Hal	Failure to pay attention to health, social, hygiene and environmental needs that contribute to optimal functioning.

Participant	Definition
Ila	Choosing not to take care of myself to the best of my ability to prolong my life.
Jan	You know what is the better thing to do for yourself but you chose not to do it. Self-neglect is when you purposefully do not do the things that you know that you should do. I think there's two forms of self-neglect. One is intentional and one is unintentional.
Kay	For whatever reason not always consciously someone has failed to provide for themselves and that can be simply not performing their ADL's. It could be not being their own advocate..., but even not self medicating when they have the pills. Not transporting or getting transportation to Dr.'s offices. A lack of performing even the basics to just be a safe and healthful as possible person.
Lea	Wanting to remain independent when you really know you can't be.
Mia	A person who chooses to remain in their environment, because of a lack of funding, lack of income, lack of resources, they're afraid to say anything to anybody for thinking they might get place somewhere and they choose to remain in this environment knowing that it's not healthy for them just for those reasons. Because they want to remain as independent as they possibly can.
Nina	When they decrease or stop performing ADL's and care for themselves.
Ona	Actions that the patients are choosing not to complete
Pam	I think it is a state to where an older patient or client comes to a point to where they are unable or unwilling to maybe to perform their ADL's or to seek help or to accept help with um, ADL's, taking their medicines, things like that that. Just with their activities of daily living and could mean with self-neglect to where they are either unwilling or unable to perform these things themselves and they will not allow someone they are not even allowing someone to assist them with this.

## APPENDIX I

## TABLES

Table 1

Demographic Characteristics of the Sample (N=16)

Variable	<i>M (SD)</i>	Median	Frequency	Percentage (%)
Age	45.9 (7.54)	45.0		
31-40			5	31.25
41-50			8	50.00
51-60			2	12.50
61+			1	6.25
Race/Ethnicity				
African-American			1	6.25
Caucasian			14	87.50
Other			1	6.25
Nursing Education				
Diploma			3	18.75
Associate degree			7	43.75
Bachelor of Science			6	37.50
Years as RN	20.3 (8.41)	18.5		
2-10			2	12.50
11-20			7	43.75
21-30			6	37.50
31-40			0	0.00
42-50			1	6.25

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*M* = Mean; *SD* = Standard Deviation

Table 2

## Home Health Practice Demographics

Variable	<i>M (SD)</i>	Median	Frequency	Percentage (%)
Employment status in Home Health				
Full-time			15	93.75
Part-time			1	6.25
Area of Practice				
Rural			9	56.25
Urban			4	25.00
Combination			3	18.75
Years as Home Health Nurse				
	11.43 (6.71)	9.0		
1-10			9	56.25
11-20			4	25.00
21-30			3	18.75
Years of Nursing Experience Before Home Health				
	9.09 (5.68)	18.5		
1-10			9	56.25
11-20			7	43.75
21-30			0	0.00

*M* = Mean; *SD* = Standard Deviation



Table 3

## Themes and Subthemes

Themes	Subthemes
Armor	It's my normal Control of territory Emotion
Psychological derivation	Undiagnosed mental illness Depression Dementia
Seclusion	Isolation by choice Isolation by others Isolation by circumstances
Nonconformity with Self-Care Conventions	Medication Hygiene Nutrition Environment
Nurses' Responses	Emotional responses Action Responses- Independent Action Responses- Interdisciplinary