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# The Perceptions of Video Surveillance and Its Influence on Cargiver Stress in the Home Care Setting

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# Walden University

College of Social and Behavioral Sciences

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Asuncion Neri-Candelaria

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Walden University
2017

Abstract

The Perceptions of Video Surveillance and Its Influence

on Caregiver Stress in the Home Care Setting

by

Asuncion Neri-Candelaria

MSW, New York University, 1998

BA, City University of New York, 1995

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human Services, Clinical Social Work

Walden University

May 2017

## Abstract

Given the stress involved in caring for elders, the propensity for abuse among the older adult population continues to be a problem, as the number of caregivers providing care in the home is increasing to meet the demand of an increasing population of older adults. One solution is to implement video surveillance in the home. The purpose of this phenomenological, retrospective and prospective study was to describe the perceptions and experiences of caregivers that affect stress in the home care setting and to describe participants' perceptions about the impact of video surveillance in the home environment on caregiver stress and elder abuse. Using a lens of critical ecological framework and privacy theory, the research questions inquired about the specific experiences of stress and the perceptions of the use of home surveillance of caregivers in the home. A sample of 9 older adult home caregivers were recruited from the United Jewish Council of the East Side Home Attendant Service Corp. Findings revealed that increased family, community, and agency involvement and support may offset the feelings of isolation of the home care environment and ensure the caregiver is given opportunities to engage in strategies designed to help cope with the inherent stressors of the job. In addition, video camera surveillance in the home care setting may provide social support through observation of the situation in the home, supporting both social control on the behavior of the caregiver and direct evidence of quality of care for the caregiver. The findings of the study help to highlight effective intervention strategies based on the specific stressors and stress relievers identified, serving to reduce the potential for older adult abuse and neglect in the home care setting.

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# Dedication

There is nothing that can be done without God's intervention, and I thank God for giving me the wisdom and perseverance that has enabled me to continue my studies. I dedicate this dissertation to my mother and father, who always believed in me. To all of my siblings, especially, my brother, Juan Neri, who is always giving me encouragement stay the course and not give up. I thank my husband Victor, who has believed in me to succeed, and has helped in various ways that have made my journey smoother. To my two sons: Antonio (and may you continue to think first before you act), wife Jaclyn, and two grandchildren Jonathan and James; and Esteban, thank you for being in my life. Finally, to all of my nieces and nephews, in particular, and especially my niece, Elizabeth, who is the most likely to succeed, despite adversities. Finally, I will forever have in my heart my nephew Larry, who passed away June 3, 2014.

## Acknowledgments

Special thanks are in order for my committee members Dr. Sylvia Kaneko for her support, and in particular, Dr. Richard Percy, Chairperson, who has been instrumental in his guidance, encouragement, and support throughout the dissertation process. I also thank all the professors throughout my years at Walden, as they helped shape my future in honing my skills in clinical social work.

I would also like to thank Betsy Jacobson, of the United Jewish Council of the East Side Home Attendants Service Corp of New York program for her gracious invitation to allow me to interview homecare workers from within the home care program.

My wholehearted special appreciation to Jennifer Gildea for her invaluable assistance.

This dissertation is for all elders, and those who will fall into the category in the future, that this dissertation will be the beginning in helping reduce caretaker stress that may lead to elder abuse, and that other researchers will continue to further this type of research for the future of older adults.

Particular thanks go to the participants in this study, who without their trust, interest, and cooperation, this study would not have been made possible.

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# Chapter 1: Introduction to the Study

The older adult population in the United States will increase to 80 million by the year 2050 (U.S. Bureau Census, 2010). Along with this increase in population size, an increase in the incidence of older adult abuse is expected (Jackson & Hafemeister, 2012). Older adult abuse and neglect by caretakers and family members continues to be a problem, with more than 10% of the elder population (over age 60) having experienced some type of abuse or neglect, excluding financial exploitation (Acierno et al., 2010). Caretaker stress has been shown to be a risk factor that is associated with increased prevalence of elder abuse in both familial and institutional care environments (Bergeron, 2001; Schiamberg et al., 2011). Caretaker stress may be a more significant problem in the home setting where abuse may be hidden behind the privacy of the home environment and where fewer reporting mechanisms are available to the older adult patient.

Researchers and practitioners need to understand the experiences of stress among the caretakers of older adults in the home care setting. There is also a need to reveal the potential behavioral changes associated with bringing social observation into the home care environment through video camera use. The perception of social observation and perceived scrutiny (i.e., caregiving behaviors being seen and/or judged) may serve to modify stress-related abusive behaviors of caregivers. From interviews with caregivers in the homecare setting, the researcher is able to gain an in-depth understanding of their unique stress experiences as well as their perceptions about the impact of social scrutiny on stress and the potential modification of behavior associated with “being watched.”

This chapter covers the following topics: (a) a brief summary of the research on caregiver stress, adult abuse, and perceived remote observation; (b) the research as it relates to gaps in the literature; (c) the purpose of the study and the research questions; (d) the conceptual framework; (e) the research methods and definitions of terms; (f) the assumptions, scope and delimitations, and limitations of the study; (g) and finally, the significance.

## Background

Caregiver stress has been identified as a significant risk factor that is associated with increased prevalence of abuse in various older adult care environments. It may be more significant in the home care setting, where abuse is often not reported and hidden from the public eye, reducing consequences to the abuser and thereby supporting the potential for increased abuse (Bergeron, 2001; Schiamberg et al., 2011). Some estimates of abuse in the home care setting in some developed countries are as high as 44% (Sooryanarayana, Choo, & Hair, 2013). Abuse of older adults may take the form of physical, emotional, or psychological abuse, along with financial exploitation (Acierno et al., 2010). Another form of abuse is neglect, —the failure to provide an appropriate level of care to the recipient by the responsible party (Giles & Helmle, 2011)., because it is an indirect form of abuse, neglect may be the most prevalent form of older adult abuse in the homecare or familial care setting, as it lacks the degree of social scrutiny and unacceptancenof physical abuse.

Research has provided insight into the risk factors associated with abuse and neglect of older adults by family caregivers and the need for intervention strategies to combat negative outcomes (Beach et al., 2005). Abusive behaviors of family caregivers often include yelling, insulting, threats of home reoval, and withholding food. Predictors or significant risk factors for these types of abusive behaviors of family caregivers were found to include greater recipient needs, and caregivers who were spouses, or caregivers who had cognitive impairments, depression, or physical limitations. Other risk factors associated with neglect include the care recipient's gender (female), age (over 85), poor health status, and depression (Penhale, 2010).

Caregiver burden and stress can contribute to development of anxiety and depression. Several factors predict anxiety disorder among caregivers: the inability of the recipient to carry out the activities of daily living (ADL), the caregiver lives with the recipient, the caregiver is female, the caregiver a poor relationship with the recipient, and caregiver's health status is poor. Depression among caregivers can be predicted by their irritability, poor health, and poor quality of the recipient-caregiver relationship (Mahoney, Regan, Katona, & Livingston, 2005). Risk factors for extreme abuse include the physical illness of recipient or caregiver, substance abuse by the caregiver, or a crisis in the life of the caregiver unrelated to the recipient's illness (Karch & Nunn, 2010). Understanding these risk factors helps identify critical areas for much needed support, education, intervention, and additional social services for caregivers (Kim & Schulz, 2008; Mahoney et al., 2005). Family caregivers and homecare providers are a critical part

of the healthcare needs of older adults and these care providers need support to reduce the incidence of abuse and negative health outcomes such as injury or serious illness (Levine, Halper, Peist, & Gould, 2010). However, research has failed to provide adequate understanding and insight into the specific stressors experienced by family caregivers in the home that may contribute to abuse. One approach left unexplored is the potential role of social observation (or being watched) in identifying precursors (stressors) to abusive behaviors or in moderating abuse (Levine et al., 2010).

The incidence of older adult abuse by caretakers and family members is likely to increase in the future with the expected increase in the older population (United States Census Bureau , 2010). Therefore, effective interventions are critical to support caretakers of older adults in a home setting. In this study, I sought to understand the potential influence of perceived social observation (Laslett, 1973) on stress and related abusive or neglectful behaviors of caregivers. In order to develop more effective prevention strategies and give caregivers the support they need, it is essential to understand the family caregivers' (a) unique experiences of stress when caring for older adults and (b) perceived impact of video surveillance as a way to provide social control (i.e., controlling effects on behavior due to social expectations of caregiving behavior).

## Problem Statement

The neglect and abuse of older adults by their caretakers and family members is a significant social problem (Brammer & Biggs, 1998; Caciula, Livingston, Caciula, & Cooper, 2010; Tam & Neysmith, 2006). In the United States, more than 1 in 10

cognitively intact elders over the age of 60 have experienced abuse or neglect other than financial exploitation from their caregivers (Acierno et al., 2010) and the incidence continues to rise with the increasing population of older adults (Jackson & Hafemeister, 2012; United States Census Bureau, 2010). One essential risk factor for abuse is caregiver stress, which has been associated with the increased prevalence of abuse in familiar (home care) and institutional adult care settings (Bergeron, 2001; Schiamberg et al., 2011).

The increase in both the older adult population and the prevalence of abuse has spurred institutional adult care settings to seek effective strategies to address caregiver stress and older adult abuse (Post et al., 2010). In organizations and institutions of older adult care, video surveillance is common (Woolrych et al., 2014). It is a management tool that supports patient safety, as well as greater accountability and social control, or the controlling effects on caregiver behavior due to being under social observation (Woolrych et al., 2014). However, in the home care setting, caregivers are not subject to the same level of scrutiny; the home setting lacks the regulation and observation required of institutional settings (Smith, Williamson, Miller, & Schultz, 2011). According to privacy theory (Laslett, 1973), public accountability increases the influence of social control, which, in turn, influences caregiver behavior; privacy, on the other hand, limits the influence of social control (Laslett, 1973; Norris, Fancey, Power, & Ross, 2013).

Thus, the privacy of home can contribute to the abuse of older adults in need of care (Laslett, 1973). Home caretakers may demonstrate abusive behaviors because they

experience high stress in a setting that lacks the social observation and social control necessary to and regulate behavior (Norris et al., 2013; Smith et al., 2011). There is a gap in the literature on understanding caregiver stress, social control, and older adult abuse in the home care setting (Bergeron, 2001; Smith et al., 2011). Therefore, the specific problem for this study was the neglect and abuse of older adults by their caretakers and the need for increased understanding of the experiences of caregivers related to stress and the potential abuse of older adult care recipients in the home care setting, as well as the perceived effects of social observation on stress and abuse in this setting.

## Purpose of the Study

The purpose of this phenomenological, retrospective and prospective study was to describe the perceptions and experiences of caregivers that influence stress in the home care setting. The goal was to describe participants' perceptions about the possible influence of video surveillance in the home environment, if any, on caregiver stress and older adult abuse. It is expected that the findings of the study will help to identify interventions to reduce older adult abuse and neglect in the home care setting.

Stress among caregivers can contribute to older adult abuse, even among loving families, and thus produce an alarming increase in older adult abuse on a large scale (Bergeron, 2001; Brammer & Briggs, 1998; Caciula et al., 2010; Penhale, 2010; Smith et al., 2011; Tam & Neysmith, 2006). However, the perception of social observation and scrutiny could serve to modify caregivers' stress-related abusive behaviors . An in-depth understanding of participants' lived experiences and perceptions is expected to yield a

greater understanding of the factors that contribute to stress and thus abuse. This understanding can be used to develop more effective interventions and support mechanisms for this population in order to decrease older adult abuse and maltreatment. In addition, because of their role as caregivers to older adults, study participants were queried about the possible influences of video surveillance on caregiver stress and elder abuse.

## Research Questions

Research Question 1: What are the experiences of stress and the factors that are perceived to influence stress levels in providing quality care to older adult care recipients among family caregivers and homecare workers in the home setting?

Research Question 2: What are the perceptions of home video surveillance of family caregivers and homecare workers and their ability to provide quality care to their family members or homecare clients?

## Conceptual Framework

To support the exploration of caregivers' perceptions of stress, social isolation, privacy, and scrutiny, a critical, ecological framework (Norris et al., 2013) was used in conjunction with the theory of privacy and family role behavior (Laslett, 1973). The critical-ecological framework combines two theories for a more complete view of the factors affecting caregiver stress, and therefore, older adult abuse: critical theory (Smith, 1987) and the ecological framework (Bronfenbrenner, 1979).The theory of privacy and family role behavior (Laslett, 1973) was used to help understand (a) the effect of family

roles and (b) the level of privacy in the home setting on caregiver behaviors is discussed briefly in this section; the discussion continues in Chapter 2 with more details.

The critical-ecological framework described by Norris et al. (2013) highlights bidirectional pathways through which the different levels of influence interact. These pathways affect the actions of the individual from an ideological context, regulatory policy and community support systems, and relational and individual factors in a holistic representation of these interactions (in this case, levels of influence that affect the caregivers' stress and the resulting behaviors). Using a holistic approach, the findings of the study were viewed through the lens of the critical-ecological framework, which can account for interactions among the macro-level ideologies that shape daily life, institutional influences, situational factors, relational dynamics, and individual orientations.

The critical ecological approach can be used to examine the influence of public ideology, institutional behaviors, interpersonal dynamics, and individual orientations on caregiver behaviors (Norris et al., 2013). For example, individualism and self-reliance are important American norms (Kluckhohn & Strodtbeck, 1961). When people become too frail to take care of themselves, they are no longer able to conform to those norms and, therefore, they lose social status. With lower status and greater dependency on others comes a greater probability of abuse. Incorporating the ecological framework, social influencers—such as social support groups, religious groups, and opportunities for respite care offered by family, friends, social groups, or organizations—can provide relief from

stress for the caregiver, reducing the danger of abuse. This type of social support may be particularly important to caregivers in a private setting.

Contemporary society is divided into public and private spheres; the family is allocated to the private sphere (Berger, Berger, & Kellner, 1973). Institutionally, the family is relatively weak, and dependent on other institutions, including economic institutions, healthcare, the state, transportation systems, and local institutions. Although the family it is located in the private sphere, it needs resources from other institutions, as in the case of adult care. Senior citizen centers, visiting nurse services, Social Security, and home care assistance can all help to relieve caregiver stress.

In addition to the critical-ecological framework, Laslett's (1973) theory of privacy and family role behavior will be used to frame caregiver stress and behavior in the home setting. This framework more specifically addresses the perceptions of caregivers related to potential behavioral changes after implementation of video surveillance in the home care setting. Surveillance will reduce privacy and increase accountability for caregiver behaviors, which in turn may increase or reduce the sense of stress among the caregivers (Laslett, 1973; Tomita, 1990). According to Laslett (1973), the common perception of the sanctity of the family, in conjunction with the level of privacy common to the family and home environment, can contribute to the incidence of abuse of older adults in need of care. The lack of accountability may contribute to a perception of no negative consequences for the abuser (Tomita, 1990).

Key to this investigation is (a) the inclusion of social observation, or "publicness," as an element of the privacy theory and (b) family role behavior as a variable in the investigation of the abuse and neglect among older adults in a family or home care setting (Laslett, 1973). As accountability influences behavior, privacy would serve to limit the influence of social control, whereas publicness would increase the influence of social control. Therefore, according to Laslett:

> If structural mechanisms which inhibit social control over the enactment of family roles have been reduced in the modern American family, then there is reason to expect greater variability in these behaviors in the more contemporary period than was true in the past. (p. 480)

## Nature of the Study

Using a phenomenological design, I was able to address the research questions via interviews with caretakers about their self-perceived experiences of (Creswell, 2009; Moustakas, 1994) stress and older adult abuse in the home care setting. The interviews provided insight into the essence of the participants' experiences, perceptions, and attitudes (Moustakas, 1994).

Such data provided an in-depth understanding of the personal experiences of stress, perceptions of precipitating factors of abuse, and the perceived impact of social scrutiny. Because this type of insight serves to gain understanding through personal, human experiences, it is essential to maintaining an ethical research practices to ensure

the safety and confidentiality of this information for the participants (Todres & Holloway, 2010), which is critical to this study, given the sensitivity of the research topic.

A purposive sample of caretakers of older adult family members and eldercare workers in the home setting was were sought through their association with the United Jewish Council of the East Side Home Attendant Service Corp. The interviews were recorded and transcribed for analysis. The modified van Kaam method of phenomenological analysis (Moustakas, 1994) was used to systematically code the data and then conduct a thematic analysis. The findings were expected to yield significant insight into caretakers' perceptions of the use of video surveillance in the home. This insight would then be used to develop strategies to address the stress of family caregivers and home caregivers and potential for abuse of older adults in the home care setting.

## Definition of Terms

*Caregiver.* The individual responsible for the care or custody of an older adult (Giles & Helmle, 2011).

*Caregiver stress.* Physical and emotional stress and strain experienced by the caregiver to an older adult (Beach et al., 2005). For this study, caregiver stress is that experienced by caregivers to older adult family members in the home setting.

*Emotional abuse.* Emotional abuse is defined by both verbal and nonverbal acts that cause distress or anguish on an elderly victim (Giles & Helmle, 2011): "

> Examples [of emotional abuse] are ridiculing the victim's attitudes, beliefs, and values, violating basic rights (i.e., obstructing religious

> freedoms of practice and reading an elder's mail), withholding everyday necessities such as false teeth or glasses, and threats or intimidation. Indeed, there is evidence that psychological distress caused by others' attacks on one's personal and/or social identity can over time be more disturbing than actually enduring physical pain for many people (p. 224).

*Home care setting.* Home care setting is the private residence of older adults or their family members where older adults may be (Beach et al., 2005).

*Older adult abuse.* Older adult abuse is harm directed at older people. This harm can take different forms, of which major forms include emotional abuse, physical abuse, neglect, and financial abuse (Acierno et al., 2010; Giles & Helmle, 2011).

*Older adult neglect.* Neglect is a specific form of abuse. It can be defined as "the negligent failure of any person having care or custody of an elder to exercise that degree of care which a responsible person in a like position would exercise" (Mosqueda, 2005, as cited by Giles & Helmle, 2011, p. 226). Neglect can also be defined as an identified need for assistance that no one was actively addressing, either no one was available or willing to meet this need (Acierno et al., 2010). Expected care would include, for example, hygiene assistance; provision of life-sustaining necessities such as food, clothing, and medical care; prevention and/or protection from malnutrition and dehydration and other safety hazards (Giles & Helmle, 2011).

*Social control.* Social control is the restrictive or supportive force exerted by others that control behaviors by either limiting behaviors that would otherwise fall

outside of what are socially acceptable or encouraging behaviors that are considered socially acceptable (Laslett, 1973). Social control works through the notion of accountability, which, in a social context, influences behavior (Laslett, 1973). As such, privacy would serve to limit the influence of social control, whereas publicness would increase the influence of social control (Laslett, 1973).

*Social observation.* Social observation, or "publicness," is included as an element of the privacy theory and family role behavior (Laslett, 1973). Social observation exerts a restrictive force on behaviors to limitations within the bounds of what is socially acceptable in a given social environment (Laslett, 1973).

*Video surveillance.* In the present study, video surveillance is a concept of social observation or monitoring private behavior. Video surveillance in this setting encompasses the putative use of video equipment to monitor common room areas of the private residence.

## Assumptions

This study was based on the following two assumptions, which are assumed to be true, but cannot be verified:

1. Participants in the study would answer the interview questions honestly despite the sensitivity of the issue.
2. Participants would clearly understand the interview questions and, using them as a guide, would be able to articulate detailed responses that will portray their personal experiences and perceptions. This assumption is necessary because

participants are asked to speak about their own experiences and perceptions. It is assumed that they are familiar with the issues related to taking care of elderly family members because they have had experience doing so.

## Scope and Delimitations

A purposeful sample drawn from a limited population of home caregivers in the greater New York City area, was used in this study. This population was chosen because it was accessible and could be conducted with the resources that I had . This study was delimited to (a) descriptive data only (no subgroup comparisons, e.g., male versus female caregivers, were conducted); (b) a maximum of 10 in-home caregivers of older adult family members or clients; and (c) qualitative methodology and small sample size. Due to the small sample size and the use of a purposeful sample, qualitative research tends to not be transferable to other people or settings. Although such research may offer insight into possible realities for other in similar situations, the findings themselves will be specific to the participants studied (Creswell, 2009; Johnson & Christensen, 2008).

## Limitations

The study focused on the perceptions and factors identified by participants about caretaker stress in a homecare setting and the perceived putative effect of video surveillance on stress and behavior. Those participants who were willing to volunteer for face-to-face interviews could introduce bias given the sensitive nature of the topic. The volunteers may have strong positive or negative opinions on the use of video surveillance and homecare, which may affect their perceptions, representing a potential bias.

The findings of the study also were limited by the participants' openness, honesty, and willingness to freely discuss elder abuse, as well as their ability to articulate their perceptions, emotions, and experiences, especially if they have engaged in neglectful or abusive behaviors. Because the perceived level of comfort and confidentiality during the interview may have a significant influence on whether participants chose to participate in the study, and the depth and detail of their responses, every effort was made to ensure participants' understanding of confidentiality measures and the comfort and privacy of the participants, allowing them to more readily offer the rich detailed responses that support strong conclusions (Moustakas, 1994). Each participant's experiences of stress and care giving are unique and variations in life circumstances, personal characteristics, and family dynamics exist for the participants in the study that are beyond its scope. Because the data analysis approach sought to reveal commonalities and themes in the data, individual or unique experiences of stress were not the focus. This limitation was considered during the analysis process.

## Significance of the Study

From the experiences and perceptions of home caregivers, I was able to gain an in-depth understanding of the factors that are felt to precipitate abuse in this setting. I was also able to gain an in-depth understanding of the perceived influence of video surveillance on the modification of behavior and its interactional effect on the relationship between caregiver and care recipient. The study is expected to contribute to social change through the description and identification of the experiences and

perceptions of older adult caretakers about stress experienced by caregivers and the possibility of introducing social observation into the home care setting through video surveillance.

As such, the study findings have the potential to add to the literature, while supporting critical social change by helping to reduce the prevalence of older adult abuse in the home care setting. Findings provide insight into the specific factors that contribute to stress among this population of in-home, caretakers of older adults. These insights could be used to help develop intervention strategies for reducing stress among family care workers. The findings support further examination of the effects of video surveillance on the incidence of older adult abuse and may help to support consideration for future incorporation of video surveillance technology into home care settings by health organizations and insurance companies providing in-home older adult care solutions in order to significantly reduce abuse among the older adult population. This study, therefore, may result in significant and important social change by contributing knowledge that can be used to reduce the incidence of older adult abuse in homecare settings.

## Summary

Chapter 1 described the study as an exploration of the lived experiences of stress and perceptions of the influence of social controls introduced through video camera surveillance among family caretakers and homecare workers of older adults. Research questions were developed to explore these experiences and perceptions that are unique to

the home care setting. Using a conceptual framework based on both the critical ecological framework and the theory of privacy and family role behavior, a phenomenological design was used to gather in-depth information on the experiences of caregiver stress and potential of social control via video surveillance in the home care setting. Data were collected from interviews with nine caregivers of older adult family members and care workers in the home care setting in the greater New York City area.

Each section of this first chapter served to support and describe the rationale, purpose, and significance of this study in light of the current problem. Chapter 2 contains a review the prior research conducted on elder abuse and stressors in the home care environment. In addition, research on the relationship between surveillance and older adult abuse is presented. Chapter 3 describes the methodological approach taken for the study, Chapter 4 provides the data analysis and findings revealed from the analysis, and Chapter 5 concludes the paper with a discussion of these findings related to both the research questions of the study and the previous literature in the field.

# Chapter 2: Review of the Literature

## Introduction

There is a plethora of research on the abuse of older adults in communities and families (Daniel & Bowes, 2011; DeLiema, Gassoumis, Homeier, & Wilber, 2012; Lowenstein, 2010; Ulrey & Brandl, 2012); but no research on the perceived influence of video surveillance in the home care setting on caregiver stress. This literature review will cover the following issues (a) demographics on older adults; (b) older adult care needs; (c) elder abuse; (d) caregivers and care recipients; (e) risk factors for elder abuse and neglect, such as caregiver stress, mental illness, age of caregiver/recipient, recipient and caregiver health status; (f) theories on adult caregiving; (g) video surveillance and elder abuse; (h) implications of research on elder abuse for practitioners, caregivers, policy makers, home care agencies, and governmental agencies; and (i) gaps in literature. The review concludes with a summary and conclusions.

The literature search was conducted to identify a variety of peer-reviewed articles for analysis and comparison through a number of literature sources to provide an academic lens. The following databases were used Pubmed, Ebscohost, Proquest, and scholar google. Searches were primarily limited to the last five years, but included relevant literature regardless of date. The following keywords were used: *caregiver stress, elder care, older adult care, home care, family elder care, older adults, elder abuse, older adult abuse, adult caregiving, video surveillance, home surveillance,* and

*caregiver surveillance*. The following topics are covered in the review: caregiver stress, risk factors associated with increased stress, and the effects of stress on the caregiver and on the caregiver's relationship with the care recipient.

## Demographics of Older Adults

In ancient Rome, people did not live past age 25 or 30 (Laurence & Harlow, 2003). In those days, older people were identified as "the opposite of the young man, whereas the man in his thirties or forties combines the better qualities of old and young" (Laurence & Harlow, 2003, p. xxx). Today, old age is identified as anyone past 65 years of age (Palley & Palley, 2000; Weiss, 2012).

There are many unanswered questions as to why there have been many changes in the population in terms of both decline and growth. Many attribute population decline to the rise in birth control and family planning. Conversely, population increase has been attributed to progress in science and medicine in particular (Lee, 2003). The trend of decrease in births, and increase in longevity will cause a significant change in the age distribution, which will equate to a ten-fold increase in the ratio of elder to children (Lee, 2003).

The 2010 population of the United States was 308.7 million, representing a 9.7% increase since 2000 (United States Bureau of Census, 2010). Out of the total population, 157.0 million were females (50.8%) and 151.l8 (49.2%) were males (United States Bureau of Census, 2010). In relation to ethnicity, according to the United States Bureau of Census (2010), the White population reported in the 2010 census was 223.6 million (or

72%) of the total population of 308.7 million; the Hispanic or Latino population during the 2010 census was 50.5 million (or 16%); and the Black population was 38.9 million (or 13%).

The older population in the United States is rapidly increasing. Dating back to the 1900s, the older population 65 years of age or older was 3.1 million. Comparatively, according to the United States Bureau of Census (2010), there were 40.3 million people 65 years or older, which represents an increase of 5.3 million over the 2000 census results, which reported 35.0 million individuals 65 years and older. Older persons 75 to 84 years old represented 13.1 million of the population, which alone represented 32.4% of population of persons 65 years and older. Older adults of age 85 to 94 numbered 5.1 million, which made up 12.6% of the population 65 years and over. Finally, older adults aged 95 years and over were reported to number 425,000 persons, or 1.1% of the older adult population (United States Bureau of Census, 2010).

This trend is projected to continue to increase such that by the year 2050, there will be an increase of approximately four times the population of older adults age 85 and over (Gorbien & Eisenstein, 2005). Huber, Nelson, Netting, and Borders (2008) posited that when it comes to the definition of elder, individuals age throughout their lifespan, beginning at birth in a continuous process of aging. White (2005) emphasized that although older people will get older, along those lines; they too will experience and increase with people reaching 85 years and higher. The ageing population is increasing worldwide, with different variations, in different parts (White, 2005).

In 2005, in comparison to U.S. figures, the New Zealand's population was half a million, with a projected increase to 1.33 million by 2051. Statistics demonstrate that the increase in the aging population for persons 65 years and older will occur between 2020 and 2030 (Dunstan & Thomson, 2006). The increase will occur in all regions of New Zealand. Two possibilities that likely contribute to this increase in the older adult population include the aging of the "baby boomer" population of individuals who were born within the period of 1946 and 1964 (United States Bureau of Census, 2011); and the current low birth rates (Dunstan & Thomson, 2006).

## Older Adults

Erber (2005) described how people tend to lump older people into a category, identifying them as age 65 and older. However, Erber pointed out that older adults do not fit into one category. For example, Erber stated that a 65 year-old can be retired, while another 65 year old can be working; or a 70 year old can have a health problem, and another 70 year old may be actively enjoying traveling; while an 80 year old may have a memory problem, and another 80 year old may have a very good memory. For these reasons, the diversity of older persons who are 65 years of age or older can be further categorized based on chronological age resulting in three groups: young-old (ages 65-74); old-old (ages 75-84); oldest-old (ages 85 plus) (Erber, 2005).

Nicholl, Wilson, and Webster (2008) projected that although the old-old will be increasing, specific to the United Kingdom, the oldest-old is expected to double every 30 years. According to Erber (2005), a person who falls under young-old will probably not

experience sensory or cognitive decline that is more common among the oldest-old population. The oldest-old group would have the highest rate of health problems and greater need for services, based on individual competence determining how the individual interacts with the environment (Erber, 2005). Therefore, if the individual's competence is too low for his environment, then the environment will be too challenging for the individual; on the other hand, if the individual risk competence is very high, then the environment will not be challenging enough for the individual (Erber, 2005).

These factors tie into the ecological model offered by Lawton and Nahemow (1973, as cited by Erber, 2005) in which "the interaction between a person and his/her environment results in some level of adaptation, which is measured in the terms of a person's emotional (affective) well being and behavior" (Erber, 2005, p. 32). The ecological model will be discussed more fully in the theories section. This model suggests that an elder is not a passive individual within the environment, but rather one who is capable of interacting with and within the environment (Erber, 2005).

Williams (1996) described an elder as someone frail with social and medical problems in need of assistance, due to poor health and living conditions. Williams postulated the benefits of residential homes for older adults, reporting that when elders are in a sheltered setting, the elders are able to express their feelings and find peer support. Moreover, the age related decrease in brain function among older adults can be slowed through continuous stimulation (Williams, 1996). Despite these benefits, not all elders want to live in a residential setting, as many prefer to stay in their homes, even

when very frail. These individuals may feel accustomed to their surroundings, their friends, and daily routine. In research conducted in 1996, Williams stated that the elder population will continue to increase, necessitating the need for residential or foster care, a prediction that rings true today based on the figures from the 2010 United States Census.

Hooyman and Kiyak (2008) reported that in 2005, the United States Census Bureau estimated that by 2050 the elder population as a whole would increase to 87 million. The young-old would increase to 44%; the old-old would increase to 32%; and the oldest-old to 24% (Hooyman & Kiyak, 2008). Hooyman and Kiyak discussed that although elders may be in poor health, there are many who demonstrate an active aging process. Active aging among the elder population consists of thinking of living their life to the fullest, even though they know they have loss of independence and there is a need to depend on others for support (Hooyman & Kiyak, 2008). However, with this trend, there will be an increase in the need for services. Many elders will be sent to nursing homes, a costly long term solution for the government and for the elder's private insurance, compared to if the elder were able to stay in their own homes being cared for by family caretakers, or home care services.

There are other forms of assistance for older adults through care management where older adults can receive service while remaining in their homes; these services can delay the placement of elders in nursing facilities. A manual on strengths-based strategies in care management was developed to assist administrators in training staff who work with older adults in this approach (Fast & Chopin, 2000). The strengths-based techniques

work by focusing on the strengths of the older adult, rather than on the illnesses. This may be a good model for caretakers to use, as it will help them to work with elders, building on the elder's strengths, rather than concentrating on their weaknesses. Thus, caregiver stress may be reduced when the caretaker focuses on something other than the negative aspects of care (i.e., illnesses or mental problems), while at the same time, the elder will also feel a high sense of self-esteem with the strengths-based focus (Fast & Chapin, 2000). The goals of the care management plan are designed by the older adult in need of care, identifying the areas the elder wants to work on, rather working from a set of imposed goals designed by someone else (Fast & Chapin, 2000).

## Conceptual Framework

The conceptual framework for the study consisted of two theories, supporting a more complete understanding of the complex issue of caregiver stress and social isolation and the potential ill effects on the care recipient. The critical ecological framework (Norris et al., 2013) and the theory on privacy and family role behavior (Laslett, 1973) will be used together to inform the research. Within the scope of abuse in a home care setting, the critical ecological framework essentially combines two conceptual theories to form a more complete view of factors affecting abuse: critical theory (Smith, 1987) and the ecological framework (Bronfenbrenner, 1979). In addition to the critical ecological framework, the theory on privacy and family role behavior (Laslett, 1973) was used to support understanding of the effect of family roles and level of privacy (reflective of social controls) in the home setting on caregiver behaviors.

**Critical Ecological Framework**

Using an ecological perspective, human behaviors are viewed as occurring in multiple and interacting contexts (Bronfenbrenner, 1979), providing a holistic approach. This type of approach allows for exploration of multiple, interacting influential factors leading to possible intervention and support. According to critical theory, actions and thoughts are affected by power relationships developed from social and historical contexts (Smith, 1987).

According to the ecological framework, human behaviors can be understood to result from multiple factors at the various levels of human ecology (Bronfenbrenner, 1979; Norris et al., 2013). Bronfenbrenner (1979) conceptualized these levels of influence to include the macrosystem (socio-historical ideologies and cultural values); the ecosystem (social regulatory structures, such as government agencies and policy and legislation); the mesosystem (relationships between individuals); and the microsystem (relationships reflecting direct interactions, such as family, friends, and formal/informal caregivers). Specific to the phenomenon of abuse of older adults in the home setting by family caregivers, the ecological framework views family interactions holistically and occurring within and between the four levels of environmental interaction, which include the family/close friends, the family's social network, community-based social support networks, and larger dominant social ideologies (Bronfenbrenner, 1979; Norris et al., 2013).

Critical theory describes the interactions between action, power, control, and transformation (Smith, 1987). In the context of this study, critical theory is used to understand the shifting power and role dynamics in the family when an older family member is in need of caregiver support. Within critical theory, everyday actions (human behaviors) are seen as impacted by power relationships, which are supported through social control (Smith, 1987). In addition, critical theory incorporates an associated element of transformation of the process that serves to disempower (Norris et al., 2013). Within the context of older adult abuse, the abuse can be viewed as a manifestation of unequal, and often transformed, power relationships within the family or with the client.

Building upon the ecological framework and the critical theory, the critical ecological framework described by Norris et al. (2013) is used in a combined approach of the ecological framework (Bronfenbrenner, 1979) and elements of the critical theory (Smith, 1987) to more accurately reflect the unique phenomenon of abuse of older adults in a home care setting. The critical ecological framework supports a holistic understanding of the levels of influence and the bidirectional interaction between these levels of influence affecting development and actions of the individual from community level to individual factors (Norris et al., 2013). Thus, using the critical ecological framework, the study findings can be understood within a holistic view that is able to account for interactions (stressors and stress relievers) between and among the macrolevel ideologies serving to shape daily life, situational factors, and relational and individual dynamics (Norris et al., 2013).

**Theory of Privacy and Family Role Behavior**

In addition to the critical ecological framework, Laslett's theory on privacy and family role behavior was used to frame the effect of family roles and level of privacy in the home setting on caregiver behaviors (Laslett, 1973). This framework more specifically addresses the perceptions of possible behavioral changes after implementation of video surveillance in the home care setting, as the privacy and resultant lack of accountability associated with the home setting and the family can lead to isolation and instances of older adult abuse and neglect (Laslett, 1973; Tomita, 1990). In addition, there may be a lack of family controls established, which may contribute to a lack of negative consequences for the caregiver (Tomita, 1990). Laslett (1973) asserted that the common perception of the sanctity of the family in conjunction with the level of privacy common to the family and home environment can contribute to the incidence of abuse of older adults in need of care.

Also, key to the topic of investigation in this study is the notion of social observation, included as an element of the privacy theory and family role behavior (Laslett, 1973). Laslett (1973) explained that as accountability in a social context influences an individual's behavior, the lack of this accountability due to privacy would serve to limit the influence of social control. Therefore, according to Laslett:

> If structural mechanisms which inhibit social control over the enactment of family roles have been reduced in the modem American family, then there is reason to

> expect greater variability in these behaviors in the more contemporary period than was true in the past. (p. 480)

That is, "publicness" increases the influence of social control.

## Elder Abuse

The definition for elder abuse can vary from state to state. In general, the term for elder abuse is any "knowing, intentional, or negligent act by a caregiver or any other person that causes harm or a serious risk of harm to a vulnerable adult" (Administration on Aging, 2013). Abuse can be psychological, emotional, physical, or financial exploitation (Administration on Aging, 2013). Physical abuse can include actions such as hair pulling, shoving, kicking, pinching, yelling, and hitting the elder. The Administration on Aging (2013) pointed out that not all outward signs of injury on the elders' body may be signs of abuse; however, being vigilant of bruises around breasts or genital area from sexual abuse, burns, and pressure marks, can be signs of physical maltreatment. Emotional signs of abuse can be withdrawal from activities, depression, or changes in alertness (Administration on Aging, 2013), while unexpected financial changes can be signs of exploitation. Symptoms of neglect show as bedsores, poor hygiene, unusual weight loss, or unattended medical needs (Administration on Aging, 2013). It is interesting to note, that frequent arguments and strain or tense relationships are also considered signs of abuse (Administration on Aging, 2013).

**Elder Abuse in New York State**

In New York State, it is estimated that the older adult population of individuals 62 years or over will be greater than the youth population under 18 years of age (Lachs & Berman, 2011). By 2030, elders 60 plus years of age will comprise 25.7% of the population. The elder population in New York State is the third largest, surpassed only by California and Florida (Lachs & Berman, 2011). According to secondary data used from the New York City Police Department (NYPD) in Manhattan in 1992 (Brownell, 1998, cited by Lachs & Berman, 2011), most reports of older adult abuse were committed by adult children. The reports to the NYPD were reported as elder abuse categories, according to the New York Penal Law (Lachs & Berman, 2011). Out of a total of 314 filings, 295 older adults 60 years and older were victims of psychological, physical, or financial abuse perpetrated by an offspring (Lachs & Berman, 2011). Brownell's (1998) study concluded that psychological abuse was the most commonly committed form of abuse (35%), while financial (34%) and physical abuse (31%) crimes were less often described and reported. However, as it will be shown below with more current research studies on elder abuse, the trend has shifted to a higher incidence of physical abuse, followed by psychological and financial abuse (Monroe County, 2008).

The NYC Department for the Aging (DFTA) is the oldest agency serving older adults in the NYC area. The agency partners with other county agencies. Since 1998, it has offered services to elder abuse victims who present with domestic violence, financial,

and emotional abuse. Out of this agency, the NYC Elder Abuse Network (NYCEAN) was born. DFTA continues to participate with NYCEAN (Lachs & Berman, 2011).

In 2009, Weill Cornell Medical College, which is affiliated with NY Presbyterian Hospital, launched the NYC Elder Abuse Center to "improve identification and treatment of elder abuse victims in NYC area" (Lachs & Berman, 2011, p. 15). The purpose of the center was to provide elder abuse intervention (Lachs & Berman, 2011, p. 15). A study was conducted by Lachs and Berman (2011) on the self-reported prevalence and documented case surveys of elder abuse. In the self-reported study, an instrument was developed to obtain information regarding experiences of elders with all forms of elder maltreatment from a large enough sample of older adult individuals that would answer the lengthy questionnaire and from a cross-section of all geographical areas in New York State (Lachs & Berman, 2011).

The instrument was developed to support data collection that would enable researchers to make comparisons between each region, being considerate of ethnic and linguistic diversity, being mindful of the cognitive impairments of some older adults, and using a protocol for protection and safety of respondents (Lachs & Berman, 2011). In the event that elder abuse was uncovered during the research study, the study was designed to offer referral assistance to the victims (Lachs & Berman, 2011). The instrument was developed to compare documented case studies with self-reported findings.

The results in the self-reported study indicated that maltreatment in various forms was pervasive throughout the state. Moreover, financial exploitation was reported by

participants as the most frequent abuse, followed by emotional abuse. With regard to the documented data, the data available from agencies was not complete or reliable enough to conduct a valid analysis on the reported cases of elder abuse. There was a gap in the data collection, as not enough information was provided to the researchers related to the documented cases of elder abuse. This was the same with all agencies as well as with Adult Protective Services, where the researchers were unable to obtain the requisite data for the documented case survey (Lachs & Berman, 2011).

Between the rural and urban areas, for example, in New York City, elders tend to receive greater assistance from non-profit agencies for older adults in terms of programs, along with the help of Adult Protective Services (Lachs & Berman, 2011). The rural areas of the state are not as well equipped as the urban areas. A comparison in New York City between self-reported and documented report statistics indicated a higher rate of self-reporting of abuse by elders in the study (92.2%) compared to a significantly lower rate of documented abuse (3.79%). Within the whole state of New York, the incidence of self-reported abuse in the study was 76 per 1000, while documented rates were 3.24 (per 1000) (Lachs & Berman, 2011).

**Protection of Elders from Abuse**

In the United States elder abuse has received attention, and policies have been set in place to address the issue (National Adult Protective Services Association [NAPSA], 2014). There are many organizations and government agencies that have been set up to protect elders from the hands of abusers. However, protection can be difficult, as elder

abuse can be perpetrated in any form: physical, psychological, emotional, sexual, financial, or neglect and has been well documented to be committed by family members, spouse/significant other, home care workers, friends, and other unspecified individuals (Lawitz, 2013). Although there have been programs instituted to protect elders from abuse, there has been a slow progress in eradicating the problem.

Adult Protective Services (APS) began around 1960; however, it was not until 1974, when the Title XX of the Social Security Act of 1974 provided states funding by the federal government under the Social Services Block Grant, that the National Adult Protective Services Association (NAPSA, 2014) was assigned to protect elders from all kinds of abuse (NAPSA, 2014). Statistics from APS indicated that in 1997, a total of 25,000 incidents were referred to social services by APS (APS, 2014). The reported statistics stated that two-thirds were adults over 60, while one-third of the cases were impaired abused, and the remainders were incidences of self-neglect (APS, 2014).

## Caregivers and Care Recipients

Caregivers are persons who are responsible for providing care. Care recipients are those persons who receive the care. Caregivers have a very special job for caring for older adults. People involved in providing care for older adults include family members (e.g., grown children, siblings), spouses, significant others, friends, and home care agency workers. In years past and in many cultures today, the family or extended family was responsible for providing the care for their elders. The use of outside sources such as nursing homes, and home care agencies, was uncommon. Today, with the increase of

home care agencies, elders receive services in their homes by home care workers or family members. However, with this increase in home care businesses, there has been a rising incidence of elder abuse by family members or home care workers.

Research by Ice, Sadruddin, Vagedes, Yogo, and Juma (2012) was conducted with Kenyan parents who had assumed the caregiving role to their children and grandchildren who had become seriously ill, had been incarcerated, were migrant workers, or had died. According to Ice et al. (2012), the grandparents did not have the requisite material resources to care for their children and grandchildren. Based on Pearlin's stress process model, it was proposed that the caregiver role may develop secondary strains that may conflict with the caregiver's responsibilities (Ice et al., 2012). The HIV/AIDs epidemic in Africa has changed the role responsibilities among parent/grandparent caregivers and has contributed to greater stress resulting from lack social and financial support, as these parents are burden with caring for their children and grandchildren.

The longitudinal study conducted by Ice et al. (2012) found that most caretakers in Kenya were women, and they were younger than non-caregivers. The caregivers had an average of 1.9 – 1.0 orphans in their homes, and both caretakers and noncaretakers had the same socioeconomic status. Variables of literacy, level of education, and marital status made no difference in the stress of participants. The woman who had more adults in their homes had less stress. The authors concluded that based on the stress model, there

are many variables that predict higher levels of caregiver stress. This study was limited to data on caregivers 60 years old and older, from a small population from a single city.

Barbosa, Figuerido, Sousa, and Demain (2012) explored the differences between primary and secondary caregiver roles. The cross sectional study was conducted from a sample of 180 dependent elders, 90 primary (family members), and 90 secondary (siblings, friends) caretakers to find out how primary and secondary caregivers cope with their roles. The study found that both primary and secondary caretakers were able to problem solve based on their experiences and expertise. However, the findings also indicated that the use of emotion cognitive strategies made little difference for secondary caretakers. Specific stressors described by caretakers included chronic diseases, poor health, depression and anxiety, lack of social life, and financial burden (Barbosa et al., 2012).

In relation to stress management, neither primary nor secondary caretakers felt able to manage stress; however, they were able to cope with stressors by taking time off or participation in other outside interests (Barbosa et al., 2012). Specifically, helpful strategies to reduce stress were most often described as “having a good cry” among the primary caretakers, and “swimming, walking or exercising” among the secondary caretaker (Barbosa, et al. 2012, p. 495). The study demonstrated that when there was another caretaker to help the primary caretaker, there was less stress associated with the caretaking role, which in turn may discourage the potentiality for elder abuse.

A study conducted by the National Alliance for Caregiving (NAC, 2009), in collaboration with AARP and funded by Metlife Foundation, incorporated an interview survey of 1,397 caregivers of different racial and ethnic backgrounds (76% White, 10% Hispanic; 11% African-American; and 2% Asian-American), who were caring for a person 50 years or older. Results of the study suggested that the majority of participants felt caregiving had no impact on their personal health (8% said it made their health better; 75% felt it had no impact; and 16% said made it worse). Descriptive results suggested that caregivers did not receive a salary for their work, and tended to be females. The caretaker chores included helping the recipient in and out of beds and chairs, housework, and cooking (NAC, 2009). Most of the caregivers stated that they experienced little physical strain, emotional stress, or financial hardship in their caregiving role. However, among caregivers who reported caring for a recipient with Alzheimer's disease, the participants tended to feel more emotionally stressed in their caregiving role, describing lack of support and caregiving assistance (NAC, 2009).

Family caregivers and caretakers are at an increased risk of depression and anxiety disorders related to the sense of burden and stress (Mahoney et al., 2005). In the study conducted by Mahoney et al. (2005), using a sample of 153 caregivers, the authors compared participants who developed depressive symptoms and anxiety to those who did not develop these types of outcomes. As part of the larger London and South-East Region Alzheimer's disease Study, Mahoney et al. conducted a naturalistic inquiry using interviews and assessment data from the Hospital Anxiety and Depression Scale (HADS),

the Health Status Questionnaire (HSQ-12), the Mini-Mental State Examination (MMSE), the Neuropsychiatric Inventory (NPI), the Cornell Scale for Depression in Dementia (CSDD), and the Alzheimer's Disease Cooperative Study Inventory- Activities of Daily Living (ADCS-ADL). Data were analyzed to identify factors associated with caregiver anxiety and depression.

Findings given by Mahoney et al. (2005) revealed that anxiety disorder diagnosed among the caregivers was predicted by recipient activities of daily living impairment, caregiver living with the recipient, being a female caregiver, reports of poor relationship with the recipient, and a poor self-reported caregiver health status. Depression among the caregivers was predicted by recipient irritability, poor reported health of caregiver, and poor quality of the recipient-caregiver relationship. These results highlight the need for intervention and education.

Levine et al. (2010) called for family caregivers to be seen as a critical part of the healthcare needs of older adults and the associated need for training and support to reduce the incidence of abuse and negative health outcomes. Levine et al. provided a description of the complexity of the roles assumed by family caregivers and the specific areas in need of support for better quality care for the older adult care recipients. In their qualitative exploration, the authors detailed the experiences of family caregivers, providing insight into the areas of risk in the home setting, where the lack of observation may play a role in failing to moderate abuse or identifying precursers to abusive behaviors.

## Contributing Factors to Caregiver Stress and Elder Abuse

The major contributor to abuse of elders, according to APS (2014), is caregiver stress. Caregiver stress can be caused from burnout, which can result in "impatience, depression, anger, and hostility…sometimes resulting in abuse" (APS, 2014, p. 2). Other factors leading to abuse of the elders by the caregiver include substance abuse, physical impairment, health status, mental illness, or mental retardation of either the elder or caretaker (APS, 2014). Elder abuse has been viewed as an occurrence that hinders the lives of elders, yet despite recognition of other vulnerable populations, the vulnerability and potential abuse of elders has remained neglected (Cardoso & Segal, 2009). Despite some financial support through government assistance to families providing elder care, caregivers remain susceptible to extreme frustration and overwhelming sense of burden in providing care to vulnerable elders due to the general lack of social support, high levels of stress, and difficulties in meeting the changing needs of dependent elders (Cardoso & Segal, 2009).

Using a conceptual framework of the ecological theory with a focus on the meso and micro ecological systems, the results of the study by Beach et al. (2005) were used to develop a risk profile for family caregivers in the home setting. Predictors or significant risk factors for these potentially harmful behaviors were found to include greater recipient needs, caregivers who were spouses, caretaker cognitive impairment and depression, and caregiver physical limitations. This profile, developed by Beach et al.,

informed the current study in terms of areas of interest and possible directions of exploration.

Karch and Nunn (2010) sought to provide a better understanding of the characteristics and factors that may contribute to the extreme case of homicide at the hands of caregivers of a population of older, care-dependent adults. Karch and Nunn conducted a secondary analysis of data from the National Violent Death Reporting System from the period 2003-2007, which were used to generate profiles of the victims and perpetrators to identify precipitating factors to the homicides. The deaths in the population of care recipients were identified as the result of neglect, intentional injury, or homicide. These care recipient deaths were often followed by caregiver suicide.

The study incorporated qualitative and quantitative data about the type of injury and relational variables of interest (quantitative) and narrative data related to the details of the incidents (qualitative). Results indicated trends or themes in the data related to physical illness of the care recipient or caregiver, substance abuse by the caregiver, and/or a crisis situation in the life of the caregiver that was unrelated to illness (Karch & Nunn, 2010). The results of Karch and Nunn's (2010) study informed the present study through insight into high risk factors to extreme abuse causing death. Understanding these risk factors assists in identifying critical areas in need of support and intervention.

**Substance Abuse**

Substance abuse by the caregiver or care recipient has been identified as a risk factor for increased stress and potential elder abuse (APS, 2014; Jogerst, Daly, Galloway,

Zheng, & Xu, 2012; Karch & Nunn, 2010). In the recent study on the impact of substance abuse by elders and caretakers in the United States conducted by Jogerst et al. (2012), alcohol and substance abuse by the perpetrator were found to be common among occurrences of abuse of elders. When the elder is affected by substance abuse, they are at a higher risk of being abused by the caretaker because of the lack of mental faculties as a result of the drug or alcohol use, which makes it difficult for the elders to protect themselves (APS, 2014). In addition, those caretakers who also abuse alcohol or drugs tend to financially exploit the older adult in order to support their drug habit (APS, 2014). Substance abuse by the caretaker can lead to physical or emotional abuse to the elder by the caretaker (APS, 2014).

**Ethnicity**

In a recent study conducted by Jogerst et al. (2012), results supported ethnicity as a factor related to elder abuse. Findings demonstrated that reports of elder abuse to the authorities were proportionally higher within specific ethnic populations, such as the Hispanic population. In addition, minority ethnicity also was found to be associated with higher investigation and substantiation rates (Jogerst et al., 2012). However, elder abuse within the minority populations does not receive the same attention in research studies, as nonminority. This is primarily due to the prevalence of minority populations living in poor neighborhoods, lacking education, or not speaking English (DeLiema, Gassoumis, Homeier, & Wilber, 2012).

DeLiema et al.'s (2012) study was aimed at investigating five types of elder abuse (psychological aggression, physical assault, sexual coercion, financial exploitation, and caregiver neglect) in minority, mostly Hispanic, communities. The authors found that the incidence of abuse was high within these communities. Additional findings demonstrated that the lack of reporting of abuse in the Hispanic community was based on having "limited English proficiency, economic insecurity, neighborhood seclusion, fear of crime, mistrust of authorities" (DeLiema et al, 2012, p. 1336). However, during the data collection for this study, participants reported feeling secure in reporting abuse because they did not feel threatened that the researchers would report it to the authorities.

**Social Stigma**

The mistreatment of older adults in society has global cultural implications because of the varying degree of value placed on elders in society; some societies highly value their elders while other societies devalue this population (Teaster, Harley, & Kettaneh, 2014). Solutions to the problem of mistreatment of older adults are limited due to the effects of societal values and discrimination, such as ageism, sexism, individualism, and family norms (Teaster et al., 2014). Ageism, or age-based discrimination is evident in medicine, the workplace, media, and supports a devaluation of older adults and the potential for abuse and neglect (North & Fiske, 2013).

Indeed, the pervasiveness of ageism, particularly in negative stereotypes of older adults as forgetful, sickly, and depressed, has researchers suggesting that this type of prejudice is more prevalent in our society than racism or sexism (Rupp, Vodanovich, &

Crede, 2005; North & Fiske, 2013). Levy and Banaji (2004) reported the unfortunate common attitude that older people are "dispensable and useless members of society" (para. 18). Underlying ageism is the general absence of older adults in the mainstream society (North & Fiske, 2013). Broad-based social and cultural theories depict older adults in our society as peripheral or invisible, low in status, lacking social agency, functionally nonreciprocating, and useless (North & Fiske, 2013; Thompson & Thompson, 2009). These notions perpetuate social stigma attached to elders as well as to caregivers, but research has remained lacking in terms of the effect of social stigma on potential abuse of older adults, particularly in a family home care setting.

## Video Surveillance

Technology growth has spurred the emergence of a "surveillance society" that incorporates an ever expanding presence of surveillance technology in daily life (Woolrych et al., 2014). In terms of the care of older adults, surveillance has long been used in institutional settings, such as care facilities. However, the use of video surveillance has emerged to monitor individuals in private settings as well as institutional settings (Sixsmith, 2013, as cited by Woolrych et al., 2014). These in-home surveillance systems are designed to improve safety and support the health and well-being of the older adult in need of care and manage high risk behaviors (Moffatt, 2008). However, socially, our homes provide retreat and refuge. According to Koskela (2000):

> Although the purpose of surveillance is supposed to be an increase in safety, its design is rather, producing uncertainty. Again, this leaves the public as passive

> subjects in a container: they are subjects in a position of not knowing their own being. (p. 250)

According to Hoffman (2013), in some states, there are video cameras in place in some nursing homes to monitor patient security by the facility or cameras put in place by family members of clients who suspect caregivers are stealing property. However, these family members may end up seeing something else—abuse of their loved one by a staff member in the nursing home. Hoffman (2013) reported on a nursing home client whose mother, who had dementia, had items being stolen from her room. The daughter decided to place a hidden camera to catch the thief. Some time had passed by before the daughter remembered the camera and reviewed the footage. She was surprised when she discovered her mother suffered abuse at the hands of the facility aides. The article described how "an aide stuffed latex gloves into Mrs. Mayberry's mouth, while another taunted her, tapping her on the head, laughing, hoisting her from her wheelchair, they flung her on a bed. One performed a few heavy-handed chest compressions" (Hoffman, 2013, p. 1).

Although legislation exists against the use of electronic monitoring due to liability and privacy issues, primarily raised by facility owners, unions, elder care lawyers, and families, the use of such cameras are permissible in some of the residents rooms in some states, such as Ohio, which revealed abuse in some facilities resulting in closure of the facility by the attorney general. General opposition to the use of video cameras in nursing care rooms tend to focus on privacy issues of the clients or because there are visitors that

come to the facilities who do not want to be videotaped. This can be addressed by simply placing a notice on the door of the residence stating that the room is being monitored (Hoffman, 2013). Many feel that monitoring may be misconstrued, and regulations need to be put in place to determine boundaries for the use of video monitoring in terms of when and how appropriate monitoring is used, ownership of the recordings, and who is authorized to view the recordings (Hoffman, 2013).

Despite regulations on the use of video monitoring, this technology is now also being used to assist older adults in maintaining independent living, as the use of technology can permit older adults to live independently in the confines of their homes, while providing family caregivers the opportunity to monitor their safety (Barlow & Venables, 2004; Matthews, 2006, Miskelly & Mickel, 2009). This is being addressed partly with assisted technology that helps elders get around their homes, such as walkers, canes, wheelchairs, emergency call systems, medication reminders; fall prevention detectors; motion sensors, and assisted bathing facilities (Cheek, Nikpour, & Nowlin, 2005; Matlabi, Parker, & McKee, 2012; Miskelly & Mickel, 2009).

According to Goldwater and Harris (2011), remote monitoring is defined as the use of sensory motion detectors and wireless technology to detect behavioral and activity changes in an independent living senior. Remote monitoring can be used to support the safety of older adults living alone by providing monitored information on the psychological symptoms, vital signs, activity in terms of motion and falls, and even the stovetop temperatures, to the assigned case worker, nurse, physician, who can then take

action if necessary (Goldwater & Harris, 2011). The use of this technology decreases the caregiver stress, and can potentially improve the sense of quality of life for the older adult care recipient living in their own home (Goldwater & Harris, 2011).

One way to monitor older adults at home is through the use of picture phones, Smith (2008). The use of these phones, according to Smith, were acceptable by the caregiver and families because their use supported fewer emergency visits and hospitalizations among the older adult care recipients and improved independent functional status for these care recipients (Currell, Urquhart, Wainwright, & Lewis, 2001; Smith, 2008). In fact, caregivers for hospice favored picture phones because the caregiver felt as though a nurse was present (Smith et al., 2002; Smith, 2008). According to Smith (2008), the use of picture phone telecare or web-camera monitoring "showed improved outcomes for homebound older adults and improved quality of life for family caregivers" (Smith, 2008, p. 77).

In Indiana, a telecare model was developed in which the caretakers monitor their clients from their homes, rather than staying overnight with their clients (Martin, 2010). The model was developed by incorporating video camera surveillance with audio equipment and sensors to provide trained caregivers oversight of overnight care to more than 100 people with developmental disabilities, who were living in homes staffed by private providers (Martin, 2010). The technology not only provided the ability for the responsible caretakers to watch more than one client at once, but use of the surveillance technology supported a considerable decrease in Medicaid expense through the use of

this model. In addition, the model was reportedly useful in assisting with medical emergencies, deterring home intruders, preventing the escalation of roommate disagreements, providing medication reminders to clients, supporting clients with conversation during some lonely nights, and other day to day duties of caregivers (Martin, 2010, p. 22). This model supports innovation toward monitoring of the elderly in their homes based on the specific services needed, rather than on location (Mason, 2006). To achieve this level of patient specific monitoring, Mason (2010) mentioned technology in the form of wireless sensors, satellite tracking via global positioning systems (GPS), medical management, and technology supporting telehealth video monitoring of surgical incisions, wound care, skin conditions, edema, blood pressure, pulse, glucose levels, and temperature (p. 72).

There are healthcare devices that elders can use in their homes that will help clinicians monitor, detect, and diagnose health issues, as well as provide certain high technology home treatment options that are available to provide intravenous antibiotic therapy, tube feedings, certain types of dialysis, and oxygen therapy (Matthews, 2006). Although this technology can provide care options, caregivers are still needed to ensure that the equipment is monitored by the client, functioning correctly, and to fulfill other duties. Despite the convenience of these high technology care options, caregivers may still experience stress related to maintaining the equipment while also dealing with other routine duties that the older adult care recipient requires.

In a study conducted by Woolrych et al. (2014), qualitative results of data from a residential facility that had previously instituted video surveillance revealed the use of surveillance as a care management tool. As a tool for providing care, the caregivers providing access to real-time data, preserving older adults' safety. The qualitative findings reported by Woolrych et al. (2014) revealed how the surveillance was being used. The key themes included that surveillance (a) provides access to real-time data; (b) preserves the safety of older people; and (c) monitors the working practices of formal careers.

These monitoring systems support increased options for the majority of older adults who opt for independent living, rather than being placed in nursing homes. More often, older people prefer to live independently in their homes (Matlabi et al., 2012), being cared for by their families or outside caretaker. However, these family caregivers may become overwhelmed and stressed because they may be caring for an adult who has dementia, Alzheimer's, or other mental or physical ailments. As a result, there could be an increased probability of abuse by the caregiver due to caregiver stress.

The research reviewed examined and discussed video surveillance in terms of telehealth, telecare, remote monitoring, and use of hidden cameras in nursing homes to detect elder abuse, and research has been conducted on the first two of the themes reported by Woolrych et al. (2014), including the use of video surveillance to help caregivers provide safe care to older adults who live alone or need surveillance to support security. However, little was found related to the third theme of monitoring the practices

of caregivers and the use of video camera surveillance with respect to monitoring the perceived effects of surveillance on caretaker stress in the homecare setting and the probability that this stress can lead to abuse of the older adult care recipients. Thus, research remains lacking with regard to the social impact of surveillance in the home setting and the perceived impact on the behaviors and attitudes of caregivers (Woolrych et al., 2014).

## Qualitative Research Methodology

Although quantitative methods have dominated research on older adult abuse, qualitative methods have been used more recently to understand community and cultural aspects of abuse and differences or similarities, definitions of abuse and perspectives on intervention services of the individuals experiencing abuse, as well as health care professional perspectives on abuse and intervention. This section of the literature review details four qualitative studies exploring older adult abuse from the unique perspectives of healthcare workers, the older adults themselves, and from nurses in different cultures. These research studies utilized data collection strategies of interviews, open-ended surveys, and document analysis.

Begley, O'Brien, Carter-Anand, Killick, and Taylor (2012) used a qualitative, grounded theory methodology to explore the perceptions of interventions and services offered to support older adults experiencing abuse. The study incorporated data gathered from 58 individuals who were 65 years of age and over using focus group discussions as the data collection tool. The focus group discussions were recorded and transcribed for

use in the grounded theory analysis. Participants revealed the perceived importance of community-based prevention and peer support for older adults at risk of abuse. Other key aspects toward prevention included choice of care provision given to the older adult individual, choice in housing, opportunities for engagement in the community, and opportunities for social support to discuss issues with others. The authors asserted that the findings support service development toward enhancing community activities supporting opportunities for older adults to share concerns in an informal setting and confidence to seek out more formal interventions if necessary.

Schmeidel, Daly, Rosenbaum, Schmuch, and Jogerst (2012) conducted a qualitative, thematic analysis to explore the perceived barriers to detection of older adult abuse and reporting from the perspective of healthcare professionals. The authors conducted 13 open-ended interviews, which lasted between 10 and 60 minutes each. In addition, demographic information was collected on each participant. The interviews were transcribed and entered into Nvivo qualitative analysis software for the thematic analysis. In total, nine nurses, eight physicians, and six social workers were interviewed ($n = 23$). The codes were grouped into categories and analyzed by profession to reveal any differences or similarities. The resulting themes from the analysis revealed similar descriptions of elder abuse by profession and perceived barriers to elder abuse detection and reporting. The barriers were separated out by category of professional orientation (beliefs about abuse, certainty before reporting, uncertainty), assessment (privacy, sensitivity, confidentiality, patient barriers, priorities), interpretation (quality of life,

dependency/autonomy, gray areas), system (laws, internal and external system barriers, reimbursement), and knowledge and education (knowledge of abuse and law, training, misinformation).

Cultural aspects of care of older adults and community contributions to care are integral to the understanding and incidence of abuse among older adults (Erlingsson, Ono, Sasaki, & Saveman, 2012). In a phenomenological, hermeneutic documentary analysis of reports of abuse, Rytterstrom, Arman, and Unosson (2013) explored the various aspects of the culture of care for older adults. The study examined 269 incident reports of suspected mistreatment of older adults. The analysis incorporated a four-step process of (a) selecting and reading the document text; (b) coding both text and the context of the text; (c) closing the hermeneutic circle, which stresses the notion that the meaning of the text is understood through incorporating cultural, historical, and literary contexts; and (d) creating a *concept bridge* to assist in forming a critical understanding of the data revealed from a phenomenological lifeworld perspective.

Findings of the study by Rytterstrom et al. (2013) revealed that older adult care is based on a social culture placing the resident needs at the center; however, care was described as task oriented and impersonal. A key preventative factor was following routines, which were felt to be critical to preventing mistreatment as a means of providing fair and equal treatment. Through a phenomenological, lifeworld perspective, the authors presented an interpretation of municipalities' care of older adults as having a focus on individual older adult freedom at the expense of vulnerability of well-being. The

authors concluded that increased awareness of the underlying care culture related to abuse can serve to help improve the understanding of care and provide better care practice. Reflecting on existing perspectives the care culture could support positive change toward integrating care culture into a broad framework for providing care (Rytterstrom et al., 2013).

Care cultures may be different across demographic and physical locations. Erlingsson et al. (2012) used a qualitative methodology to compare nurse reactions to elder abuse across nationality and cultural divides. For the study, data were collected from 81 community-based nurses residing in Sweden and 124 public health nurses in Japan using an open-ended questionnaire. The questionnaire asked participants to respond to three hypothetical cases of older adult abuse. A qualitative, content analysis was used to code and analyze the data. Response patterns from the responses to the open-ended survey questions provided themes related to awareness, assessment, and intervention. The authors noted that despite cultural differences between the Swedish and Japanese nurses, response similarities pointed to the universal "humanness" of the problem of older adult abuse and of the nurses' responses to the abuse.

## Summary

Although literature was evident identifying elder abuse and prevalence of elder abuse, as well as the risk factors associated with elder abuse, little research was found on defining intervention strategies to reduce such abuse. The literature related to reduced

abuse tended to focus on the levels of caretaker stress and strategies for helping caregivers to avoid their own risk factors correlated to abuse. However, a gap in the literature was evident in the use of home video surveillance techniques applied to elder care in a home setting. Although video cameras have been used in organizations and institutions of elder care, the home setting generally does not offer this type of surveillance.

The prevalence of older adult abuse by home caretakers and family members is likely to increase in the future with the expected increase in the older population (United States Bureau of Census, 2010). Therefore, effective interventions to support caretakers by providing strategies to reduce and control levels of stress associated with caring for an older adult in the home care setting are critical to the prevention of older adult abuse. Of interest to this study concerning the home care environment and the lack of social observation in such settings (Laslett, 1973) is the potential influence of perceived social observation on stress and related abusive behaviors of caregivers. In order to develop more effective prevention strategies and support to caregivers, it is essential to understand the experiences stress among family caregivers or caretakers to older adults.

As the older adult population increases, it is important to understand the experiences and perceptions of family and others in home caregivers to older adults. Chapter 3 presents the methodology of the study that will serve to uncover the experiences of participants and help identify specific intervention strategies to reduce older adult abuse and neglect in the home care setting.

# Chapter 3: Methodology

## Introduction

This phenomenological study explored the experiences of family caregivers of older adults and home care workers who provide care in the home setting. Caring for a family member or older individual in the home setting can be a significant burden and a source of stress for the caregiver. This stress can affect the quality of care for the older adult care recipient. In this study, data were collected in the form of textual data resulting from semistructured interviews with a purposeful sample of nine caregivers. The recorded and transcribed data were used to represent the experiences and perceptions of the participants with regard to the stress of caring for an older adult family member or client at home and the perceived influence of video surveillance. From a conceptual framework based in critical ecological theory and the theory of privacy and family behavior, a high level of stress combined with a lack of social control in the home care setting could contribute to an increased propensity for stressful situations to elevate to abuse or neglect (Laslett, 1973; Norris et al., 2013; Tomita, 1990). As the population of older adults continues to increase, it is important to understand the experiences and perceptions of family and other in home caregivers to the elderly. The findings of the study could help to identify interventions to reduce older adult abuse and neglect in the home care setting.

## Research Method, Design, and Rationale

A phenomenological design was used for this study. It is inquiry-based and uses an inductive process of exploring a phenomenon or an occurrence via questions, narrative descriptions, and analysis of emerging themes, and incorporates the use of interview data to accomplish this goal (Creswell, 2009). More specifically, the phenomenological design offers the ability to explore the lived experiences of a group of participants related to a phenomenon (Creswell, 2009). In this study, the research questions focused on their experiences with, and perceptions of, the stress associated with providing care for an older adult family member or client in the home.

Research Question 1: What are the experiences of stress and the factors that are perceived to influence stress levels in providing quality care to older adult care recipients among family caregivers and homecare workers in the home setting?

Research Question 2: What are the perceptions of home video surveillance of family caregivers and homecare workers and their ability to provide quality care to their family members or homecare clients?

### Research Method

Qualitative research is useful when the goal is to describe complex phenomenon through an in-depth study of a small group of individuals (Creswell, 2009). Because qualitative data are typically collected in a natural setting (Creswell, 2009; Moustakas, 1994), qualitative methods are often responsive to the specific local situation and needs

of the participants or other stakeholders (Johnson & Christensen, 2008). In this way, qualitative research is also described as a means of exploring how and why questions about a phenomenon using the words and common responses of participants (Creswell, 2009; Johnson & Christensen, 2008).

**Research Design**

The phenomenological design offered the ability to explore the lived experiences of a group of participants (Creswell, 2009) with specific experiences of the phenomenon of caregiver stress associated with providing care to an older adult family member or client, the perceived influence of introducing social controls in this setting. Phenomenology supports further understanding what happens in the home care setting and how abuse/maltreatment can be avoided in this setting. Using a transcendental phenomenological approach, I gained insight into the essence of the experiences and perceptions of the participants (Creswell, 2009; Moustakas, 1994), which provided valuable understanding toward the development of strategies to combat abuse, maltreatment, and neglect among this population of older adults.

Phenomenology focuses on the meaning and essence of the lived experiences of the individuals in the study, seeking an in-depth understanding of the nature of individual experiences in the everyday world and how we, as individuals, make sense of those experiences (Patton, 2002). Along with a focus on individual experiences, phenomenology is also used to identify, through analysis, emergent common or shared ideas, which can be used to identify the findings and develop the conclusions both

individually and for the group of participants as a whole (Moustakas, 1996; Patton, 2002).

**Rationale**

The particular strengths of phenomenological research highlight the rationale for use in this study. One of the key strengths of phenomenological research is the direct interaction with participants. This direct interaction, typically through conducting interviews, allows for clarification through follow-up and probing questions as well as observation of non-verbal responses, supporting a more in depth understanding (Kvale & Brinkmann, 2009; Moustakas, 1994). The findings will, therefore, offer detailed insight into the lived experience of stress and burden and the unique situation of participants providing care in the home setting. The use of narratives in expressing these insights promotes recognition and understanding among the readers, providing interpersonal knowledge by describing participants in specific situations holistically (Todres & Holloway, 2010). According to Todres and Holloway (2010), this type of insight helps to humanize the knowledge, which may be critical to maintaining an ethical base of practice.

The phenomenological design was appropriate for the research study, as the goal of the research was descriptive in nature, seeking to identify common experiences that describe and define stress and potential abusive or neglectful behaviors among caregivers of older adult family members or clients in the home. From the essence of the experiences of family caregivers or home care workers, I was able to gain an in-depth

understanding of each participant's experiences of stress and factors felt to contribute to potential for abuse or maltreatment as well as the perceptions of participants with regard to the perceived impact of social scrutiny and the potential modification of behavior associated with "being watched."

Interviews are often the primary method of data collection in a qualitative study, as a means of obtaining the participants' perceptions and experiences (Creswell, 2009, 2013). Through semi-structured interviews, I was able to explore participants' views and perceptions, allowing for the identification of themes and patterns in the data (Creswell, 2009). Shared experiences serve as thematic conclusions that provide insights into the phenomenon (Patton, 2002). The findings provided valuable understanding toward the development of strategies to address the stress of caregivers toward reducing the potential for associated abuse and neglect of this population of older adults.

Other designs were considered for this study, including ethnography and case study. However, because the participants were not representative of a specific ethnic origin, and the participants were not recruited from one or a few particular sites or locations (such as a nursing home), ethnographic and case study research were deemed less appropriate for the study. Phenomenology maintains the needed focus on the lived experiences of the participants for this study.

## Role of the Researcher

I served as the primary instrument in conducting face to face interviews with the participants in a natural setting (Creswell, 2009; Moustakas, 1994). The interview

protocol consisted of an introduction, in which I discussed the study, obtained consent to participate, and asked the designated questions, recording responses via both handwritten notes and digital audio recording (Creswell, 2009). During the data collection and analysis process, I remained consistent with the phenomenological concept of epoche, which requires that I refrain from personal judgment and to view the phenomenon under investigation in the absence of bias and preconceived notions (Moustakas, 1994). The epoche begins as a personal and self-reflective process in preparation for the data analysis and phenomenological reduction; however, the epoche is a continuous process that does not end with phenomenological reduction (Moustakas, 1994).

> A solitary activity in which its nature and intensity require my absolute presence in absolute aloneness. I concentrate fully, and in an enduring way on what is appearing before me in and in my consciousness . . . everything becomes available for self-referral and self-revelation. (Moustakas, 1994, p. 87)

Phenomenological epoche and data reduction requires that I bracket out presuppositions and assumptions, providing for the discovery of the data in its purest form (Patton, 2002), thus the term *bracketing*. The bracketing process enables the research to be based on the research questions and therefore focused on the specific phenomenon under investigation (Moustakas, 1994).

## Participant Selection

The present study maintained a focus on the perceptions of the caregiver family members or home care workers providing caregiving who may have experienced severe

stress in providing this care and their thoughts and opinions of the impact and use of video camera surveillance in the home. Thus, the sample was drawn from a population of caregivers of older adult home care patients in the greater New York City metropolitan area. I sought to include at least four family caregivers (related by blood) and four home care workers (unrelated to the care recipient). Caregivers of older adult patients who receive regular visits from the United Jewish Council of the East Side Home Attendant Service Corp were given an introductory, informational letter asking for volunteer participants (see Appendix B for copy of Invitation Letter).

The United Jewish Council of the East Side Home Attendant Service Corp is a large home health care organization in New York, offering access to a large pool of potential volunteers from the New York City area for participation in the study. In the state of New York, an estimated 260,000 older adults had reportedly been victims of at least one form of abuse between 2008-2009 (Lachs & Berman, 2011). Many of these older adults are visited by visiting nurses regularly. To be included in the study, a caregiver must have been the primary caregiver for the older adult care recipient in the household, age 18 years and older, and be willing to freely volunteer for the study.

**Sampling**

The sample was a purposeful sample of caregivers in the New York City area. Purposeful sampling is a non-probabilistic sampling method in which the research setting and participants are specifically chosen due to their likely ability to provide the necessary information for the study (Creswell, 2009; Patton, 2002). Therefore, for this study,

voluntary participants were purposefully sought through their association with the United Jewish Council of the East Side Home Attendant Service Corp. A recruitment letter was given to caregivers who may be interested in voluntarily participating in the study.

The purposeful sampling plan enabled me to obtain an appropriate sample that would provide data that could be used to answer the research questions of the study (Creswell, 2009). The ability to obtain such an appropriate sample for the study is critical in qualitative research because participants must be able to provide specific narratives to be used to provide clarity and depth to the exploration of the phenomenon (Neuman, 2003). Thus, the selection of participants in qualitative research must be focused on purposefully obtaining such a sample.

The study combined purposeful sampling techniques with convenience sampling, another form of non-probability sampling, in which subjects are selected because of their convenient accessibility and proximity to me (Castillo, 2009). Using convenience sampling, the participants are selected due to their ease of recruitment. Because of size of the target population on a national scale, a convenience sample was used in this study to draw from a smaller population of caregivers of older adults in the New York City area.

**Sample Size**

Recommendations for specific sample sizes in qualitative research are loosely defined compared to the specific sample size calculations associated with quantitative research. In contrast to the relatively large sample sizes recommended to support validity in quantitative research, qualitative research typically incorporates small sample sizes

(Creswell, 2009, 2013). Recommended sample sizes for a qualitative sample generally fall between 1-25 participants (Creswell, 2009, 2013; Polkinghorne, 2005). However, Patton (2002) asserted that qualitative sample size determination lacks specific rules, but rather depend on the purpose of the study, the desired data to be obtained for usefulness in the study, the necessary credibility and how to achieve it, and finally, what can feasibly be obtained given time and resource limitations of the study.

Based on the review of the research recommendations related to qualitative sample sizes offered by Creswell (2009), Polkinghorn (2005), and Patton (2002), the selected sample size included a total of 8-10 caregiver participants, with the final number of participants included in the study at nine. The selected participants were asked to voluntarily participate in the study. This sample size was selected due to the expected availability and willingness of voluntary participants in the New York City area and the need to obtain in-depth data for analysis. The data obtained from the open-ended interview questions was expected to be able to provide for rich and descriptive findings.

## Procedures for Recruitment and Data Collection

After receiving IRB approval from the university [IRB approval number 06-25-0058416] and written consent for cooperation from the United Jewish Council of the East Side Home Attendant Service Corp, a purposeful sample of nine caregivers to older adult family members or home care clients in the New York City area were recruited for participation in this study. Contact information was obtained from the United Jewish Council of the East Side Home Attendant Service Corp and a recruitment letter was given

to potential participants who may be interested in the study. The selected participants were asked to voluntarily participate in the study.

The collection of data for this study incorporated semi-structured interviews, using open-ended questions that allowed for narrative responses from the participants (Creswell, 2009). Interviews began with demographic questions, including caregiver age and ethnicity; caregiver relationship to care recipient; availability of other family members to help with care; care recipient age, circumstances, difficulties, and living arrangements. These demographic data were used to describe the sample and to understand the specific circumstances surrounding the care relationship. All participants were asked the same semi-structured, open-ended interview questions during individual, face to face interviews. Follow up or probing questions were used to clarify or generate greater understanding of individual responses, and therefore, were likely different for each participant. Interviews were anticipated to last from 30-60 minutes. Caregivers were interviewed at a location of their choice, to maintain confidentiality of being observed/overheard by others during the data collection (e.g., a private conference room at a local library).

The interviews began with introductions, a discussion of the purpose of the study, and a review of the consent form. Participant confidentiality also was discussed and I explained the use of pseudonyms in place of their actual names as a means of protecting their confidentiality in this study. Through the use of pseudonyms, participants should have been encouraged to fully disclose relevant perceptions and experiences. Interviews

were documented using field notes and audio recordings of the discussion (Creswell, 2009). Interviews concluded once all interview questions had been answered and participants no longer had information to add. The audio recordings of the interviews were transcribed into Microsoft Word ®. NVivo qualitative analysis software was used for the analysis of the transcribed data. The interview questions were developed based on the research questions of the study and on the literature reviewed pertaining to caregiver stress, quality of care for the older adult care recipient, and social controls in the home care setting (Bergeron, 2001; Smith et al., 2011; Tomita, 1990). These interview questions are documented in Appendix A.

## Data Analysis and Interpretation Plan

The objective of a phenomenological data analysis is to provide detailed descriptions of the experiences and perceptions of individual participants while searching for common patterns shared by the group of participants (Polit & Beck, 2006). For this study, the data were analyzed using the modified van Kaam method of phenomenological data analysis (Moustakas, 1994). Phenomenological analysis is a method used to capture the perceptions of participants, which are seen as the primary source of knowledge (Moustakas, 1994). The exploration generates a vivid depiction of the experiences of the individual participants as well as common experiences and perceptions among the group of participants as a whole (Moustakas, 1994). The phenomenological model, as presented by Moustakas, focuses on four elements: epoche, phenomenological reduction, imaginative variation, and synthesis of meanings and essences.

Qualitative analysis of the transcribed data was used to identify common responses that revealed themes from the data obtained from the participants (Creswell, 2009, 2013). These themes represent the perceptions and experiences described by the participants as a whole. Phenomenological analysis is used to capture perceptions of participants in an exploration of a phenomenon, providing a uniquely rich and detailed description of the experiences and perceptions of both the individual participants and the group of participants as a whole (Moustakas, 1994). Within a phenomenological approach, the primary source of knowledge stems from the individual's perceptions (Moustakas, 1994). The data analysis for the study followed the seven-step modified van Kaam phenomenological analysis model, as detailed by Moustakas (1994). Moustakas offered the following seven step approach to phenomenological analysis:

1. *Listing and Preliminary Grouping*: List every expression relevant to the experience (Horizonalization).
2. *Reduction and Elimination*: To determine the Invariant Constituents: Test each expression for two requirements:
    a. Does it contain a moment of the experience that is a necessary and sufficient constituent for understanding it?
    b. Is it possible to abstract and label it? If so, it is a horizon of the experience. Expressions not meeting the above requirements are eliminated. Overlapping, repetitive, and vague expressions are also

eliminated or presented in more exact descriptive terms. The horizons that remain are the invariant constituents of the experience.

3. *Clustering and Thematizing the Invariant Constituents*: Cluster the invariant constituents of the experience that are related into a thematic label. The clustered and labeled constituents are the core themes of the experience.
4. *Final Identification of the Invariant Constituents and Themes by Application*: Validation: Check the invariant constituents and their accompanying theme against the complete record of the research participant. (a) Are they [themes] expressed explicitly in the complete transcription? (b) Are they compatible if not explicitly expressed? (c) If they are not explicit or compatible, they are not relevant to the co-researcher's [participant's] experience and should be deleted.
5. Using the relevant, validated invariant constituents and themes, construct for each co-researcher [participant] an *Individual Textural Description* of the experience. Include verbatim examples from the transcribed interview [or other qualitative data].
6. Construct for each co-researcher [participant] an *Individual Structural Description* of the experience based on the Individual Textural Description and Imaginative Variation.
7. Construct *for each research participant* a *Textural-Structural Description* of the meanings and essences of the experience, incorporating the invariant

> constituents and themes. From the Individual Textural-Structural Descriptions, develop a Composite Description of the meanings and essences of the experience, representing the group as whole. (Moustakas, 1994, p. 121)

Nvivo 10 qualitative analysis software was used to assist the analysis through providing a workspace to organize the data during the coding and categorization process and to track the frequency of occurrence of common statements and responses of participants. During the coding process, relevant data were categorized (or coded) by content into headings representative of the concept discussed (Creswell, 2009, 2013; Merriam, 1998). This coding process was conducted to identify and develop themes and patterns from the data. Nvivo 10 software assisted me in managing the qualitative data. As such, I was able to classify and sort the data using the program, as well as note the frequency and location of each occurrence. The Nvivo workspace was used to carry out the coding process as well as to review the codes and heading (or nodes) created for further categorization.

## Quality and Trustworthiness

Validity and reliability are terms typically used in quantitative research to describe whether the findings are accurate from my standpoint, the participant, or the readers of an account, as well as whether the approach is consistent across different researchers and projects (Creswell, 2009). The corresponding terminology in qualitative research includes quality and trustworthiness or credibility and transferability. In qualitative, naturalistic inquiry, credibility and rigor are points of evaluative concern and,

therefore, the validity and reliability of the study are important considerations, reflective of the quality and accuracy of the data.

The study incorporated thick description and member checking to support credibility and quality (Creswell, 2013). Thick description in the written text helps to capture and convey the meaning and essence participants give to their experience, which allows the reader to understand and relate directly to the setting and discussion of the shared experiences of the participants (Creswell, 2009; Moustakas, 1994). Member checking provides an opportunity for the participants to (a) review the data collected from the interview process and my interpretation of that data, and (b) confirm the accuracy of that data (Creswell, 2009). Using member checking in the study, participants in the study were given the opportunity to review the transcription and notes from the interview as well as the final analysis results and to provide feedback on the interpretation and accuracy of the data that were collected. Therefore, the transcribed text of the interviews and the final analysis interpretation were forwarded to participants for review of accuracy.

As a qualitative study, the results were not generalizeable to a larger population of similar family/client caregivers. Although not generalizable to a larger population, the conclusions drawn from the experiences and perceptions of the participants from this population of caregivers can be used to shed light on the possible perceptions of other caregivers to older adult family members or clients in the home setting, and therefore, potential strategies to support this population. However, it is noted that the use of

voluntary participants may have supported unintentional recruitment of individuals with strong positive or negative opinions on the use of video surveillance and older adult homecare, introducing additional bias.

Addressing transferability in qualitative research, Yin (2009) suggested reporting a detailed protocol for data collection so that the procedure of a qualitative study might be replicated in another setting. Therefore, the collection and analysis of the data in this present study strictly followed the data collection and analysis procedure as described. In addition, the use of Nvivo10 qualitative analysis software supports the quality of research by helping to limit instances of human error in the coding and analysis process.

## Informed Consent and Confidentiality

Potential participants were recruited through an informational solicitation letter with contact information of potential participants obtained through cooperation with the United Jewish Council of the East Side Home Attendant Service Corp. This recruitment solicitation provided caregivers with essential information on the purpose of the study and participation in the study. Individual caregivers who expressed interested in participating in the study were asked to contact me directly, at which time I checked the inclusion criteria and discussed the informed consent process with the caregiver.

The informed consent included pertinent information for the potential participant, which included the purpose of the study, a description of the interview process and what would be expected of participants in terms of tasks and time commitment, identification of any risks associated with the study, a discussion of how the researcher would maintain

participant confidentiality and how the data would be protected and stored, and the option to withdraw from participation at any time. When signing the consent form, participants were asked to categorize themselves into one of two groups for participation, (a) family caregiver (related by blood), or (b) home care worker (not related to the care recipient). After review of the consent information, individuals who continued to express voluntary intent to participate were scheduled for a one-on-one interview. At the time of the interview, but prior to beginning the interview questions, the researcher again reviewed the consent form with the participant, answered any questions, and asked the participant to sign the informed consent form. In order to continue with participation in the study, each participant was required to sign the informed consent form in the presence of the researcher prior to conducting the research interview.

The researcher was responsible for protecting the rights of participants and ensuring participant confidentiality. Participation in this study was voluntary. Participants were given a $20 gift certificate for their participation in the study. I discussed and directly addressed with potential participants that access and quality of United Jewish Council of the East Side Home Attendant Service Corp. would not be affected by participation or nonparticipation in the study and that participants were free to discontinue participation at any time with no consequence. Although there were no foreseeable risks to participants from this study, participants were informed of the responsibility of the researcher to disclose suspected abuse according to the university, local, state, and federal laws. Special precautions to protect participant confidentiality

included the use of a pseudonym in place of participants' actual names, and the avoidance of collection of personal identifiable information. The participants were informed that the interview would be audio recorded and that the audio data would be transcribed and electronically archived by me on an external computer USB drive and kept in a secure, locked file cabinet for the required period of five years. Upon fulfillment of the five year requirement, all electronic data and paper informed consent documents will be destroyed.

## Ethical Considerations

Ethical issues were inherent in this study, as it directly dealt with a vulnerable population (Rudestam & Newton, 2007). Efforts to address these ethical concerns included ensuring that the researcher (a) obtained consent for participation in the study from participants, (b) provided full disclosure of all risks and benefits of participation, and (c) used pseudonyms in the study to maintain participant confidentiality. The confidentiality of participants is an important aspect of the research process.

Given the sensitive nature of this study topic, it was critical to provide assurances of confidentiality to participants in order to obtain honest and accurate interview data. Potential participants were sought on a voluntary basis, with no coercion to participate and a clear distinction offered between study participation and care services. In order to support participant confidentiality, participants received a pseudonym and no personal identifiable information was obtained during the interview process. Efforts also were made to ensure the comfort of participants at all times, particularly during the interviews,

and the understanding that they could discontinue participation at any time. Interviews were limited to 30-60 minutes to avoid undo stress on participants.

All participants were required to sign an informed consent form in order to participate in the study. I visited interested participants, at which time, the study was thoroughly explained to the participant, any questions were answered, and the participant, if desiring to continue to participate in the study, was asked to sign the informed consent. Given the sensitive nature of the topic of interest, it was critical that each participant fully understood their role in the research study, any risks or benefits of participation, and the purpose of the study. For this reason, I visited each participant to obtain informed consent.

## Summary

This chapter has provided a discussion of the research methodology that was employed in the study and the various aspects of the methodology. A qualitative, phenomenological design was chosen for the study, using semistructured interviews. Chapter 3 included a discussion of the appropriateness, or rationale, for choosing the qualitative, phenomenological research design, as well as a description of the plans for sampling, data collection and analysis, the protection of participants, and issues of validity and reliability, or quality and trustworthiness. Chapter 4 presents the results of the analysis of the interview data and Chapter 5 offer a discussion of the qualitative findings in relation to the research questions and the relevant research literature and the implications of these findings.

# Chapter 4: Data Analysis and Results

## Introduction

The purpose of this qualitative, phenomenological study was to understand the experiences of older adult care providers in the home setting with regard to experiences of stress and perceptions of the impact of the use of video surveillance in the home setting on caregiver stress. This chapter details the analysis process and results from the data collected for the study. Data were collected using semi-structured interviews from a purposeful sample of nine care providers. Interviews were audio recorded and transcribed for analysis. From the data, themes were revealed, shedding light on the experiences and perceptions of the participants. The findings address the research questions of the study as follows:

RQ 1: What are the experiences of stress and the factors that are perceived to influence stress levels in providing quality care to older adult care recipients among family caregivers and homecare workers in the home setting?

RQ 2: What are the perceptions of home video surveillance of family caregivers and homecare workers and their ability to provide quality care to their family members or homecare clients?

This chapter covers the following topics: analysis of the data obtained from the nine interviews, a description of the sample in terms of demographic data, the process of data coding and analysis ( to explain how the themes were developed), the results, which are based on the themes and supported with quotes from the interviews.

## Description of the Sample

Despite efforts to recruit family caregivers as well as private caregivers, all nine participants were hired personal caregivers. They were between the ages of 35 and 63, of various ethnic origins, and their recipients were between the ages of 65 and 102. Four of the care recipients lived with a husband or other family member who did not provide direct care, four lived alone, and one lived with the care provider. Table 1 shows the demographic characteristics of the sample.

Table 1

*Demographic Characteristics of the Sample*

| Age | Ethnicity | Age of care recipient | Living condition of care recipient | Availability of other family members |
|---|---|---|---|---|
| 35 | Dominican | 65 | Lives with husband or family | Other family available but do not provide care |
| 45 | Hispanic-Latino | 75 | Lives alone | No family available |
| 56 | African | 89 | Lives with caretaker | Available, but do not provide care |
| 49 | Puerto Rican | 81 | Lives alone | Available, but do not provide care (visits only) |
| 49 | Hispanic-Latino | 75 | Lives alone | Available, but do not provide care |
| 60 | Dominican | 81 | Lives with family | Available, but do not provide care |
| 59 | Dominican | 92 | Lives alone | No family available |
| 45 | Dominican | 65 | Lives with family | Family provides some care |
| 56 | Dominican | 97 | Lives alone | No family available |

## Data Coding and Analysis

A phenomenological analysis was conducted using the transcribed interview data obtained from a sample of nine older adult care providers. The aim of the study was to understand the experiences of stress and perceptions of the use of video surveillance in the older adult home care setting. To accomplish this goal, the seven-step modified van Kaam method was employed to code key words and phrases (termed invariant constituents) and reveal themes from the interview data, which were used to identify the essence of the experiences of these participants (Moustakas, 1994). NVivo10® qualitative analysis software was used to provide an organized workspace to complete the analysis.

The seven-step van Kaam process of phenomenological analysis, as described by Moustakas, includes listing and preliminary grouping (horizonalization), reduction and elimination, clustering and thematizing the invariant constituents, final identification of the invariant constituents and themes (validation), generation of individual textural descriptions, construction of individual structural descriptions, and the production of textural-structural descriptions (Moustakas, 1994). Finally, the analysis uses composite descriptions in the form of overarching themes in order to represent the essence of the experiences and perceptions of the group as a whole. The first four steps of the modified van Kaam method (Moustakas, 1994) were used to code the relevant statements and phrases and to develop the thematic categories. The participant responses or statements represent the experiences and perceptions of the participants with regard to providing

older adult care, the associated stressors, and their specific perceptions of the use of video surveillance in the home care setting.

## Findings

Through the coding and analysis of the data, thematic categories were developed to represent the lived experiences of participants with regard to providing older adult care in the home setting and their perceptions of the use of video surveillance. These thematic categories are presented individually with textual examples directly quoted from the interview data to support enhanced understanding of the experiences and perceptions of each participant, while also supporting commonality of the response type using frequency determinations (i.e., how many participants reported or mentioned the same response). Through an analysis of both the individual details offered in each interview and the common responses noted across the set of nine interviews, the researcher was able to understand the perceptions of the group as a whole.

### Circumstances and Responsibilities of Care Providers

The first thematic category was developed from participants' descriptions of the specific circumstances and responsibilities they have with their current caregiving situation. The nine participants specifically described personal care (bathing, toileting, grooming), food preparation and feeding the care recipient, and administering and tracking medications for the care recipient. Additional common responsibilities included housekeeping and taking the care recipient to the doctor's office or other appointments.

Table 2 illustrates the common responses offered by participants and the frequency of mention of each response among the nine interview participants.

Table 2

*Common Responses for Circumstances and Responsibilities of Care Providers*

| Response: Circumstances and responsibilities | Number of participants to give this response |
|---|---|
| Personal care; bathing, grooming, bathroom | 6 |
| Food preparation and or feeding | 6 |
| Medication | 6 |
| Housekeeping | 4 |
| To doctor or other appointment | 3 |
| Shopping | 2 |

Most participants described responsibilities of personal care provided to their care recipient. These included bathing, grooming, and assisting with toileting, food preparation and assisting with feeding, keeping track of medications and ensuring the care recipient takes medications according to specified medical instructions, and general housekeeping. Other assistance mentioned by participants included doing laundry, assistance getting the care recipient to the doctor or other medical visits, and shopping. Some care recipients, as noted by the caregivers, use a walker or have severe difficulty getting around and need assistance ambulating.

**Personal Stressors**

The second thematic category, caregiver personal stressors, was developed from participant discussion of personal experiences of stress and perceptions of factors that contribute to caregiver stress. Common responses among participants revealed themes of patient stubbornness; rudeness or lack of respect for the care provider; instances when the patient is difficult, acts out or is hostile; and difficulties with patient wants (i.e., when patient wants something he or she cannot or should not do). These experiences were discussed as particularly stressful to the care providers.

Table 3

*Common Personal Stressors of Participants*

| Response: Personal Stressors | Number of participants to give this response |
|---|---|
| Patient stubbornness | 3 |
| Rudeness; lack of respect | 3 |
| Difficulties dealing with patient wants | 3 |
| When patient is difficult, acts out, is hostile | 2 |
| Fear that the patient will fall, get hurt, or die | 2 |

The participants commonly described issues with the care recipient's lack of respect and rudeness toward the care provider. The care recipients were reported to think of the caregivers as a "maid" or "slave" who is not offered respect and is put down. Participants also described dealing with the patient acting out. These difficult situations

can be unpredictable and, therefore, the caregiver remains uncertain as to the current situation when arriving to work. For example, Participant 4 explained:

> She is on all these medications that make her act out and be rude a lot of the times. This is the problem that most girls [caregivers] have with clients; they do not want to deal with clients that are rude or act out or lash out. … I do not think it is personal, but it is hard to deal with. … When you get to work you never know what you are going to be facing.

The participants described the care recipient's mood as determining the level of stress for that particular day. If the patient is in a "bad mood" (Participant 2), the caregivers expressed that the day will be "very stressful." The opposite was also described.

Another problem contributing to stress among the participants was patient stubbornness. Participants described difficulties getting the care recipient to do what they need to do because the care recipient does not want to do it, or difficulties because the care recipient wants to do something they should not do and will not listen to the advice of the caregiver. This was also described by two other participants, who mentioned how the care recipient will not always want to do what is needed, such as taking medication or eating, and this stubbornness can escalate to hostility and anger, also contributing to stress among the participants. This acting out can become more hostile, also contributing to stress among the participants. These instances of difficulty with the clients, particularly when escalated, were noted by the participants to create significant stress. The last

common response was stress reported from fear that the patient would fall, otherwise hurt him or herself, or even die. Two participants described this type of stress.

**Perceived Effect of Video Surveillance**

The third thematic category, perceived effect of video surveillance, was developed from participant responses to questions regarding the perceived effect of the presence of a video camera, perceived positive and negative effects of video camera use, and how use of video surveillance may hinder or improve quality of care provided. All nine participants felt the presence of the video camera would not affect the care provided, good or bad, because they would do their job to the best of their ability, regardless of the presence of a camera in the home. Participant 9 explained, "If you are sure of what you are doing, it does not matter whether there is a camera or there is not a camera." The participants described doing their job 150% regardless of video presence.

Six participants mentioned positive effects of video camera use, such as the protection of both the care recipient and care provider. In describing how the presence of the camera can protect the care provider, the participants explained how the care recipients may be untruthful, how the camera can be an insurance in terms of proving their job quality, revealing the notion of providing protection to the care provider. Participants also noted the benefit of protecting the care recipient; although one participant felt the camera would not affect her own personal work, she described the camera as a means of protection for the care recipient.

In terms of negative effects of the use of video camera in the home, participants commonly noted privacy issues, and that the care provider would feel additional stress and nervousness, not wanting to be watched. Three participants described an effect of feeling nervous, anxious, or worrying about the camera being present. For example, one participant also described how the camera would make her feel nervous, which would negatively affect her work by contributing to her stress. Table 4 illustrates the commonality of the responses and the subsequent development of common themes.

Table 4

*Perceived Effect of Video Camera in Home*

| Response: Perceived effect of video camera | Number of participants to give this response |
|---|---|
| No effect; do job regardless | 9 |
| Positive effect | 6 |
| Protection | 6 |
| Protect the caregiver | 4 |
| Protection of patient | 1 |
| Feel it is good | 3 |
| Would help find things when patient loses stuff; reduce stress on caregiver | 1 |
| Negative effect | 5 |
| Privacy issues | 3 |
| Make stressful, nervous/not work well/ don't want someone watching | 3 |
| Behavioral changes due to use of camera | |
| Does not or should not affect | 4 |
| Checking self; know being watched | 3 |

Lastly, in terms of specific behavioral changes that may result from the use of the video camera, similar to the previous responses, participants felt the presence of the camera would not or should not affect any behavioral changes (4 participants), would affect the care provider in that she would be checking herself, knowing she is being

watched, and would be negative or have fear that someone is watching all the time, even in private locations like the bathroom. Half the participants specifically stated that the camera would not affect their behavior as a care provider.

In terms responses of participants commonly describing checking themselves if a camera is present, Participant 3 noted the need to be more careful in what you are doing and how you react. Similarly, another participant described behavioral effects in terms of watching ones reactions to care recipient behaviors. In these ways, the camera presence could potentially support improved quality of care.

**Agreement or Disagreement with Camera Use**

The fourth thematic category, agreement or disagreement with use of camera, was formed by participant responses to the question of whether or not they agreed with the use of video camera surveillance in the home care setting. The participants were generally split on their perceptions of agreement with four agreeing with the use of the camera, four disagreeing with the use of the camera, and one both agreeing and disagreeing (i.e., seeing both positives and negatives to the use).

Among participants who agreed with the use of the camera surveillance, the participants cited the protection of the care worker and the care recipient. One participant noted the camera can be used to protect care recipients from abuse. Alternatively, the camera could be used to protect the care provider, as was explained in detail by Participant 8, in which the participant described the camera as a security aid for the caregiver, particularly when dealing with Alzheimer's or other dementia in the care

recipient, who may commonly accuse the caregiver of taking things or when something happens to the patient (e.g., a fall).

Other participants disagreed, some not providing a reason, and others citing privacy issues, stating that maintaining privacy is more important. Participant 5 noted the belief that the camera should be used for entering and exiting only. Lastly, one participant offered reasons for both agreeing and disagreeing with the use of the video camera in the home, noting the benefits of the camera when a person lives alone for their own safety, but noting that others may feel uncomfortable with the surveillance. Table 5 provides the responses and frequency of the responses to demonstrate commonality of the agreement or disagreement data.

Table 5

*Agreement or Disagreement with Use of Camera in Home*

| Response: Agreement or Disagreement with use of camera | Number of participants to give this response |
|---|---|
| Agree | 4 |
| To protect care worker | 3 |
| To protect patient from abuse | 2 |
| Disagree | 4 |
| Due to privacy issues | 1 |
| Both agree and disagree (patient safety if alone and privacy issues) | 1 |

**Support Mechanisms or Opportunities Felt to Reduce Stress**

The fifth thematic category describes participant perceptions of support mechanisms or opportunities that were felt to reduce stress or were felt to potentially reduce stress. The two common responses included family support (visitation, needed supplies, etc.) (3 participants), and agency support (supervision of home, arranging schedule, ensuring breaks and time off when needed). Table 6 provides all the responses offered by participants, both common responses and single responses (mentioned by only one participant), indicating potential support mechanisms.

Table 6

*Perceived Support Mechanisms toward Reducing Stress*

| Response: Support | Number of participants to give this response |
|---|---|
| Family support and visitation, needed supplies | 3 |
| Agency support; supervise home, arrange schedule, breaks, time off | 3 |
| Taking time off when needed | 1 |
| Have no stress | 1 |
| Older adult training on how to be respectful of care provider | 1 |
| Rest; proper rest is critical | 1 |
| Patient alarm for help | 1 |
| Walker or wheelchair | 1 |
| Increased compensation; salary | 1 |
| Help with cleaning etc, non-patient care responsibilities | 1 |
| Good matching up between clients and caregivers | 1 |

Family support was considered to be a mechanism to reduce stress by the participants in this study. Family visitation and support was described by Participant 5, for example, as important to both the well-being of the care recipient and the reduced stress of the care provider. Participant 3 described the need for family support in terms of providing necessary supplies.

Lastly, some participants individually mentioned the need for time off, or rest when needed so that the care provider was able to handle the stress of the job. Sometimes, this would be provided by the agency, other times, perhaps the family could provide the needed time off for the home care provider. Participant 4 described the importance of the caregiver being well rested and how the agency could support the care providers in this way by not pushing them to work longer hours.

**Themes: Composite Descriptions of Meanings of Experiences**

Stemming from the thematic categories, the data were further clustered and categorized into overarching themes, highlighting common responses that served as the conclusions for the group of participants as a whole. Combining the high frequency common responses of the thematic categories with the individual descriptions of experiences, the following overarching themes were revealed in this analysis and serve as the composite descriptions of the meaning of the experiences and perceptions for participants in this study. The first two themes of focus on personal care and stress of negative care recipient attitude and behaviors are used to address the first research

question, in which the researcher sought to understand the personal experiences of stress and the factors perceived to influence stress among this population of care providers. The remaining themes serve to shed light on the second research question, in which the researcher sought an understanding of the perceptions of participants with regard to the use of home video surveillance.

**Focus on Personal Care**

The caregiver maintains a focus on personal care (bathing, toileting, grooming), food preparation and feeding, administering medications, shopping and transportation to doctor, and light housekeeping. The caregivers in this study described their work as task oriented, providing the essential personal care in terms of bathing, grooming, and nourishment for the care recipient.

**Stress of Negative Care Recipient Attitude and Behaviors**

Specific stressors on the care provider were revealed to be patient stubbornness; rudeness and lack of respect for the care provider, instances when the patient is difficult, acts out, or is hostile; and difficulties with patient wants (i.e., when patient wants something he/she cannot or should not do).

**No Perceived Effect of Video Camera on Care Provided**

Perceptions of the presence of the video camera were that it would not affect the care provided by the care provider because the care provider would do their best job regardless of the presence of the camera in the home. The caregivers in this study almost unanimously asserted that the quality of care provided would not be affected by the

presence or absence of a video camera for surveillance. They did feel, however, that the camera offered certain positives and negatives associated with their agreement or disagreement with the use of cameras in the home care setting.

**Positive and Negative Effects of Video Surveillance: Protection versus Privacy**

Findings supported both agreement and disagreement of the participants with the use of the camera, with perceptions of the positive and negative effects of video camera use. Positive effects were noted in terms of the protection of both the care recipient and care provider. Participants highlighted protection of the care provider resulting from the camera recording events to support or prove quality of work of care provider. This is particularly relevant when the care recipient is hostile or complaining about the care received. The camera also offers protection from abuse to the care recipient. Perceptions of negative effects of video camera use included privacy issues, and that the care provider would feel additional stress and nervousness, not wanting to be watched.

**Caregiver Concerns for Privacy Issues with Video Surveillance**

In terms of specific behavioral changes that may result from the use of the video camera, similar to the previous responses, participants felt the presence of the camera would not or should not affect any behavioral changes in terms of quality of caregiving to the care recipient (4 participants). However, participants did feel the presence of the camera would affect the care provider in that she would be checking herself, knowing she is being watched, and would have a negative attitude or have fear that someone is watching all the time, even in private locations like the bathroom.

### Caregiver Support from Family Involvement and Agency Supervision

Support can be gained from family support (visitation, needed supplies, etc.) and agency support (supervision of home, arranging schedule, ensuring breaks and time off when needed). Participants felt that support from the family and or the agency was critical to ensuring the caregiver has the necessary breaks, time off, and resources needed to provide high quality care. Family involvement was primarily noted in terms of visitation and providing the needed supplies. By visiting, family members can allow the caregiver a break. Agency involvement for caregivers who are not related to the care recipient included supervision of the care setting, ensuring the caregiver has appropriate scheduling, breaks, and time off, as well as fair compensation.

## Summary

This chapter has presented the findings of the qualitative, phenomenological data analysis of nine interviews with older adult home care providers related to the specific experiences of stress and the potential effect of the use of home video surveillance on care provider stress. The analysis revealed several overarching themes that served as the conclusions for the analysis, offering insight into the essence of the experiences and perceptions of the participants. The themes generated from the analysis included: (a) personal care work provided by the care providers; (b) patient stubbornness; rudeness and lack of respect for the care provider, instances when the patient is difficult, acts out, or is hostile; and difficulties with patient wants; (c) perceptions of the presence of the video camera were that it would not affect the care provided; (d) both agreement and

disagreement of the participants with the use of the camera, with perceptions of the positive and negative effects of video camera use; (e) no general effect on care provider work, but potential effects in terms of care provider checking herself, knowing she is being watched, and would be negative or have fear that someone is watching all the time, even in private locations like the bathroom; (f) support gained from family support and agency support. Chapter 5 will provide a discussion of these findings in relation to the research questions of the study as well as to prior research in the field.

# Chapter 5: Discussion, Conclusions, and Recommendations

## Introduction

The purpose of this phenomenological study was to understand the experiences of care providers for older adult in the home setting; the emphasis was on experiences of stress and the perceptions of the use of video surveillance in the home care setting. The nine participants were recruited from a population of caregivers of older adults in the greater New York City metropolitan area who received regular visits from the United Jewish Council of the East Side Home Attendant Service Corp. The themes revealed were used to address the following research questions:

RQ1: What are the experiences of stress and the factors that are perceived to influence stress levels in providing quality care to older adult care recipients among family caregivers and homecare workers in the home setting?

RQ2: What are the perceptions of home video surveillance of family caregivers and homecare workers and their ability to provide quality care to their family members or homecare clients?

The themes revealed in this phenomenological study described the home care workers' focus; personal stressors; perceptions of the effect of the use of video surveillance in the home; and helpful resources and supports for the home caregiver. Through analysis, the study's themes were narrowed to the following five.

1. *Home caregivers' primary responsibilities of personal care*: The caregivers' primary responsibilities were described as personal care (bathing, toileting, grooming), food preparation and feeding, administering medications, shopping and transportation to doctor, and light housekeeping.
2. *Primary stressor of difficult care recipient behavior*: Specific common stressors on the home care provider included stubbornness; rudeness and lack of respect for the care provider, being difficult, acting out, hostility; and patient inappropriate wants (i.e., something he/she cannot or should not do).
3. *No perceived effect of video surveillance on care provided by caregiver*: According to the participants, the video camera would have had no effect on care because the provider would do her or his best job regardless of the presence of the camera in the home.
4. *Perceived protection of both caregiver and care recipient with video camera use, but concerns for privacy issues*: Participant perceptions of the positive and negative effects of video camera use included the protection of both the care recipient and care provider (positive) and privacy issues (negative). Notably, the camera was described as offering protection from abuse to the care recipient while also offering protection of the care provider resulting from camera recording events to support or prove quality of work of care provider. Despite the advantages of perceived protection for both caregiver and care recipient, privacy issues were a noted concern, such as the care

provider feeling additional stress and nervousness, not wanting to be watched or being concerned about being watched in private locations. This concern resulted in both agreement and disagreement of the participants with the use of the camera.

5. *Importance of family and agency support to caregiver*: Participants described that caregiver support can be gained from family support (visitation, needed supplies, etc.) and agency support (supervision of home, arranging schedule, ensuring breaks and time off when needed).

## Discussion of the Findings

Older adult care is based on social and cultural norms with a focus on the needs of the care recipient, but generally described as task oriented and impersonal (Rytterstrom et al., 2013). However, the healthcare workers in this study described a focus on providing personal care to the older adults in their care. This included bathing, toileting, grooming, food preparation, and feeding; these tasks were in addition to administering medications, shopping, providing transportation, and housekeeping. These general duties that were focused on personal care aligned with NAC (2009) descriptions of caretaker chores, which included helping the recipient in and out of beds and chairs, housework, and cooking. This task orientation can be seen as a way to prevent mistreatment, as Rytterstrom et al. (2013) found routines to be a key preventative factor of abuse.

**Experiences of Stress and Factors Perceived to Influence Stress (RQ1)**

Perhaps the biggest risk factor for older adult abuse is caregiver stress (NAC, 2009). Looking at specific stressors described by the participants in this study, the care providers described difficulties with patient behaviors as most stressful, difficulties such as patient stubbornness, rudeness, lack of respect, and hostility toward the care provider. The care providers in this study highlighted patient attitudes and behaviors that may affect them emotionally, supporting a type of stress that could increase the likelihood of caregiver burnout, and turn care recipient hostility toward the caregiver into caregiver hostility toward the care recipient. Although not directly noted in other studies in terms of these types of patient behaviors, this finding supported previous research that has suggested more emotional stress in the caregiving role when dealing with Alzheimer's or dementia patients (NAC, 2009), and significant stress related to burnout, causing impatience, depression, anger, and hostility toward the care recipient (APS, 2014). These factors have been related to increased incidence of abuse (APS, 2014).

Other factors mentioned in the literature found to be related to increased risk of harmful behaviors or abuse included caregiver or care recipient substance abuse, physical impairment, health status, mental illness, or mental retardation (APS, 2014), and greater recipient needs, spousal caregivers, caregiver cognitive impairment and depression, and caregiver physical limitations (Beach et al., 2005). The findings of this study did not collaborate these factors specifically, but the link between more difficult care recipients

with mental disorders such as Alzheimer's or other dementia, and the noted stressors of care recipients who are more difficult to manage in terms of their attitude and behavior seems evident. Care recipients who demonstrate aggressive, hostile, disrespectful behavior (which can be common among those with forms of dementia) present a specific challenge to caregivers, as noted by the study participants, in terms of increased stress on the caregiver.

Similar care provider stressors mentioned in other research, but not noted by the participants in this study, included chronic diseases, poor health, depression and anxiety, lack of social life, and financial burden (Barbosa et al., 2012). These specific factors may be lacking from the findings in this study due to the inclusion of only hired care workers (i.e., no family caregivers). Specifically, financial burden and lack of social life (Barbosa et al., 2012) may not be issues for the hired caregiver (such as the participants in this study) compared to the family caregiver who is also dealing with the financials of the older adult care recipient and devoting all of their time to the care recipient, as opposed to a hired caregiver who may split the caregiving load with other hired caregivers. Indeed, Barbosa et al. (2012) found that when another caretaker was available to help the primary caretaker, less stress was associated with the caretaking role, supporting this notion. This supporting role is key, as the findings of this study also support the importance of family involvement, which is discussed further in the following sections.

The study by Beach et al. (2005) used an ecological framework to examine these stress factors within the home care setting. This is critical due to the external factors of

perceptions, attitudes, and stigma that can affect the availability of additional family caretakers and the quality of older adult care (Levy & Banaji, 2004; North & Fiske, 2013; Thompson & Thompson, 2009). Increased stigma could limit family involvement, even in cases of hired caregivers. These family members offer needed respite and support to the primary caregiver. This type of support is noted later in the discussion of participant suggested support mechanisms.

**Perceptions of the Use of Home Video Surveillance (RQ2)**

Specific to the use of video cameras in the homecare setting, care provider participants in this study generally supported the use of video surveillance in the home as a means of protection. Accordingly, in home security or surveillance systems are designed to support the safety, health, and well-being of older adults in need of care and to manage high risk behaviors (Moffatt, 2008). As noted by previous research as well (Moffatt, 2008; Woolrych et al., 2014), the participants in this study described the camera as providing protection from abuse to the care recipient directly and by monitoring of the care provider. However, a unique finding of this study was that among the participants in this current study, the idea of protection was often described from a different perspective from the prior literature, in which the focus was on the protection of the care recipient.

Although participants in this study did describe the video surveillance as used to ensure the safety of the older adult care recipient, the participants also described that the video surveillance can serve to protect the care provider. These caregivers, confident in the quality of the work they provide, felt the camera could provide evidence of their

quality of work, particularly with care recipients who demonstrated hostile, negative behaviors. In this way, the camera would provide evidence as to quality of work to agency or hiring family in situations when the care recipient may complain or accuse the care provider of poor quality of care.

This perceived threat of being accused of poor care is the direct result of the privacy of the homecare setting. Although prior research has supported the use of video surveillance to help caregivers provide safe care to older adults who live alone to provide surveillance to support security of the older adult, little research has been conducted examining the use of video cameras as a means of monitoring the practices of home caregivers. In the same way, research remains lacking with regard to the social impact of surveillance in the home setting and the perceived impact on the behaviors and attitudes of caregivers (Woolrych et al., 2014). Prior research such as Koskela (2000) and Rapaport (2012) has suggested that in-home surveillance systems can provide for increased safety, but also acknowledged the production of uncertainty or misinterpretation related to public scrutiny of an unknown situation, and whether the camera actually provides support for the care provider in this way.

The caregivers in this study generally felt the presence of the video camera would not affect the care provided or their personal behaviors as caregiver in any way because the care providers felt they would do their best job regardless of the presence of the camera in the home. In that light, the participants were split in terms of agreement for or against the use of the camera in the home setting. Participants highlighted positive effects

in terms of protecting the care provider by recording events to support or prove quality of care provider work. However, negative perceptions related to video camera use included privacy issues, and that the care provider would feel additional stress and nervousness, not wanting to be watched. Among the participants citing negative effects of video camera use, specific behavioral changes noted stemming from the use of the video camera were that the care provider would be checking herself, knowing she is being watched, and eliciting a negative reaction or have fear that someone is watching all the time, even in private locations like the bathroom.

**Social Support Through Family Involvement and Agency Support**

Finally, the participants in this study suggested that support can be gained from family support (visitation, provision of needed supplies, etc.) and agency support (supervision of home, arranging schedule, ensuring breaks and time off when needed). Research supports that the increased susceptibility of caregivers to extreme frustration and overwhelming sense of burden when providing care to vulnerable older adults is primarily due to the lack of social support, high levels of stress, and difficulties in meeting the evolving needs of the dependent older adult care recipient (Cardoso & Segal, 2009). The findings of this study supporting the need for social support and time off when needed align with research that supports caregiver strategies to reduce stress of taking time off, participating in outside interests, and participation in exercise to cope with stressors (Barbosa et al., 2012). In addition, Barbosa et al. (2012) concluded that when another caretaker was available to help the primary caregiver, there was less stress

associated with the caregiving role. Prior research has supported the importance of community-based prevention and peer support for older adults at risk of abuse (Begley et al., 2012). Given the results of this study and prior literature, social, community-based prevention could also be directed at the caregivers in terms of providing adequate social support for those responsible for providing the care to older adults.

From a critical ecological perspective, social perceptions, negative attitudes, and stigma associated with older adult care may be affecting the availability and participation of family members in caretaking responsibilities (Levy & Banaji, 2004; North & Fiske, 2013; Thompson & Thompson, 2009), limiting family involvement, even in cases of hired caregivers, such as those interviewed for this study. Through the critical ecological framework, bidirectional family interactions can be understood holistically, occurring within and between the four levels of environmental interaction, which include the family/close friends, the family's social network, community-based social support networks, and larger dominant social ideologies (Bronfenbrenner, 1979; Norris et al., 2013). These ideologies shape daily life, situational factors, and relational dynamics (Norris et al., 2013).

The family members of the care recipients discussed in this present study, even when living nearby or even with the care recipient, were not noted to be participatory in the care of the older adult and yet, their support was felt to provide relief from stress among the care providers interviewed. These family members can offer needed respite and support to the primary caregiver. Social and community programs or agency

programs intended to support greater family involvement in the care of the older adult could prove beneficial. For hired caregivers specifically, this support could also come from the hiring agency, as noted by the participants in this study. The agency should be responsible for ensuring adequate time off for the workers to avoid burnout or overwork, and to participate in outside and social activities known to support being able to cope with the stressors of the caregiving environment (Barbosa et al., 2012).

This framework also addresses the perceptions of possible behavioral changes after implementation of video surveillance in the home care setting, as the privacy and resultant lack of accountability associated with the home setting and the family can lead to isolation and instances of older adult abuse and neglect (Laslett, 1973; Tomita, 1990). According to the privacy and family role theory (Laslett, 1973), accountability in a social context influences an individual's behavior, and as such, the lack of this accountability due to privacy would serve to limit the influence of social control. Contrary to what would seem logical from the privacy and family role theory perspective, participants in this study contended that their care would remain consistent regardless of the presence of the camera, as their focus is in providing quality of care. However, participants' confidence in proving the quality of care to others, even in instances of difficult care recipients, was noted as improved with the presence of the camera.

## Limitations of the Study

This study of home care providers was limited to a sample of nine hired, non-related (i.e., not family members) home care providers. Despite efforts to recruit family

caregivers, this researcher was not able to successfully recruit these participants. Due to this limitation, the findings are specific to hired home health care workers and not family care providers. The findings, therefore, lack the critical family dynamic with a family member as the primary care provider, which may contribute to different findings.

Although this study provides the strength of revealing detailed experiences of the participants for heightened understanding of the situations and settings that contribute to caregiver stress, the qualitative nature of the study limits the generalizability of the study. The study findings are not generalizable beyond the study sample population, but the findings can provide insight into possible stressors and experiences of stress for other home caregivers.

Finally, despite efforts to support participant confidentiality and comfort during the interview process, the study was limited to the level of detail and openness of the participants with regard to the topic. Given the sensitive nature of this topic and the relationship with potential for older adult abuse in the home care setting, participants may not have been completely open and honest with regard to their perceptions, particularly in relation to personal stressors and the use of video surveillance and the perceived behavior changes that may result from the presence of the camera. In an effort to support openness and honesty among the participants to provide accurate findings, participants were reminded of procedures to protect their confidentiality and interviews took place in a comfortable, relaxed, and private location.

## Recommendations for Further Research

Findings of this study can be extended to better inform the literature on the topic, extending to larger populations or different settings through additional research. It is recommended that a similar study be conducted using family home care providers to identify differences or similarities in stress experiences and possibly reveal the impact of the family dynamic among care providers in this setting. Family responsibilities and changing power and relationship dynamics can affect how individuals relate to each other, including in a caregiving relationship (Laslett, 1973). Changing role responsibilities among family caregivers has been shown to contribute to greater stress resulting from lack of social and financial support (Ice et al., 2012). A qualitative study specific to the dynamics of family caregivers and the new roles they have in the family would inform the literature specific to this growing dynamic.

Given that the findings of this study were not generalizable beyond the immediate population of hired home caregivers to older adult care recipients, a quantitative study seeking to identify the incidence of high frequency stressors and perhaps the specific relationship between care recipient attitudes and negative behaviors toward the care provider and level of provider stress would help to identify key stressors in the home care setting, which may be unique from other care settings. In addition, quantitative research can be used to evaluate the effects of support strategies, comparing stress levels before and after implementation of various support strategies, such as increased family involvement/visitation, regular exercise, and a variety of agency support mechanisms

(requirements for breaks, scheduling regulations, etc.) to support coping with stress among caregivers.

Lastly, although ethnicity and income information was not collected specifically in the present study, conducting another similar study in which these variables are also collected would allow the researcher to compare the results along social class lines to identify potential differences.

## Implications of Findings

Modern family conditions, particularly of dual working households in which fewer family members are available to provide full-time care for their older adult family members due to responsibilities of work, children, or other obligations, are supporting an increased need for hired home health workers, particularly older adult caregivers in the home care setting (Hooyman & Kiyak, 2008; Nicholl et al., 2008). With the increasing older adult population, the increasing popularity of homecare, the declining availability of family members to care for the aging, and the increasing incidence of older adult abuse, current social changes support the need to examine the stress and other factors that contribute to or alleviate the potential for maltreatment of older adults in need of care in the home setting. Findings from this research study (a) identify key stressors specific to the home care setting related to difficult care recipient attitudes and behaviors, (b) support strategies for helping caregivers cope with these stressors to reduce potential for maltreatment, and (c) assist in understanding the caregiver perspective on home video

surveillance and whether this type of surveillance contributes to or reduces caregiver stress in the home care setting.

The suggested strategies for coping with caregiver stress are considered at different social-ecological levels, including strategies for family members, caregivers themselves, and agencies involved in the placement and scheduling of caregivers. With the identification of primary stressors among caregivers, suggestions for positive coping strategies, and perspectives on video surveillance in the home, this research contributes to knowledge and understanding of older adult care in the home environment and the support systems needed to ensure quality care for the older adult population. At the family level, the findings support increased involvement of family members (not designated as the primary caregiver) can support better quality of care to the older adult by reducing stress on the primary caregiver. Findings support the potentially positive impact of family members who increase visitation, or plan to provide a lunch break for the caregiver, or other designated breaks to relieve the caregiver and provide opportunity for exercise or other social interactions. In addition, agency programs can support reduced caregiver stress and/or enhanced coping with existing stress by providing adequate breaks, supervision of the home care environment, adequate staffing to avoid overwork, and exercise programs or other social events for hired caregivers. On a larger scale, community programs designed to promote socialization of both the older adult care recipient as well as caregivers can promote positive social interactions and coping with

the stressors of caregiving by removing the isolation that can be problematic in the home setting (Norris et al., 2013).

## Recommendations for Practice

Findings of this study support several recommendations for practice. These recommendations are related to (a) identifying specific stressors in the home care environment for primary caregivers of older adults, (b) supporting caregivers by providing strategies and guidelines such as …… for better coping, and (c) the use of video surveillance in the home. Caregiver stress is the foremost predictor of older adult maltreatment and abuse (APS, 2014). Results of this study highlight specific stress related to negative care recipient attitudes and behaviors toward the caregiver: stubbornness; rudeness and lack of respect for the care provider; instances when the patient is difficult, acts out, or is hostile; and difficulties with patient wants (i.e., when patient wants something he/she cannot or should not do). Concurrently, the findings supported the need for adequate rest, time off, exercise or other social activities outside the care environment, and family and agency support to help the caregiver cope with these stressors. In circumstances in which the care recipient has a tendency to demonstrate these negative or more hostile behaviors, it is recommended that agencies ensure the caregiver scheduling allows for adequate time off, breaks during the day, opportunities for exercise or organization-wide social activities. Although reducing these types of stressors may not be possible, putting some programs in place by the agency could provide the needed relief to caregivers to ensure the best quality of care by

supporting ways that caregivers are able to copy more effectively with the stressors present.

Caregivers should encourage family involvement and support, understanding that the inclusion of family social support is believed to promote less stress for the caregiver, and as a result, higher quality of care for the care recipient. Agencies that promote family involvement and patient and family education on the benefits of family involvement will likely benefit from caretakers who are less stressed.

In terms of video surveillance, it is recommended that agencies and private home care employers consider placement of video cameras in the home, given both older adult care recipient and caregiver consent, particularly for situations in which the care recipient tends to be hostile or negative toward the care provider. Caregivers reported perceptions of less stress in terms of the video as a security measure for the caregiver in providing evidence of the quality of care they are providing to the care recipient, despite potential complaints or misunderstandings, supporting job security and enhanced patient care. Care must be taken to avoid private areas such as bathrooms or other areas in which an individual should and would assume privacy.

## Conclusion

The major contributor to abuse of older adults is caregiver stress (APS, 2014). Although it may not be possible to reduce the stress on caregivers, this exploration of the experiences of stress among a sample of nine older adult home caregivers revealed that a greater sense of family and community involvement and support may offset the feelings

of isolation of the home care environment through increased family involvement and visitation, enhanced agency involvement and supervision, and ensuring the caregiver is given opportunities to engage in strategies designed to help cope with the inherent stressors of the job. In addition, video camera surveillance in the home care setting may provide social support through observation of the situation in the home, supporting both social control on the behavior of the caregiver and direct evidence of quality of care for the caregiver. A more socially supported caregiver will be more likely to be able to cope with the intrinsic stress of the caregiver role, reducing potential for older adult maltreatment and abuse. Protecting the caregiver from extreme stress, isolation, maltreatment, and or misunderstanding of quality of care will serve also to protect the care recipient from maltreatment and support high quality care to older adult care recipients.

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# Appendix A: Interview Questions

**Demographic Questions:**

1. What is your age?
2. How would you describe your ethnicity and/or race?
3. In terms of the older adult you care for:
    a. What is your relationship to the care recipient?
    b. How old is the care recipient?
    c. Can you explain the circumstances requiring care or the specific difficulties the older adult in need of care requires assistance with?
    d. What are the living arrangements of the care recipient (e.g., living alone, living with you, etc.)?
4. Although you are the primary care provider, are there any other family members that contribute to caring for this older adult?

**Primary Interview Questions:**

1. Describe for me your circumstances and your responsibilities in caring for your older adult family member or client.
2. Please describe your personal experiences of stress related to providing care for your older adult family member or client.
3. What specific factors do you feel affect your stress levels that may affect how you respond to or care for your older adult family member or client, both positive and negative?

4. How do you think the presence of a video camera for surveillance in the home might affect your stress levels?
5. How do you think the presence of a video camera might help your ability to provide appropriate, quality care for your family member or client?
6. How do you think the presence of a video camera might hinder your ability to provide appropriate, quality care for your family member or client?
7. How do you think the presence of a video camera might affect behavioral changes on your part related to the care of your older adult family member or client, if any?
8. Do you agree with or disagree with the use of video camera surveillance in the home setting and why? Please explain your answer.
9. What specific support mechanisms or opportunities do you feel would be most helpful in relieving the stress related to providing older adult care at home?

Appendix B: Invitation Letter

## Invitation Letter

Dear Participant,

This letter is to request your permission for participation in a research project. The purpose of this study will be to describe the perceptions and experiences of caregivers that contribute to and influence stress in the home care setting. As part of this purpose, the study is designed to describe participant perceptions related to the possible influence of video surveillance in the home environment on caregiver stress and older adult abuse. There will be a $20 gift certificate compensation for participation in the study. The findings of the study may help to identify specific intervention strategies to reduce caregiver stress and older adult abuse and neglect in the home care setting.

The study will be based on a 30-60 minute interview with me as the researcher in which you will be asked questions about your experiences of providing care for an older adult in the home, your thoughts on caregiver stress and how it may be affected by the use of video cameras in the home, and a series of demographic questions such as age, ethnicity, and the caregiving situation. The interviews will be audio recorded and transcribed into a Word document. You will be asked to review the transcript for accuracy and to review the study findings for accuracy of conclusions drawn.

I will be the only one who has access to these transcriptions. If at any time during the interview, you choose to withdraw from the project, interview data will be destroyed immediately. Your participation is voluntary. Although there are no foreseeable risks in participation of this study, you may withdraw from the study at any time and for any reason. There is no penalty for not participating or withdrawing. Participation and records

of participation will be confidential. To ensure that data collected cannot be linked back to participants, data will be kept in a secure location. In addition, names and identifiable information will not be included in the dissertation.

I am doctoral student at Walden University in Minnesota. This research is part of my dissertation. I am working under the direction of my Chairperson, Dr. Richard Percy (rpercy@waldenu.edu ) Human Services program. If you have any questions regarding this study, please contact me at (917) 750-4830 or at asuncion.neri-candelaria@waldenu.edu. This project has been reviewed according to the Walden University IRB procedures governing your participation in this research.

Your signature below indicates your willingness to participate in the study. Please return the signed letter to me within three days, if possible. Thank you.

Sincerely,

Asuncion Neri-Candelaria

I have read the consent letter above. I understand the parameters of this research and I am a willing participant.

_____

Participant's name

## Appendix C: Summary Plan of the Research Results

To provide research participants access to a summary of research results, given sensitive research content, the recommendations offered by Fernandez et al. (2012) were followed. A return of a *Summary of Results* document to the research participants will be drafted upon completion of the study. Accordingly, this summary will include the following:

Summary of Results for Dissertation Research Study Titled:
*The Perceptions of Video Surveillance and Its Influence on Caregiver Stress in the Home Care Setting*

Thank you for participating in my research on the stressors involved in home elder care and the potential impact of video surveillance in a home care setting.

**Risks and Benefits of Receiving Results:**
There are risks and benefits to receiving research results. The information obtained in the results may be directly useful to personal and health care decisions; however, research results with adverse implications may cause individual distress. Careful consideration should be given before accepting to review the results of the research when acting as a participant. However, it is noted that for this study, participants were asked to review the results of the research as part of the member checking process of validating the findings.

As noted in the consent for participation in the study, given the possibility of experiencing some psychological or emotional feelings, the following mental health providers who offer low cost care may be contacted for follow-up.

New York City Free Clinic – (917) 544-0735
16 East 16th Street, New York, NY 10003
Weill Cornell Community Clinic – (646) 962-9222
505 East 70th Street, 1st Floor, New York, NY 10021
St. Anthony Free Clinic – (718) 401-9705
421 East 155th Street, New York, NY 10458

Should you have any questions with regard to these results, these questions should be further directed to your personal health care provider.

**The following results are provided for the study entitled:**
The Perceptions of Video Surveillance and Its Influence
on Caregiver Stress in the Home Care Setting

**This study was conducted by: Asuncion Neri-Candelaria.**
**Date of Study Completion: May 2017**

**Background and Purpose of the Study:**
There is a need for greater understanding of the stress experiences of older adult caregivers in the homecare setting due to the potential for abuse given the level of privacy and lack of social observation that would otherwise serve to limit this behavior.

From interviews with caregivers in the homecare setting, the researcher was able to gain an in-depth understanding of their unique stress experiences as well as their perceptions of the impact of video surveillance on stress and the potential modification of behavior associated with "being watched."

The specific problem under investigation was the need for increased understanding of the experiences of caregivers related to stress in the older adult home care setting, as well as the perceived effects of social observation on stress and the potential for development of abusive behaviors.

The purpose of this study was to describe the perceptions and experiences of caregivers that contribute to and influence stress in the home care setting. As part of this purpose, the study was designed to describe participant perceptions related to the possible influence of video surveillance in the home environment on caregiver stress and older adult abuse.

**Summary of the Study Procedures:**
Study participants were asked to participate in a 30-60 minute interview with the researcher in which they were asked questions about their experiences of providing care for an older adult in the home, participant thoughts on caregiver stress and how it may be affected by the use of video cameras in the home, and a series of demographic questions such as age, ethnicity, and the caregiving situation. The interviews were audio recorded and transcribed into a Word document. Participants were then asked to review the transcript for accuracy and to review the study findings for accuracy of conclusions drawn.

**Major Findings of the Study:**

The suggested strategies for coping with caregiver stress are considered at different social-ecological levels, including strategies for family members, caregivers themselves, and agencies involved in the placement and scheduling of caregivers. With the identification of primary stressors among caregivers, suggestions for positive coping strategies, and perspectives on video surveillance in the home, this research contributes to knowledge and understanding of older adult care in the home environment and the support systems needed to ensure quality care for the older adult population. At the family level, the findings support increased involvement of family members (not designated as the primary caregiver) can support better quality of care to the older adult by reducing stress on the primary caregiver. Findings support the potentially positive impact of family members who increase visitation, or plan to provide a lunch break for the caregiver, or other designated breaks to relieve the caregiver and provide opportunity for exercise or other social interactions. In addition, agency programs can support reduced caregiver stress and/or enhanced coping with existing stress by providing adequate breaks, supervision of the home care environment, adequate staffing to avoid overwork, and exercise programs or other social events for hired caregivers. On a larger scale, community programs designed to promote socialization of both the older adult care recipient as well as caregivers can promote positive social interactions and coping with the stressors of caregiving by removing the isolation that can be problematic in the home setting (Norris et al., 2013).

Findings of this study support several recommendations for practice. These recommendations are related to (a) identifying specific stressors in the home care environment for primary caregivers of older adults, (b) supporting caregivers by providing strategies and guidelines for better coping, and (c) the use of video surveillance in the home. Caregiver stress is the foremost predictor of older adult maltreatment and abuse (APS, 2014). Results of this study highlight specific stress related to negative care recipient attitudes and behaviors toward the caregiver: stubbornness; rudeness and lack of respect for the care provider; instances when the patient is difficult, acts out, or is hostile; and difficulties with patient wants (i.e., when patient wants something he/she cannot or should not do). Concurrently, the findings supported the need for adequate rest, time off, exercise or other social activities outside the care environment, and family and agency support to help the caregiver cope with these stressors. In circumstances in which the care recipient has a tendency to demonstrate these negative or more hostile behaviors, it is recommended that agencies ensure the caregiver scheduling allows for adequate time off, breaks during the day, opportunities for exercise or organization-wide social activities. Although reducing these types of stressors may not be possible, putting some programs in place by the agency could provide the needed relief to caregivers to ensure the best quality of care by supporting ways that caregivers are able to copy more effectively with the stressors present.

Caregivers should encourage family involvement and support, understanding that the inclusion of family social support is believed to promote less stress for the caregiver, and as a result, higher quality of care for the care recipient. Agencies that promote family involvement and patient and family education on the benefits of family involvement will likely benefit from caretakers who are less stressed.

In terms of video surveillance, it is recommended that agencies and private home care employers consider placement of video cameras in the home, given both older adult care recipient and caregiver consent, particularly for situations in which the care recipient tends to be hostile or negative toward the care provider. Caregivers reported perceptions of less stress in terms of the video as a security measure for the caregiver in providing evidence of the quality of care they are providing to the care recipient, despite potential complaints or misunderstandings, supporting job security and enhanced patient care. Care must be taken to avoid private areas such as bathrooms or other areas in which an individual should and would assume privacy.

**Significance of the Study:**

Modern family conditions, particularly of dual working households in which fewer family members are available to provide full-time care for their older adult family members due to responsibilities of work, children, or other obligations, are supporting an increased need for hired home health workers, particularly older adult caregivers in the home care setting (Hooyman & Kiyak, 2008; Nicholl et al., 2008). With the increasing older adult population, the increasing popularity of homecare, the declining availability of family members to care for the aging, and the increasing incidence of older adult abuse, current social changes support the need to examine the stress and other factors that contribute to or alleviate the potential for maltreatment of older adults in need of care in the home setting. Findings from this research study (a) identify key stressors in the home care setting related to difficult care recipient attitudes and behaviors, (b) support strategies for helping caregivers cope with these stressors to reduce potential for maltreatment, and (c) assist in understanding the caregiver perspective on home video surveillance and whether this type of surveillance contributes to or reduces caregiver stress in the home care setting.

**Future Directions in Related Research:**

Findings of this study can be extended to better inform the literature on the topic, extending to larger populations or different settings through additional research. It is recommended that a similar study be conducted using family home care providers to identify differences or similarities in stress experiences and possibly reveal the impact of the family dynamic among care providers in this setting. Family responsibilities and changing power and relationship dynamics can affect how individuals relate to each other, including in a caregiving relationship (Laslett, 1973). Changing role

responsibilities among family caregivers has been shown to contribute to greater stress resulting from lack of social and financial support (Ice et al., 2012). A qualitative study specific to the dynamics of family caregivers and the new roles they have in the family would inform the literature specific to this growing dynamic.

Given that the findings of this study were not generalizable beyond the immediate population of hired home caregivers to older adult care recipients, a quantitative study seeking to identify the incidence of high frequency stressors and perhaps the specific relationship between care recipient attitudes and negative behaviors toward the care provider and level of provider stress would help to identify key stressors in the home care setting, which may be unique from other care settings. In addition, quantitative research can be used to evaluate the effects of support strategies, comparing stress levels before and after implementation of various support strategies, such as increased family involvement/visitation, regular exercise, and a variety of agency support mechanisms (requirements for breaks, scheduling regulations, etc.) to support coping with stress among caregivers.