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Facilitators and Barriers for Home Health Aides Detecting and Reporting Elder Abuse in New York City

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FACILITATORS AND BARRIERS FOR HOME HEALTH AIDES DETECTING AND REPORTING ELDER ABUSE IN NEW YORK CITY

by

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This manuscript has been read and accepted for the Graduate Faculty in Social Welfare in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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ABSTRACT

Facilitators and Barriers for Home Health Aides

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Elder abuse impacts close to 13 percent of older adults in the US. It exists in secret, with only about one in 24 cases becoming known to the systems that can provide intervention. As baby boomers age and the general population lives longer, for example New York City is expecting to have up to 1.3 million adults by year 2030, the number of people impacted by abuse is expected to drastically increase. A gap exists in the current span of knowledge and practice applications about the issue, particularly around homecare services. Home health aides, a rapidly growing profession, provide direct and often intimate care, leading to development of trusting relationships, which may lead to disclosure of experienced abuse. This cross-sectional, exploratory study utilized Grounded Theory methods to learn about the intrinsic and extrinsic facilitators and barriers to detecting and reporting elder abuse among home health aides in New York City. The two aims of the study were to learn about the extent of the aides' knowledge about elder abuse and to explore their motivational factors regarding its reporting. The Self-Determination Theory, which establishes motivation by presumed satisfaction of three psychological needs: autonomy, competence and relatedness provided a theoretical orientation to this study. The purposive sample consisted of 17 certified home health aides working with older

adults in licensed home care agencies. Data was collected via semi-structured interviews conducted in English. The two main identified themes were “Elder abuse is multidimensional” and “Personal, organizational and economic drivers influence reporting”.

The participants’ responses mirrored the well documented lack of universally utilized definition and their knowledge about the issue was stated to have been obtained from multiple sources, including personal experiences of caregiving for family or friends. The motivation to report abuse was expressed as a moral obligation with the barrier described as potential negative consequence. The facilitator to gaining knowledge about elder abuse, as well as motivation to report, was found to be largely intrinsic in nature. The extrinsic motivator, the participant identified quality of connection to the home care agency, seems in turn to have the potential to be either the facilitator or a barrier. The findings suggest an opportunity for minimizing barriers to identifying and reporting elder abuse by home health aides.

Key words: elder abuse, home health aides, identification of elder abuse, reporting of elder abuse, motivation to report elder abuse, theory of self determination

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CHAPTER I: INTRODUCTION

The United States population of adults aged 65 and older is expected to exceed 72 million by the year 2030, up from 40 million in 2010, with about 1.3 million residing in New York City alone. People are also living longer; by 2035, the number of people aged 85 and older is expected to reach over 11 million and close to 19 million by 2050 (Administration on Aging, 2013, 2016; Center for Urban Future, 2013; Jackson & Hafemeister, 2013; Poo, 2015).

Elder abuse (EA) is a unique challenge facing this rapidly aging population. It is estimated that 10 to 13 percent of older Americans (about five million) have experienced some type of abuse (Mariam et al., 2015; NYC Elder Abuse Center, 2009; National Council on Aging, 2014). A recent New York State prevalence study (2011) found that an estimated 141 out of every 1,000 New Yorkers has experienced abuse since turning 60 years old (NYS Elder Abuse Prevalence Study, 2011). The issue, however, remains a largely secretive issue with only about 1 in every 24 cases being reported (WHO Facts Sheet, n.d.). Older adults exposed to abuse are at a greater risk of poor physical and mental health outcomes, higher rates of institutionalization and premature mortality than their peers who are not abused (Rovi et al., 2009; WHO Fact Sheet, n.d.).

The intimate nature of home care services allows an opportunity to identify and report abuse that an older adult may be experiencing. Close to five million people obtain home care services annually (Centers for Disease Control, 2016). The “home care workforce” doubled in ten years prior to 2015 and it is expected to grow as the needs continue to expand (Buch, 2018). If an older adult is engaged in a trusting and protective relationship with their home care aide, they may feel safer disclosing an abusive situation (Kelly, 2017; Lam & Garcia-Roman, 2017; Mathias & Benjamin, 2003). It is therefore essential for home care aides to be well-trained and

knowledgeable about available supportive resources to prevent and treat elder abuse. There is a substantial gap in the literature, however, which limits our understanding of how prepared and supported homecare aides are in addressing elder abuse in their work.

Definition of Elder Abuse

Elder abuse (EA) is commonly defined as harm to a person over 60 years of age, caused by direct or indirect action or inaction (National Center for Elder Abuse, 2016; World Health Organization, n.d.). The lack of action is classified as neglect or abandonment and refers to failure of a caregiver to meet an older adult's basic needs, whether intentionally or not. The 1987 Amendment to the Older Americans Act (Public Law 100-175) categorizes elder abuse into the following types: Physical, Psychological and Emotional, Sexual, Financial and Neglect or Abandonment (AoA, 2014; NCEA, 2014). Indirect abuse may include unsanitary living conditions and lack of food or medical devices such as hearing aids, eyeglasses and dentures. Cases of self-neglect due to diminished capacity are sometimes excluded from the definition of abuse, as are broad-spectrum crimes such as muggings. Cases of domestic violence across the lifespan are subject to much debate around whether they should be categorized as elder abuse once an individual reaches the age of 60 (Anetzberger, 2012; Band- Winterstein, 2015; Burnes et al., 2014; Dong, 2012; Imbody & Vandsburger, 2011). The United Nations formally recognized elder abuse as a public health issue in 2002 and in 2012 declared June 15th as the World Elder Abuse Awareness Day (WEAAD) (Beaulieu et al., 2015; Marquand & York, 2016; WHO, n.d.).

In 2016, the Centers for Disease Control (CDC) released definitions of core elements of elder abuse with hope of standardizing national research and practice (Irving & Hall, 2018; Narenberg, 2019).

Distinctions between Child Abuse, Interpersonal Violence, and Elder Abuse

Child abuse and interpersonal violence (IPV) literature have been conceptually linked to elder abuse. Current research, however, reminds us that despite some overlap elder abuse is a field that is unique and must stand on its own (Cramer & Brady, 2013; Kane et al., 2011). For one, older adults, unlike children, are presumed to have the legal right to self-determination, making any participation in EA programs voluntary (Burnes et al., 2014). This leads to complex outcomes of professional reporting, complicating it and giving professionals' pause when considering whether to report suspected abuse, even when mandatory reporting is in place (Rodriguez et al., 2006). Furthermore, the role of a caregiver is often intertwined with that of a potential abuser, whose personal characteristics and struggles, such as those of psychological, social or economic nature are potentially further aggravated by the stress of caregiving responsibilities. Self-determination and the unique characteristics of the abuser are arguably the most distinguishing factors separating elder abuse from other types of abuse (National Adult Protective Services Association, n.d.; NCEA, 2017).

Self-determination is the right to have a choice in decision making. Self- determination is identified by the Code of Ethics of the National Association of Social Workers as one of the ethical responsibilities of social workers to uphold (National Association of Social Workers (NASW) Code of Ethics, 2000).

The right to self-determination for adults can only be restricted by legal guardianship proceedings, where there is reasonable cause for concern about endangerment of self or others,

or a limited mental capacity, such as in cases of developmental disability, ("Guardianship of an Incapacitated Adult", NYCcourts.gov, n.d.). A person is therefore entitled to make what may be considered poor choices, including those about their own safety, such as wanting to continue living with their abuser. By law, however, it is their right to make and live with such choices. For example, an adult experiencing IPV may not be forced to cease contact with their abuser. A child who is being abused, however, may be removed from the home against their wishes.

Legal capacity of older adults drives the debate about their right to self-determination, including the right to make choices some may deem undesirable. Determination of capacity is a matter of law, (under Article 81 of New York's Mental Hygiene Law) and requires an assessment to be conducted by a medical professional (NYCourts.gov, n.d.). In cases of guardianship proceedings, it is required that an individual is deemed to not have capacity to make decisions for him or herself in order to be appointed a legal guardian. However even in cases of established cognitive limitations, such as with diagnosis of dementia, the person still holds some right to self-determination and may still have some capacity to report abuse. In practice, ageism and other assumptions about older adults often lead to questions about whether they are capable of making sound decisions to express their right to self-determination (Rupp et al., 2005; Ward, 2000). As a result, the right of self-determination may be honored more in cases of adult IPV than in cases of elder abuse. (Band-Winterstein, 2015; Barner & Mohr Carney, 2011; Lundy & Grossman, 2009; Roberto et al., 2013). This point of distinction between law and social norms is specifically addressed within in National Adult Protective Services Association (NAPSA) guidelines, which stress client's right to self-determination (NAPSA, n.d.)

Another important factor distinguishing elder abuse from child abuse and IPV is the reasoning or the conscious, or subconscious drive of the abuser (Cramer & Brady, 2013; Kane et

al., 2011). Abuse of older adults can be in part driven by burdens of caregiving, including "role reversal" for children who become caregivers, or sometimes simply the overall "opportunity" of a situation, such as in cases of financial exploitation (NAPSA, 2016; Wolf & Pillemer, 1986). IPV involving younger adults, on the other hand, has been attributed more to power and control, with high rates of dangerous and sometimes deadly recidivism (Mills, 1998).

The unique nature of elder abuse also emerges in intervention and outcome goals, such as separating the survivor from the abuser (Cramer & Brady, 2013; Kane et al., 2011). In cases of IPV, interventions are usually not focused on relationship repair, as they are in many elder abuse cases that involve caregiving and/or co-dependent relationships, where harm reduction has been found to be possible (Band-Winterstein, 2015; Burnes et al., 2014; Cramer & Brady, 2013; Crockett et al., 2015). Harm reduction also respects the person-centered approach from the public health perspective (Narenberg, 2019; Teaser & Hall, 2018).

These distinctions between abusive situations are not always straightforward and there may be overlap of characteristics, such as when the duration of IPV extends into older adulthood, thus becoming EA. To that point, research indicates that 26.5% of women over 65 experience life-long IPV and that approximately 11% of EA cases have an intimate partner as an abuser (Brossoie & Roberto, 2015). Elder abuse victims who have been experiencing violence across the lifespan may respond positively to IPV-focused interventions more than those designed to treat elder abuse (Kane et al., 2011).

Elder Abuse Risk Factors

Identifying those at risk of elder abuse is challenging as the issue touches communities across all gender, race, class, and other social contexts. Most abusers in community settings tend to be family members (Anetzberger, 2012). While many of the estimated 34 million American

caregivers of older adults experience some level of financial, physical and mental health burden, including inadequate social supports, it does not necessarily lead to abuse (McUlsky et al., 2016; Narenberg, 2019). Empirical research suggests that EA is driven by the characteristics of the victim, the abuser and overall situation, including a build-up of emotions due to life-long relationships (IPV or Domestic) and violence (Acierno et al., 2010; Anetzberger, 2012; Biggs & Haapala, 2010; Burnes et al., 2014; Heisler, 2012; Labrum et al., 2015).

The characteristics of the abuser may include mental illness or developmental disabilities, substance abuse struggles or involvement with the criminal justice system (Crockett et al., 2015; Labrum et al., 2015; Smith, 2015). Motivation of the offender, as with other crimes, is attributed to factors such as greed, history of unemployment, financial dependence on the victim, and the status of the relationship with the older adult (Anetzberger, 2012; Lachs & Pillemer, 2004; NCEA, 2014; Robinson et al., 2014). Situational stressors may include familial role reversal, where children or victims of IPV become caregivers, financial hardships and resource struggles (Pickering et.al., 2015).

Middle-aged adults who are simultaneously caring for children and older adult are often referred to as the "sandwich generation". Today about 20% of the approximately 44 million caregivers of older adults make up multigenerational households (Binstock & George, 2011; Poo, 2015). Caregiving for "sandwich generation" has a particular potential to cause significant psychological, physical and financial strain, which, despite best intentions, may result in built up resentment and relationships changes. Structural supports for caregivers are inadequate (Nerenberg, 2019). Some studies point out the complexity of mother-daughter-caregiver relationships, particularly regarding obligation in light of chronic conflict, because it is the

daughters (and the daughters-in-law) who continue to be the primary caregivers of older adults (Labrum et al., 2015; Pickering et.al., 2015; Poo, 2015; Smith, 2015).

Typical risk factors of the victim include cognitive or physical limitations. Some reports indicate that incidence of abuse of cognitively impaired adults to be as high as 50%. (NCEA, 2014). This raises particular concern as there are about 5 million people diagnosed with Alzheimer's disease alone, with someone developing it every 67 seconds (Alzheimer's Association, 2014, NCEA, 2014; Poo, 2015; Roberto & Jarrott, 2008). The National Elder Mistreatment Study found that the increased probability of financial exploitation was correlated with a victims' physical disability and dependence, including assistance with the Activities of Daily Living (ADLs) (Acierno, et al., 2010; NCEA, 2013).

Older women have been found to be statistically most often victimized (National Center for Victims of Crime, 2017). Such may be due to the same factors identified in domestic violence situations as well as the fact that women live longer than men (Crockett et al., 2015). Living with the offender has also been found to increases the risk for abuse (Burnes et al., 2014).

One cannot approach discussion about older adults without acknowledging ageism. Ageism, defined as discrimination against people based on age (Collins English Dictionary, 2012), has been accepted, condoned and even normalized within our society. A 2009 report indicated about 80% of older Americans had experienced age discrimination (Bruhn & Rebach, 2014; Jackson & Hafemeister, 2013; North, 2015; Poo, 2015). Thus, a line can be drawn from a devalued individual to justification of their mistreatment and neglect, including not seeking assistance around it (Liepert et al., 2019)

Overview of Homecare Services

Paid caregiving services emerged in the late 1980s out of necessity as women, who have

traditionally stayed home and provided caregiving, began entering the workforce at increased rates (Rolf, 2016). As welfare reform policies were implemented in 1990s, homecare agencies qualified to receive tax incentives by participating in welfare-to-work programs (Buch, 2018).

In New York, there are two types of homecare agencies: Licensed Home Care Services Agencies (LHCSAs) which provide privately paid (funded "out of pocket" or by long term care insurance) services and Certified Home Health Agencies (CHHAs), which provide short-term rehabilitative and skilled nursing care covered under most insurance, including Medicare and Medicaid. Both types of agencies are regulated and licensed by the New York State Department of Health (DOH) and those with Medicare certification are accredited by the Joint Commission, the accrediting body of healthcare organizations in the United States (Friedman et al., 2015; DOH.gov). The regulations include being bonded and insured, and employing certified and licensed professionals, such as nurses and home health aides. Many agencies either operate under both licenses or have contracts allowing them to simultaneously provide services that are covered by insurance and are privately paid. Such is due to the fact that most insurance providers do not cover long term care or coverage for what may be considered "custodial care", or care for a condition that is not expected to improve (Moon, 2016).

Both LHCSAs and CHHAs provide assistance with Activities of Daily Living (ADLs), including bathing, dressing, toileting or eating. Home health aides, who are the direct care workers providing the hands-on personal care, are also able to travel with clients to appointments, prepare meals, complete light cleaning and provide companionship (Buch, 2018) In each case, a Registered Nurse (RN) conducts an initial assessment of needs and creates a Plan of Care (POC), which is shared with the client's physician. The POC provides a specific list of duties to be completed by home health aides upon each visit. The nurse provides supervision to

home health aides, who are under strict directives of following POCs precisely, and are not allowed to provide any additional care such as wound care (NYS Health Profiles NYSDOH, n.d.)

Standard hiring requirements for direct care workers include being over 18 years of age, having legal ability to work in the U.S. and having successfully completed the home health aide certification. The three-week NYSDOH- designed multilingual certification courses are provided free of charge by many agencies and consist of hands-on-training, overview of standards and passing of an examination (PeopleCare.com, n.d.). To date the course does not include any direct information about elder abuse (PeopleCare.com, n.d..; NYS Health Profiles NYSDOH, n.d.). Homecare agencies must provide at least 12 hours of annual trainings and supervision by RNs in order for the certifications to stay active. When HHAs, who are considered paraprofessionals are not employed by a licensed agency, their certifications are invalidated after two years (PeopleCare.com; NYS Health Profiles NYSDOH, n.d.).

Other than the certification, there are no educational standards for home health aides such as completion of a high school diploma (PeopleCare.com; NYS Health Profiles NYSDOH, n.d.). As LHCSAs are private agencies with their own organizational policies, however, some agencies may require a minimum educational level for home health aides. All applicants must complete drug tests and criminal background screens via state and national databases. Basic command of the English language is not always a requirement as multilingual and multicultural aides are in demand to accommodate the diverse population of NYC residents.

Rationale and Significance

Research on elder abuse has primarily focused on its prevalence, with limited studies on risk factors, interventions, or evaluation of interventions (NCEA, 2016). The home care literature

tends to focus on nursing professionals rather than paraprofessionals, and there appears to be no research on home health aides' knowledge and perceptions of elder abuse (Lo et al., 2010). Research driven by identified needs in social work practice is essential, as understanding what interventions work or what needs improvement has the potential to enhance the experiences of the approximate four million home health aides and improve the quality of life for their clients (Moen & DePasquale, 2017; Poo, 2015).

The proposed study aims to identify home health aides' experiences and perceptions around detecting and reporting elder abuse. Home health aides are often the first responders in a situation of elder abuse, thus understanding the facilitators and barriers to detecting, reporting, and intervening will help prepare them for this critical role.

Research Question and Study Aims

The research question guiding this study is: What are the intrinsic and extrinsic facilitators and barriers to detecting and reporting elder abuse among home health aides in New York City?

The main aims of the study are to (1) describe home health aides' knowledge about elder abuse, and (2) explore their motivational factors, or barriers, regarding its reporting. This includes learning about the aides' self- efficacy as well as external supports provided by the agency of employment or other sources. The extrinsic component will examine the environmental circumstances of the home health aide, including the homecare agency, which impact the aides' motivation and capacities.

CHAPTER II: LITERATURE REVIEW

The following will review the current state of elder abuse and home care services research. It will also aim to provide a context for the study, including impact of ageism and socio-economic marginalization of both older adults and homecare workers.

History of Elder Abuse Research

The first national study of EA incidence was conducted in 1996 by The National Center on Elder Abuse (NCEA, 1998). Although it was conducted two decades ago, it remains relevant as many of the findings guide us in our knowledge about EA. The data were collected from APS reports and community agencies serving older adults in 15 nationally representative states and focused on elder abuse cases involving older adults over 60 years of age in community settings. The study specifically excluded cases involving institutional settings such as nursing homes. It focused on abuse, financial exploitation, neglect and self-neglect; these subtypes are operationalized based on literature and definitions utilized by the participating agencies, which is important to note as no universally utilized definition exists. Findings indicated that in 1996 among the 450,000 new, unduplicated cases, only about 1 in every 5 cases was reported to APS. Subsequent studies put this number as high as 1 to 10-24 cases (Lifespan et al., 2011). This did not include self-neglect, which added an additional 150,000 cases. Adults over 80 years of age were found to have two to three times greater potential for abuse. In 1996 adults over 80 years of age made up about 20% of the older adult population and those who were physically unable to care for themselves made up close to 50% of the sample. The study also found that about 90% of abusers were relatives, including two thirds being spouses and children. Most reports of abuse came from family members (20%) and hospitals (17%). Racial demographics identified 8 out of 10 reports to be of Caucasian elders.

Over a decade later, in 2008, the National Elder Mistreatment Study was a national survey in the United States that aimed to not only establish prevalence of elder abuse but also to identify the victim's risk factors (Acierno et al., 2009; Acierno et al., 2010). Based on census data, a probability sample of 5,777 older adults and 813 proxies (in cases where the older adult was lacking physical or cognitive capacity) was obtained utilizing a Random Digit Dialing method (RDD). Questions focused on experiences of abuse, by subtype, within the past year as well as on the status of health and social supports. Participant age range was 60-97, with an average age of 71. Over 60% of the participants were women and 85% identified their racial identity as white. Researchers found that approximately 1 in every 10 people reported to have experienced at least one form of abuse with 1.2% reporting two or more forms of abuse. The study also found that intimate partners or spouses were much more likely offenders than adult children. The most frequent form of abuse reported, at 5.9%, was neglect. The next, at 5.2%, was financial exploitation by a family member, followed by emotional (4.6%) and physical abuse (1.6%).

In addition to the national, broad scope studies some local analyses on understanding how EA manifests within specific geographic areas have also been conducted. Most notably, the 2011 New York State prevalence study, the largest and most comprehensive statewide study to date, interviewed a sample of 4,156 older adults or their proxies, and 292 agencies, including law enforcement (Lifespan of Greater Rochester et al., 2014). Researchers found that an estimated 141 out of every 1,000 New Yorkers experienced some type of abuse since turning 60 years old. This statistic is in line with the national figure of about 13.5% (Mariam et al., 2015; NCEA, 2016). That leads us to estimate that approximately 260,000 older New Yorkers have been

victims of abuse within the past year, with only 11,432 (4%) identified as having received agency-based interventions.

A study of social factors affecting health and aging identified elder mistreatment as an important variable impacting physical and mental health five years after reported abuse (National Social Life, Health and Aging Project (longitudinal study- first wave: 2005-2006) Acierno et al., 2010; Anetzberger, 2012; Wong & Waite, 2015). This prevalence survey of over 3,000 older adults (aged 57-85), focused on verbal, physical and financial abuse only and as noted, included people under 60 years of age. It found women, younger participants, and people with disabilities to be at a higher risk for verbal mistreatment and African Americans to report a higher prevalence of financial exploitation.

MetLife Mature Market Institute calculated the national financial cost of elder abuse for the first time in 2008 and found that losses to victims totaled approximately $2.6 billion (Anetzberger, 2012; Stiegel, 2012; Roush et al., 2012). In 2009, the individual losses have been reported to be at $2.9 billion and in 2010, the U.S. Government Accountability Office estimated $5.4 million in funds misappropriated by guardians, (although not all of them were older adults) (Anetzberger, 2012; NCEA, 2014). In additional to the national estimates, only one statewide financial estimate of elder abuse appears to have been conducted: in 2009 Utah found an approximate loss (beyond individual and including the government) of $52 million, a figure based on only 57 APS cases (Stiegel, 2012). Significantly, the additional national costs include those of avoidable hospitalizations and premature institutionalizations (Dong, 2012; NCEA, 2014).

Home Health Aide Identification and Reporting of Elder Abuse

Self-reported surveys indicate higher numbers of elder abuse than what is reported to intervening agencies, such as Adult Protective Services (Acierno et al., 2010; Lifespan of Greater Rochester et.al., 2011; NCEA, 2014). A study about elder abuse related "help-seeking" indicated that annually approximately 15% of those in need end up being connected to "formal support services" (Burnes et al., 2019). In NYS, for example about 260,000 older people self-identified to have been abused in the past year but only under 12,000 cases were seen within social service agencies (Lifespan of Greater Rochester et al., 2011). Reasons for low reporting by older adults are varied and may include shame and self-blame, which are common feelings among victims of abuse (Band- Winterstein et al., 2015; NCEA, 2017; Truong et al., 2019). Older adults may also experience fear if they depend on the abuser for care and support, in which case they may see the relationship as the only option in avoiding institutionalization in a nursing home (Brossoie & Roberto, 2015; Crockett et al., 2015; Smith, 2015). Some older adults who have faced a lifetime of negative experiences, such as sexism, racism or other discrimination and oppression, within public institutions may not trust or desire to interact with such institutions, thus making it unlikely that they would report abuse. Some may want to protect their alleged abusers from interactions with the criminal justice systems (Truong et al., 2019). Lastly, the older victims may be physically isolated or have cognitive impairments limiting their opportunities for reporting abuse.

For professionals, low reporting may be attributed to inadequate education and supervision around elder abuse, lack of standardized definitions, underutilization of assessment tools, and lack of trust in available resources (Schmeidel et al., 2012; Truong et al., 2019). A needs assessment study reviewing barriers in rural Iowa for example, indicated that "a large

portion of agencies" did not provide any trainings on elder abuse (Peitz et.al. 2019). Furthermore, a recent review of barriers around detection of abuse in healthcare indicated that disclosure should be perceived as a process that may take time, and several interactions (Truong et al., 2019). Medical professionals also consider the importance of rapport with their patients and may see reporting abuse as violating that rapport (Rodriguez, et al., 2006).

A 2009 review of 19 studies of social work and health care professional decision-making process when working with older adults revealed that workers receive limited supervisory guidance and their perceived inadequacy of intervention to address the client's circumstances was a major barrier to reporting EA (Killick & Taylor, 2009). The review also noted the very real concerns about complexity of EA among workers, such as perceptions of dependency on abusers and fear of nursing home placements are similar to concerns of older adults themselves. These complicate intervention strategies and often result in workers facing ethical dilemmas. Professionals were found to struggle with not only the fear of correctly identifying EA, given the varied cultural contexts (their own and their clients), but also with trusting existing systems to provide effective interventions that would not negatively impact or unnecessarily burden clients' lives. (Killick & Taylor, 2009).

One particular study involving home health aides was conducted in a London care home rather than client's residence, noted lack of available work and concern about being removed from the case, as well as fear of retaliation by client or abuser, including asking for a change in aide, may be contributing factors to hesitation in bringing up suspicion of EA to homecare supervisors (Cooper et al., 2013). The study also noted that what some aides may recognize as abuse in a form of neglect, may be rectified with proper training and more available staff.

Studies about homecare services are limited and most samples include nurses or healthcare professionals other than home health aides who spend the most time with clients. In an ethnographic study by Buch (2018) that examined two home health agencies between 2006 and 2008, the complex components of elder care are discussed, as are the risk of financial exploitation of older adults within the "intertwined boundaries" of trust, self-determination, and client capacity. The study's discussion of elder abuse, however, is limited, which seems reflective of the overall lack of public discourse about the issue.

Another example of elder abuse discourse being marginalized in eldercare literature is the Spring 2016 issue of *Journal of The American Society on Aging - Generations* entitled *"America's Eldercare Workforce: Who Will Be There to Care?"* The focus of the issue was the ever-growing needs of homecare and caregiving, however, there was no direct discussion of elder abuse. The contributors reviewed the needs for person centered care (Young & Siegel, 2016), need for additional training and supports (Dawson, 2016; Busby-Whitehead et al., 2016; Warshhaw & Bragg, 2016), role of nurses (Mueller et al., 2016) and technology in homecare services (Gitlin & Hodgson, 2016; Kernisan, 2016) as well as the current state of homecare (Rolf, 2016).

Facilitators and Barriers to Elder Abuse Reporting

The few studies of EA intervention outcomes clearly agree on the unique nature of this issue, and that the physical separation of the alleged abuser and victim is usually not the desired solution. Decisions to report EA are impacted by prior experiences of reporting elder abuse without having the situation of abuse change (Killick & Taylor, 2009; Rath, 2012; Solomon & Reingold, 2012). Literature, however limited, indicates that some interventions do not result in a significant difference in the clients' circumstance. One program evaluation of an intervention, for

example, found that status of abuse upon discharge from an elder abuse program remained unchanged in nearly one-third of cases (Burnes et al., 2014). This NYC-based Mistreatment Status at Case Closure (MSCC) study utilized data from a large social service agency providing services for elder abuse (not APS) to predict future risk for EA. This program evaluation tested the standard operation of the program where the intervention was a combination of social and legal services available to people experiencing elder abuse. This unique program within a large organization providing services for older adults, includes attorneys employed by the agency who work collaboratively with the social workers in cases of evictions, orders of protection or financial abuse investigations. It is also unique to have this type of intervention provided by an agency other than APS.

Factors associated with MSCC included race, the influence of medical conditions, limited social supports, and living arrangements. MSCC indicating the level of future risk for EA was measured as either low, moderate, or high/unchanged. For the purpose of this program evaluation, three independent researchers collaborated on the measurement of each case in order to enhance reliability of this measure. The three-level indicator created was the first of its kind instrument utilized to measure MSCC. The study found the levels to be lower in cases with dual (social worker and attorney) intervention (62%) as compared to cases where only social services were utilized. For the purpose of this study, the "intervention" is considered to be the provision of social and legal services by the social worker and attorney of the program. Legal-social work collaborative was also found to have a high retention in the program rate of close to 72%, which speaks to the complexity of EA circumstances (Burnes, et al., 2014).

A 2013 United Kingdom focus group study of 36 hands-on care workers such as home health aides and nurses in residential care facilities inquired about knowledge regarding known

abuse and asked about willingness to use an instrument to anonymously report it (Cooper et al., 2013). After discussion about revisions to the instruments, participants in three focus groups filled out the anonymous form. While the residential care facility setting is notably different than community homecare, workers lack of knowledge about reporting options was identified as a major barrier to reporting abuse. Additionally, the focus groups found that "institutional flexibility" and team work is perceived to have the power to minimize neglectful situations, such as a patient waiting for a long time to have soiled clothes or diapers changed, which many identified as abusive. Lack of immediate or appropriate attention to need was mostly attributed to insufficient personnel, limited resources or institutional constraints (such as for example, forcing patients to eat when they are not hungry because the kitchen is open only during certain hours). Lack of knowledge on how to interact with clients who are difficult to deal with was identified in cases where coercion was observed. Varied understanding and agreement about what constitutes abuse is perpetuated by a lack of definitional consensus regarding the issue. The study concluded that organizational flexibility and educational enhancement would support the workers' identified needs (Cooper et al., 2013).

While a number of assessment tools are available, they are criticized because they are fragmented and not uniformly utilized as well as often not designed for a multidisciplinary range of professionals and hence do not address the varied bases of knowledge (Imbody & Vandsburger, 2011; NCEA, 2016). Many tools are found to be limiting in reliability, validity, and research replications. Some examples include the Conflict Tactics Scale, created in 1978 to assess family violence, the Brief Abuse Screen for the Elderly (BASE) which is only 5 questions long and necessitates a depth of professional understanding of the issue and the Elder Assessment Instrument (EAI), which has been noted to be impractical due to length (42

questions) (Imbody & Vandsburger, 2011). National Center on Elder Abuse provides a brief on some instruments available but notes that they are not mandated, leaving each organization or program to follow their own, if any, protocol (NCEA "Elder Abuse Screening Tools for Healthcare Professionals", 2016).

This dissertation was inspired by a study of health care professionals: physicians, nurses and social workers, aimed to identify knowledge and perspectives around elder abuse in Iowa, a state with mandatory EA training for all mandated reporters (Schmeidel et al., 2012). A total of 23 participants (nine nurses, eight physicians and six social workers) answered 13 interview questions about their perceptions of the types of abuse they may encounter in their work settings (clinics, not homes), reporting criteria and organizational practices, including what they could suggest as areas of improvement. The study did not include home health aides. Analysis of themes found that barriers to identifying and reporting included education about the topic and systems as well as discomfort asking about it, particularly addressing it in front of caregivers or asking for privacy, and instead focusing on concrete tasks. Perception that "someone else was going to address it" was also identified: nurses expected doctors and social workers to speak with patients about it and doctors expected social workers to investigate it. Participants also expressed the need for additional evidence before making a claim of abuse, specifically stating the importance of self-determination and concern about harming the relationships they have built with their patients and caregivers. They were also concerned about potentially making the abuse situations worse by involving outside systems, be it social services or criminal justice, as they did not have much trust in their capacity to enact substantial change. The study also found that among the participants, social workers had most knowledge about the processes of reporting and were most willing to follow up on it, whereas nurses and physicians indicated gaps in basic EA

knowledge and confusion about reporting mandates and professional responsibilities. This exploratory study concluded the need for more comprehensive training and education for healthcare professionals. The lack of theoretical framework was one limitation that this dissertation addresses by utilizing the guiding theory of self-determination .

Home visiting providers of care for older adults have substantial access to develop a relationship with them and to witness or uncover potential situations of abuse (Friedman et al., 2014). Research on home care reporting of elder abuse is limited and the focus tends to be on home visiting nurses rather than home health aides, potentially due to nurses having "mandated reporter" status (Thobaben, 2017). One cannot help but wonder, however, how much of it is also an outcome of the invisible status of aides, whose work, however skilled, is not embraced as professional (Buch, 2018; Poo, 2015).

As of 2015, only 32 states mandate home health care providers to report EA and questions about abuse are not part of the home health care assessment required by Medicare (DOJ.gov, n.d., Friedman et al., 2014). In NYS home health aides are mandated reporters for child abuse but not elder abuse, unless specified by the agency's policy, because while professionals are mandated reporters based on their licensure, New York state lacks the mandatory elder abuse reporting statutes (American Bar Association, 2016). When reporting abuse of an adult, capacity is questioned, therefore also raising an issue of ageism (Irving & Hall, 2018; Narenberg, 2019). Presently (2019) New York is the only state without mandatory elder abuse reporting statutes.

Research shows that detection of EA may take time and numerous interactions. A multi-state study (New York, West Virginia and Ohio) of secondary data from the Medicare Primary and Consumer-Directed Care Demonstration project (1998-2002) indicated that visiting nurses

were able to identify a 7.4% prevalence of elder abuse, relative to approximate 11.4% national rate of abuse experienced by people 60 and older in the past year (Acierno et al., 2010; Friedman et al., 2014; NCEA, 2010). West Virginia and Ohio have mandatory EA reporting laws. The nurses visited patients on average once per month and cases of elder abuse were identified over the course of the 24 months the study took place. It took an average 10.5 nursing visits to identify abuse. The few studies looking at identification process focused on a single visit. Varied conceptualization of elder abuse further complicate direct comparisons. This multistate study indicates that in Michigan Home and Community Based Services abuse was identified about 4.7% of time and in Iowa based Medicaid program for older adults (who reside at home but qualify for nursing home placement) abuse was identified about 21% of the time (Friedman et al., 2014). In New York State, home care agencies are the second highest referral source for Adult Protective Services, with 12.64% of referrals coming from home care agencies. Health care institutions are most common referral source, with 21.63% of referrals (Lifespan of Greater Rochester, et al., 2011).

As the population ages, so does the need for competent workforce. Lack of appropriate education on the topic contributes to the low rates of recognition, which limits opportunities for interventions and belittles recognition of EA as the significant public health issue that it is (Antezberger, 2018; Brossoie & Roberto, 2015; Heisler, 2019; Irving & Hall, 2018; Marquand & York, 2016; Narenberg, 2019). For example, while a Bachelor's degree is a prerequisite to work for APS in New York City, the degree can be in any discipline, often resulting in a lack of academic preparedness to work in the public human services sector. Furthermore, APS workers can have been noted to have excessively high caseloads vying for their attention (Narenberg, 2019). Home health aides in NYC, while mandated to complete statewide standardized training

in order to obtain certifications, are not mandated to receive elder abuse training, nor are they required to have any educational background (Department of Health, 2017; Mathias & Benjamin, 2003). To that end, agencies make their own policy determinations regarding educational backgrounds, resulting in many not requiring high school diplomas or verification of education from other countries. In NYC, Cooperative Home Care Associates (CHCA), the largest US worker-owned company located in the South Bronx for 30+ years, identifies an average individual enrolling in their training program to be a woman born outside of the US with an average reading level at the 6th grade (Rolf, 2016).

As Ernst et al. (2014) point out, organizations continue to be heavily reliant on staff experience, known as "practice wisdom" rather than trainings. This perpetuates the illusion that just because someone has worked in a field in the past, they are knowledgeable and confident about the tasks required of them. Lack of opportunities for trainings misses the opportunities to improve competence and therefore confidence and contributes to frustration over psychological needs. That frustration is a contributing factor to employee burnout and worker turn-over rates (Ryan & Deci, 2017). Provision of training indicates the importance of services provided (Poo, 2015). Furthermore, studies indicate that practice knowledge is perceived to be of a higher value than formal training: for example, an examination of Registered Nurses' decision-making regarding EA indicated a reliance on experience and intuition over education in the medical field (Jackson & Hafemeister, 2012; Meeks-Sjostrom, 2013). Yet studies demonstrate that education, training and structural supports make a difference in day-to-day experiences with clients experiencing abuse, which can be challenging or even intimidating (Cairns & Vreugdenhil, 2014). Training for NYC nursing home employees was found to significantly increase the EA

knowledge base and the ability to identify and report resident-on-resident abuse (Teresi et al., 2013).

The field of homecare is underfunded and socially undervalued yet by some estimates about 68% of older adults will at some point require long-term home care services (Family Caregiver Alliance, 2015; Marquand & York, 2016). Another estimate indicates about 12 million adults currently in need of homecare services (Poo, 2015). Low insurance reimbursement for service resulting in low pay for professionals and paraprofessionals makes the overall desirability to work with older adults so low that the field is grossly understaffed: by some estimates there is a need for at least 1 million new aides (Rolf, 2016; Warshaw & Bragg, 2016). Home health aides have been dubbed "a hidden workforce" and are in many ways marginalized despite it being the fastest growing segment of the healthcare industry (Poo, 2015; SEIU, 2012). They are one of the lowest paid employees in the labor force and often earn near minimum wage. Median income is around $13,000/year while the US poverty level for 1 person is $12,060/year (U.S. Bureau of Labor Statistics, 2017; U.S. Department of Health and Human Services, 2017; Rolf, 2016). Most home health aides are women, women of color and/or immigrants, qualify for Medicaid as the agencies rarely offer health insurance, have insecure housing and work for multiple agencies as overtime regulations restrict the number of hours agencies will authorize (Dawson & Langston, 2016; Dawson, 2016; Poo, 2015; Rolf, 2016).

The general shortage of professionals who are adequately trained in EA is well documented and reviews of the caregiving workforce find limited training, supports and funding (Barker & Himchak, 2006; Dawson & Langston, 2016; Marquand & York, 2016; Schmeidel et al., 2012). The challenge, as identified in the special 2016 caregiving focused issue of Generations by the American Society on Aging, is to adequately accommodate the mind, body

and spirit of providers and consumers alike (Rolf, 2016). This means empowerment as much as higher wages, health benefits and job protections as well as training and education for the workforce, which is currently not growing as fast as the demand for it. Retooling for an Aging America 2008 report by the Institute of Medicine proposed some changes addressing these needs, which have been adapted by the 2010 Affordable Care Act but subsequently never funded (Dawnson & Langston, 2016; Marquand & York, 2016).

Conclusion of Literature Review

Elder abuse is unacceptably underreported (Brossoie & Roberto, 2015; Crockett et al., 2015; Smith, 2015). Research indicates that provision of training, supportive supervision and resources may promote an improvement in workers' ability and willingness to participate in the intervention process (Cairns & Vreugdenhil, 2014; Killick & Taylor, 2009; Teresi et al., 2013). Home health aides, however, have been systematically excluded from this research so it is unknown whether similar interventions to improve reporting of EA are effective with paraprofessional workers.

Given that the field is expected to grow as rapidly as population of older adults, the need for more in-depth recognition of workers, as well as increased resources, is necessary. Importantly, due to the intimate nature of their jobs, home health aides have an opportunity to be on the frontlines of its identification and reporting (Barker & Himchak, 2006; Dawson & Langston, 2016; Marquand & York, 2016; Schmeidel et al., 2012). Despite limited finances, organizations are positioned to support home health aides in addressing situations of elder abuse. Understanding better the barriers and facilitators in home health aides' identifying and reporting of elder abuse will inform organizational interventions that may help improve prevention, reporting, and treatment.

CHAPTER III: THEORETICAL FRAMEWORK

Theory of Self-Determination

In order to conceptualize the experiences of home health aides and their approach to work, this study will utilize Ryan and Deci's psychological theory of Self-Determination (SDT) established in 1985 (Ryan & Deci, 2000, Ryan & Deci, 2017). The following review of the theory of Self Determination demonstrates how organization changes may improve performance and motivation of workers. It will also provide a guiding conceptual framework for answering the research question examining facilitators and barriers experienced by home health aides in detecting and reporting elder abuse in New York City.

SDT explains the varied ways in which personal, or "intrinsic" and social or "extrinsic," factors influence and sustain human motivation. This concept incorporates psychological needs and values with outside controls (Deci & Flaste, 1995; Ryan & Deci, 2017). Components of the theory have been studied since the 1980s with multiple applications in health and well-being, sports and exercise, education and most notably for the purpose of this project, organizational behavior (Ng et al., 2012; SDT.com, n.d.).

The Theory of Self-Determination proposes that psychological needs, much like biological needs, must be supported in order for an individual to have a cohesive and authentic self that is best prepared to productively interact with the world (Deci, 2017). Fulfillment of psychological needs leads to overall wellness that affects both motivation and behavior. When an activity fulfills someone's psychological needs, it is more likely that the individual will gain pleasure from the activity, be more invested in it and have a higher level of productivity over longer periods of time than someone who does not feel fulfilled by an activity. The theory acknowledges diversity of motivational factors as well as demands of modern life and proposes

ways in which the individual and society can adjust behaviors in order to accomplish the best and most rewarding outcomes.

The theory centers around three specific needs: autonomy, competence and relatedness (Desi & Ryan, 2000; Ryan & Deci, 2017; SDT, 2017). These needs allow for the extrinsic motivational factors to become integrated within the self, or accepted as one's own values, in turn leading to the most authentic and sustainable level of motivation. Researchers argue that frustration with these needs, such as lack of skill, lack of external supports or overbearing control, may lead to feelings of helplessness and general "amotivation" or detachment (Ryan & Deci, 2000). Intrinsic motivation (i.e. motivation that has the long term and highest performance) may be accomplished by satisfaction of these needs, including integration of extrinsic motivational components such as financial rewards. (Hodgins & Knee, 2002).

The homecare field workers are marginalized and under-paid. The homecare agencies are presented with an opportunity to enhance promotion of their workers' value by providing educational and supportive resources, which research indicates may lead to more engaged and productive workforce. That could potentially translate to a greater involvement with clients, greater understanding of what constitutes elder abuse and greater willingness to discuss it with their supervisors, triggering a process of intervention. Home health aides, while incentivized by salaries and steady, reliable work are also motivated by personal values and drives, which can be integrated with those of the organization just as well as they can lead to amotivation. Tapping into that potential to enhance each aide's connection to the agency and client, comfort with knowledge and skill, and trust in support, could result in a more committed workforce and greater rates of reporting of abuse.

Autonomy

The concept of autonomy refers to the freedom of choice, or control, a person may have over any given activity or decision. It is not meant as being "independent" but rather to have "ownership" of actions and performing them in accordance with one's authentic values and overall self (Deci, 2015; 2017). The extent to which autonomy of action exists impacts the experience, behavior and performance of an individual (Ryan & Deci, 2017). We are rarely truly free to go about our lives as we please, particularly at work, and within SDT, autonomy is understood to exist on a continuum, with a reminder that people have choices.

Extrinsic motivation is the most commonly utilized path to motivation toward unfulfilling or undesired tasks, as driven by mandates of a workplace but with a sacrifice of creativity, wellness of body and spirit and sustained level of performance (Deci & Flaste, 1995; Landry et al., 2016). It may also be introjected (i.e., partially accepted), provided the outcomes and rewards somewhat match ones' own (Landry et al., 2016). Extrinsic motivation, such as a salary, may be completely out of one's control and result in passiveness and even resistance. Feelings of guilt or fear, such as the potential of job loss, may also lead to introjection of extrinsically provided motivators (Koestner & Losier, 2002) The full integration of extrinsic motivation, such as supervisor's praise, provides for the most complete sense of autonomy where one's actions are genuinely in accordance with values of self. The flexibility of choice pushes creativity and innovation forward and is most likely to sustain motivation long term and supervisory support of that autonomy translates into better workplace morale (Deci & Flaste, 1995).

Home health aides' work is in many ways autonomous. While they are supervised and belong to an agency, their tasks are completed in isolation, in the very intimate setting of clients'

homes. One may argue, however, that their work is not autonomous at all, as they are given specific directives on what is, and is not to be completed at each shift. The question then is, how restricted are they in terms of being able to tap into their resources of knowledge and critical thinking to become actively involved with their clients and be on the lookout for signs of abuse? How much "ownership" do aides feel over the tasks they complete and the relationships they build with clients? The answer lies in the positive organizational contributions boosting autonomy within the controlling guidelines of regulations.

Competence

Competence refers to an individual's ability to develop and utilize personal aptitudes (Deci, 2017). It is a set of skills and knowledge obtained from experience, both personal and employment related, and can be sharpened by continuous education and training. Home health aides who have an opportunity to build on their knowledge are by that measure more engaged in their work. An agency's provision of education about elder abuse may increase the aides' confidence in the ability to better recognize its signs. Knowledge about measures to combat abuse may be key to reporting abuse in cases when a client comes forth and discloses abuse to an aide. Competence enhances self-confidence and nurturing its expression by acknowledging it and providing opportunities for its development engages employees' interest and motivation in tasks (Elliot et al., 2002; Landry et al., 2016; Ryan & Deci, 2017).

Inability to pursue one's interest would stand in a way of meeting this psychological need for competence, and potentially lead to frustration (Deci & Ryan, 2000; Krapp, 2002). Workers who are not provided with educational enhancements pertaining to their expected tasks and contingency circumstances, such as abuse, may withdraw their interest from work, resulting in minimal effort in completion of required tasks. Further expression of rebelliousness and

insubordination, such as minimal contact with supervisors, could follow. In the personal nature of homecare services, such loss of an opportunity in not only identifying abuse but in minimal relational involvement and engagement with clients would present a paramount, and avoidable, loss.

Relatedness

The last component of SDT theory, relatedness, refers to a sense of belonging. Deci (2012) specifically states that "relatedness is experience both in being cared about and in caring" (p.86). How aides perceive their relationships with their clients, supervisors and the agency as a whole may influence the way they interact with clients. In this instance, the "security of a home base," as coined by Ronen and Mikuliner (2011), matter tremendously and may very well color the velocity of active involvement in cases of observed abuse. In homecare, the value an agency places on their mission and how it is able to connect it to the value of work conducted by home health aides contributes to the development of the connection between the agency and its workers.

Relatedness is of particular interest in the context of this study, as its establishment may prove to be difficult for employees who work in separate locations (i.e., in the homes of clients) and do not have the opportunity to meet each other, making the development of a collaborative, supportive work environment more challenging.

Application of Self Determination Theory

The Theory of Self Determination has been studied in many contexts of economic and political systems as well as within personal and organizational domains such as human development, medicine, sports and academics (Deci & Flaste, 1995; Deci et al., 2017; Frederick-Recascino, 2002; Ryan & Deci, 2017). Research indicates that when people are internally

motivated in tasks, they are more interested and engaged in them, they are more likely to conduct them for longer periods of time and task completion brings them more satisfaction. That internal motivation has been aligned with that seen in children at play, in that children do not require any extrinsic motivation or any extrinsic incentive to play, as they play for the pure joy of it (Deci, 2014). That joy is enhanced by supportive external forces, such as encouragement for exploration and experimentation, provision of education to enhance competence and allowance for some autonomy. These variables increase individual's self-confidence and therefore encourage them to take more risks with their creativity and innovation (Ryan & Deci, 2017).

The power of internal motivation has been documented in studies concerning personal behaviors regarding health, such as for example, being compliant with taking medications (Ryan et al., 2008; Williams in Deci & Ryan, 2002). It has been widely accepted that despite tremendous advances in medicine, individual lifestyle choices such as diet greatly impact health outcomes (Ryan & Deci 2017). Changing maladaptive behaviors is difficult to accomplish and even more difficult to maintain, despite the objectively sound knowledge of benefits for doing so. One study on positive health outcomes found that medical professionals have the capacity to increase their patients' well-being and treatment compliance by supporting their autonomy, competence and relatedness by involving them in the decision-making process (Ryan et al., 2008).

Research further indicates that when clients' choices about their goals are respected and when they are involved in designing the steps of care and intervention, they are much more likely to follow through and have successful outcomes (Mariam et al., 2015). For example, the Eliciting Change in At-Risk Elders (ECARE) study tested an intervention of caseworkers' motivational interviewing with older adults and caregivers. This study focused on the impact of

individual empowerment and capacity to make life-changing decisions in order to reduce risk for abuse (Mariam et al., 2015). The ECARE interventions were specifically tailored to clients' vision of what needed to be done, ensuring a guiding but non-judgmental approach. The key component of the intervention, alliance, relied on trust and understanding the complex nature of each individual case as well as respect of client wishes regarding services and assistance. The study involved psychology graduate students and a care manager, all supervised by an elder abuse specialist, and implemented a pre-and post-intervention functioning checklist. The instruments included a "problem checklist", developed by the researchers and a Prochaska & DiClemente's Trans-Theoretical Model of Change Identification (1983). The model involves stages of change (pre-contemplation, contemplation, preparation, action, and maintenance), which are utilized to assess it. ECARE outcomes indicated that 75% of participants progressed at least one stage, with about 43% progressing to "action and/or maintenance" stages. Risk factors such as eviction, dependency, and isolation from resources, were scored. The pre-posttest analysis indicated an increase in the strength of the working alliance and a decrease in the risk factors such as "economics and housing". The outcomes pointed to the usefulness of developing a working alliance specifically with focus on acknowledging the sensitive nature of EA and the many factors that impact cooperation and completion of risk reducing treatment.

The impact of organizational capacity to meet the psychological needs of workers has also been studied within SDT. For example, an intervention training was conducted in an inpatient psychiatric facility for youth with the goal of reducing the negative experiences attached to aggressive clients who were deemed to be at risk for being physically restrained. The intervention was the collaborative discussions about treatment, enhancing autonomy, competence and relatedness of staff regarding implementation of tactics with less physical force.

The outcome showed not only an internalized change in staff utilizing this different approach but also higher levels of satisfaction in patients (Deci & Olafsen et al., 2017).

Having an "organismic readiness," that is, an internalized preparation and drive to change, is considered the strongest path to long lasting change, regardless of the external motivators (Deci & Flaste,1995; Ryan & Deci, 2002). Such readiness comes with accepting limitations and external controls that may exist, giving to way to freedom of choices within a world that mandates a certain level of obligatory responsibilities, such as paying taxes or following organizational protocols (Williams, 2002).

Studies regarding employee turnover and burnout rates, a topic quite relevant to homecare, have indicated that supervisory support and enhancement of competency may counteract these rates as it leads to increased job satisfaction (Deci & Olafsen et al., 2017). This has been tested in several areas (Deci et al., 2017): Richer et al. (2002) found that autonomy was correlated with less emotional exhaustion in business school alumni, and a Flemish study found that overall frustration with psychological needs leads to overall higher levels of exhaustion (Deci et al., 2017). Furthermore, Fernet et al. (2010) found autonomy to be correlated with less burnout in college employees, and Trepanier et al. (2013) found that autonomous motivation resulted in lower stress levels at highly demanding work (Deci et al., 2017). The importance of autonomous motivation on employees' health and company's well-being has also been studied in several work environments such as a telecommunication company (Gagne et al., 2000), a bank (Baard et al., 2004) and manufacturing (Liu e al., 2011) with similar outcomes: meeting the psychological need of autonomy impacts job satisfaction and burnout rates (Dec al., 2017).

A dated (1989) but notable intervention in a Fortune 500 company provided trainings for supervisors and employees around autonomy and initiative. Following this educational

intervention, employees expressed greater trust in corporate management (Deci et al., 2017). Well prepared, visionary leaders could be transformational and have a long-term impact on individuals and organizations, as opposed to being merely transactional where the expectation of performance is based solely on compensation (Deci et al., 2017).

A series of studies on "contingent" rewards for engagement, completion, and performance, have been conducted and a meta-analysis (Deci et al., 1999; Ross, 1975) indicated that the control of the "pay for performance" negatively impacts intrinsic motivation as well as motivation for tasks that are not rewarded at all (Deci et al., 2017). In the worst-case scenario, "pay for performance" may deter ethical practice, such as cheating if teachers are rewarded for student scores, production of a diluted product or even illegal increase in stock prices. Base salaries been found to moderate motivation and promote an environment in which fostering of psychological needs is possible (Deci et al., 2017). Alas, motivation is difficult to analyze and studies on "pay for performance" have been riddled with controversy in that such a real world socio-economic concept cannot be properly studied in a controlled environment (Deci et al., 2017). Yet supervisors who are charged with creating highest productive environments need tools and SDT has demonstrated sufficient evidence to warrant further examination of psychological needs and agency wellness (Ryan & Deci, 2017).

Intrinsic and Extrinsic Motivation

Intrinsic motivation stems from individual's internal sets of values, beliefs, and aspirations and is autonomous and theoretically free of extrinsic motivators, such external pressures and controls (Deci & Flaste, 1995; Vallerand & Ratelle, 2002). Meeting the needs of autonomy, competence and relatedness contributes to building and sustaining intrinsic motivation. Intrinsic motivation may also come from internalized external sources, including

salaries and supervisory expectations as well as the societal value placed on the work being conducted. Research indicates that focus on fulfilling employees' psychological needs leads to internalization and integration of extrinsic factors into one's own values; it enhances the buy-in to the organizational goals and values, ergo creating workers whose intrinsic motivations become aligned with the organizational goals and values (Deci & Ryan, 2000; Deci et al., 2017; Lanry et al., 2017; Ryan et al., 2008).

People's actions are heavily influenced by their internal motivation, which includes the internalized perception of outcome values and desire to accomplish self-imposed goals bringing psychological satisfaction (Deci & Ryan, 2000; Deci et al., 2017; Sheldon, 2002). The internal motivation values pleasure and control over tangible rewards such as money. This has been studied in regard to motivation in a workplace, where employees are extrinsically rewarded via salaries, despite studies that show that internal motivation results in more productive, dedicated and committed employees (Deci et al., 2017; Kasser, 2002; Landry et al., 2016; Ryan et al., 2008).

The goal of studying the motivations of those who go above and beyond their basic job functions is to tap into those intrinsic resources that can be developed and nurtured externally via agency sponsored resources. That can be accomplished by collaborating with workers and promoting integration of organizational values into one's own intrinsic values. Collaboration and provision of rationales for given tasks is just one of the ways to promote competence and autonomy, the most necessary components of internalization and integration (Ryan et al., 2008). Given the interpersonal nature of homecare services, it is prudent for the aides to be observant, engaged and concerned about the totality of their client's well-being, beyond the extent covered by their assigned job tasks and including whether they experience abuse.

Intrinsic motivation is a very complex phenomenon as motivations may vary within an individual. For example, Ryan and Deci (2000) studied motivations of students doing homework and found that some were intrinsically motivated because they were interested in rewards such as good grades and praise while others were simply trying to avoid parental scorn (Ryan & Deci, 2000). Both groups, however, completed the tasks and this lack of distinction has been pointed out to be the downside of the theory. One may argue that as long as there is motivation, it can be tapped and molded by external resources. Outcomes may include a more comprehensive involvement in the day-to-day practice, such as an increased engagement with clients, expressing curiosity regarding their interests, and increased attention to the details of the physical environment of the work setting. In other words, being more present and active with clients, beyond the simple completion of tasks. Since the theoretical comprehension of motivation is not clean cut, researchers have pondered whether it is actually irrelevant in practice and found that pressured motivation negatively impacts the worker's capacity to sustain it (Silva et al., 2014). Research indicates that as long as motivation continues to be controlled and pressured, and it is not truly internalized or at least integrated, over time the level of interest and productivity will decrease (Deci & Flaste, 1995; Ryan & Deci 2017, p.190). This may lead to worker burnout and even separation from the agency, putting clients and agency at a loss.

CHAPTER IV: POLICY CONTEXT

Policies addressing elder abuse have been notoriously limited and fragmented (Elder Justice Coalition, 2014; HHS.gov n.d.). The most recent federal elder justice initiatives, such as the Elder Justice Act of 2010, suggest a massive, if not historic, shift in the attention brought to the issue. This chapter describes the evolution of policies and the role of relevant advocacy organizations in the field of elder abuse and elder justice

Key Policies

The First White House Conference on Aging in 1961

After WWII, President Truman began the process of evaluating policies put forth for older adults. Most notably it resulted in the expansion of Social Security benefits and call for ongoing review of needs. The White House Conference on Aging Act (Public Law 85-908) was signed into law in 1958 by President Eisenhower, with the first official conference taking place under his leadership in 1961. The Conference has now been held every decade, with the most recent one in 2015 (HHS.gov, 2016). The conferences have been instrumental in community advocacy for elder justice, such as President Obama's call for reauthorization of the Older American's Act.

The Older Americans Act of 1965

The Older Americans Act of 1965 was created in order to ensure provision of community based social programs for older adults. It resulted in creation of the Administration on Aging to serve as a federal umbrella organization providing supports to local programs and managing state grants. The Older Americans Act defines older Americans as those over 60 years of age, which is an important distinction from the usually used age of 65, of Social Security eligibility (AoA, 2016; Elder Justice Coalition, 2014). President Obama reauthorized the act for three years in

2016.

Title XX of the Social Security Act 1974

The Adult Protective Services history can be traced to the 1960s, when the Administration on Aging provided partial funding for programs focusing on the protection of vulnerable older adults (NAPSA, 2016). The initial community buy-in was low, however, and only about 20 such organizations existed by 1968. Adult Protective Services organizations are the primary responder to cases of elder abuse (Dong, 2012; Nerenberg et al., 2012; Rath, 2012; Solomon & Reingold, 2012). The 1974 passing of Social Security Title XX Act allowed the expanded utilization of the so-called Block Grants (SSBG) funding to supplement the limited funding serving this population, ultimately mandating provision of social programs for victims of abuse (Burnes et al., 2014; NAPSA, 2015; Nerenberg, 2006). Title XX of the Social Security Act (U.S. Code §§1397-1397f) is administered by the Office of Community Services, Administration for Children and Families, Department of Health and Human Services (SSA.gov, 2016). The recognition of EA phenomena begun to gain publicity in the 1980s, and while funding continued to be a challenge, by 1981 all states had some type of agency providing protective services for adults (Anetzberger, 2012).

The Elder Justice Act of 2010

The last few years have seen a major shift in policies addressing EA. For the first time in history federal elder abuse initiatives have been put in place, beginning with the establishment of the 2010 Elder Justice Act (EJA H.R. 3590). EJA was first introduced in 2003 by Senators John Breaux and Orrin Hatch, members of Senate's Special Committee on Aging, but failed to pass multiple times until 2010, when it passed as a 22-page part of the Patient Protection and Affordable Care Act (148 PPACA). The Act amends Title XX of the Social Security Act and

mandates the Department of Health and Human Services (DHHS) to oversee federal elder abuse resources and initiatives and includes authorization of $777 to be allocated over the next four years. By 2016, however, only $8 million has been released, up from $6 million to date in 2013 (Collelo, 2017; EJC, 2016, Narenberg, 2019).

The challenge in obtaining funding for protection of older adults has been historically noted. In 1985 Senator Pepper, a known advocate for elder justice, reported that about $.2.91 was spend per adult on protective services while $22.14 was spend per child. In 1991 that number was $3.80 per adult to $45.03 per child. Today, the total $777 million funding for Elder Justice Act meekly compares to the $7 billion allocated per year for child protective services (Dubble, 2006; NAPSA, 2016).

Elder Justice Act mandated federal oversights to ensure institution and coordination of services across jurisdiction, including the formation of Elder Justice Coordinating Council and funding the National Training Institute for Surveyors. Details of the Council's five meetings (2012-2014), and the Congressional report calling for ongoing federal oversight, have been made publicly available. Section 6 of EJA specifies that APS programs are to be included in Congressional reports. Additionally, the Advisory Board on Elder Abuse, Neglect, and Exploitation has been charged with designing a multidisciplinary strategic plan for funding forensic centers that will allow provision of scientific and investigative services (The Elder Justice Coalition, 2016). It is expected that the multidisciplinary approach will coordinate the efforts of the fragmented systems (such as medical, social service and criminal justice, for example) often involved the investigation and prosecution of EA cases. The Act also indicates intent to fine long-term care facilities for failure to report alleged abuse or for unjustly retaliating against employees who come forward with information. To date all but New York State have

mandatory elder abuse reporting statues (American Bar Association, 2016).

The Elder Justice Act has allocated $100 million per year, for 4 years to Adult Protective Services and additional $100 million (total) for grants focusing on improvement of APS practices (the Elder Justice Coalition, 2016). The Act directly addresses the necessity of having appropriate training for staff and availability of national resources by creating a National APS Resource Center (Congress.gov, 2016). This was not a small feat and in fact a major indicator of a shift in recognizing complexity of EA necessitating specialized and focused response. Funding has also been allocated to improve collection and standardization of APS data and research but by 2013 only $2 million has been released with 2018 amount standing at $12 million (Narenberg, 2019). This is important as time and time again, inadequate or unreliable data set have been noted to limit validity, generalizability and potential for replication of research (Rizzo et. al., 2014).

U.S. Department of Justice Initiatives 2013

In 2013 and following the Elder Justice Act, the U.S. Department of Justice (DOJ) passed the Elder Abuse Victims Act. In 2014 DOJ established the Office of Elder Justice, not to be confused with the initiative under the Health and Human Services barring the same name (HHS.gov; Justice.gov). That same year, DOJ launched an informative and resourceful Elder Justice Initiative website, (Justice.gov). In 2015, and following the White House Conference on Aging, DOJ also revised the Victims of Crime Act (VOCA) guidelines to specifically include support for victims of elder abuse. In 2016 the federal funds for VOCA were increased to $3 billion (Justice.gov).

Stakeholders and Advocacy Organizations

National Committee for the Prevention of Elder Abuse

Dr. Rosalie Wolf, a pioneer in the field of EA and a co-editor of a groundbreaking book on elder abuse and family conflict (Wolf & Pillemer, 1986) founded the National Committee for the Prevention of Elder Abuse in 1988. The following year she founded the Journal of Elder Abuse & Neglect in order to provide a platform for research dissemination (NCPEA, 2014). The NCPEA (2014) identified areas in need of development: the definitions, prevalence, theoretical explanations and consequences. These areas of focus continue to be on the forefront of research today (Anetzberger, 2012; Narenberg, 2019). While the journal continues, in 2018 the organization closed (Narenberg, 2019).

National Adult Protective Services Association (NAPSA)

The National Adult Protective Services Association (NAPSA; formerly known as the National Association of Adult Protective Services Administrators), a national nonprofit, was established in 1989 with the purpose of providing information and support to the jurisdictionally fragmented APS programs. The organization is highly involved in advocacy and the leadership makes every effort to testify at Congressional and Senate hearings promoting the cause of elder justice.

The goal of the organization is collaboration and resource sharing with local organizations as well as creation of forums for ongoing discussions addressing the ever-changing landscape of needs (NAPSA, 2015). Furthermore, it has established the annual APS conference in the 1990s and, with the funding from AoA, the National APS Resource Center in 2011. One of NAPSA's most followed accomplishments has been the creation of APS best practice guidelines upon which many of the jurisdictional policies are based. They underscore clients' right to self-

determination, and utilization of the least restrictive form of treatment (NAPSA, 2015). This is noteworthy as currently there are no federal mandates or standards for APS. The NAPSA Education Committee in 2013 recommended Minimum Program Standards, including ethical and service guidelines, the program's philosophy, expected core activities and necessary training protocols. Additionally, the committee laid out proposed strategic goals, which included a focus on operations, training, policy and public education. To date there appears to be no reports on the reach of the guidelines or adaptation of the policies by individual jurisdictions.

In 2015, the Administration for Community Living also put out a draft of Voluntary Consensus Guidelines for State APS Systems with the purpose of moving toward standardizing the provision of services (ACL, 2015). This is a momentous show of federal support for APS and their practices, although it is important to know that is it not specifically focused on EA. The expectation is for the guidelines to be modified based on the comments received from the public on the ACL website, until December 2015. To date the final version is not yet available (ACL.gov, 2016).

Homecare Association of America

Much like NAPSA, the Homecare Association of America was created in order to provide a common place for providers to share resources, create industry standards and offer guidance for providers of non-medical and privately paid homecare services (NCAOA.org). It is not a mandated or accrediting body. Access is restricted by paid membership to local chapters which, unlike with NAPSA, greatly limits what a lay person may access on the website. As it is focused on services of interest to for-profit homecare agencies, membership includes discounts on advertising and marketing services and products such as uniforms as well as allows for access to social media platforms. The association's mission promotes "professionalism…through

education and best practices" and "leadership conferences" and webinars are organized for members. The ethical guidelines include the client's right to "be free from abuse, discrimination and exploitation" (hcaoa.org). There are chapters in 19 states and New York does not have any local chapters listed. The national impact or overall utilization of the association was not possible to gauge.

Elder Justice Coalition

In 2003, the Elder Justice Coalition (EJC) was launched with a purpose to promote the newly proposed Elder Justice Act and generally advocate on a federal level for elder justice. The founding members, five organizations serving older adults (National Committee for the Prevention of Elder Abuse, National Academy of Elder Law Attorneys, National Association on State Units of Aging (currently the National Association of States United for Disability and Aging), National Association of Adult Protective Service Administrators and National Association of State Long-Term Care Ombudsman Programs) came together to provide support and advocacy for legislation. The latter includes support of the Elder Abuse Victims Act and the Home Care Consumer Bill of Rights. Today EJS counts over 900 members and continues to advocate and lobby for federal funding, with a goal of keeping the topic of elder abuse on the forefront of research, practice and political agendas (EJC, n.d.).

Conclusion of Key Policies and Advocacy Initiatives

As Baby Boomers began entering their Medicare years in 2011, they illuminated the needs of all older adults (Poo, 2015) While phrases like "silver tsunami" and other catastrophic terms to describe the aging population may be ageist and have negative connotations (FrameWorks Institute, 2017), the public discourse about the changing demographics reminds us all of the need to adjust our shared economic and social landscapes. While not all of us will

become victims of elder abuse, all of us may become victims of ageism (Blancato & Ponder, 2015, Narenberg, 2019; Poo, 2015). We are faced with a fantastic opportunity to improve the culture around ageing. Passing the 2010 Elder Justice Act was a positive step for elder abuse advocates, but there is a long way to go, particularly in the area of funding which continues to lag drastically behind funding allocated for child abuse and interpersonal/domestic violence. Business as usual will no longer suffice as people are living longer and relying on more homecare services than previous generations (Blancato & Ponder, 2015; North & Friske, 2013; Narenberg, 2019).

CHAPTER V: METHODS

This cross-sectional exploratory study utilized Grounded Theory (GT) methods to examine what facilitates detection of elder abuse and what motivates its reporting. GT was developed by Glaser and Strauss (1967) to explore social phenomena and potential relationships between them (Creswell, 2013, Glaser & Strauss, 1967; Oktay, 2012; Padgett, 2008). GT allows data to guide the inquiry, offering an alternative approach to theory development in exploratory studies. Data collection and analysis are iterative, development of codes, concepts and themes are ongoing and detailed memoing facilitates attention to the richness of complex data (Creswell, 2013; Oktay, 2012).

The objective of this study was to understand the home health aides' (HHA) motivation to identify and report elder abuse, and to discover barriers which may hinder the detection or reporting of it. The orientation of the study is pragmatic as it is rooted in, and relevant to, practice (Oktay, 2012). Qualitative inquiry using GT is appropriate for this study as it has the potential to uncover rich and unrestricted data around a phenomenon that is not yet studied (Padgett, 2008). This chapter will describe the details of the study design, sampling and recruitment, ethical considerations, data collection, trustworthiness, rigor and data analysis.

Setting and Sample

A purposive sample of home health aides was recruited via licensed home care services agencies (LHCSA) in New York City. To participate in the study, the aides were required to meet the following criteria: be able to communicate in English, to have home health aide certification, and to be employed by a licensed agency specializing in services for older adults. The U.S. Elder Justice Act of 2010 (EJA H.R. 3590) defines the term "older adult" as someone 60 years of age or older, although the World Health Organization has recently proposed to use

age 65 (WHO, n.d.). Participants were not excluded due to their age, identified gender, religion, immigration status, income level, or other identified or protected status. Protected status, as described by the Federal Policy for the Protection of Human Subjects also knowns as the "common rule" (1991) includes vulnerable populations such as people who are pregnant (or children or prisoners) (HHS.gov n.d.).

The proposal called for up to twenty participants to be interviewed for the study. Homecare staff and participants were encouraged to identify other potential participants. To the researcher's knowledge, no participants were referred by other participants. In total 18 home health aides were interviewed, with data from 17 of the 18 interviews utilized for analysis (the audio recording of one interview malfunctioned and there was insufficient information in the notes and memos). This sample size is similar to the Schmeidel et al., (2012) study interviewing professionals about their perceptions regarding elder abuse. That study included nine nurses, eight physicians and six social workers. After 18 completed interviews, data saturation was determined by repetitive answers.

Demographic data was tracked on a Microsoft Excel spreadsheet. The self-identified gender of nearly all participants was female, with one participant identifying as male. Race and ethnicity were self-reported as Black and/or African American by 14 participants. One participant identified as Hispanic, and one participant identified as Haitian and one "other" (born in Haiti). Only four of the participants were born in the US (three in NYC, one in the South). Ages ranged from 32 to 73 years-old, with an average age of 51.7 years. The average time each participant spent working as an HHA was 12 years, with a range from one to 32 years. There was a broad range of educational levels among participants, with two participants having completed high school, four with General Education Diplomas (GED), one a high school diploma from the

US and six with high school diplomas from outside of the US. Additionally, two participants completed "some college" and one obtained a Bachelor's Degree in teaching from Jamaica. One participant had a Master's Degree in Human Development from Ghana and expressed interest in getting a Master's in Social Work. The demographic details are outlined in Table 1 below.

Table 1

Sample Characteristics

		Frequency (#)
Gender	Female	16
	Male	1
Race/Ethnicity	Black or African American	14
	Hispanic	1
	Haitian	1
	Other	1
Country of Birth	Barbados	1
	Congo	1
	Dominican Republic	1
	Ghana	4
	Haiti	2
	Jamaica	1
	Trinidad/Tobago	2
	United States	4
	St. Lucia	1
Education	Less than High School	2
	High School or GED	11
	Some College	2
	College or Graduate Degree	2
Age	Mean = 51.7 (s.d. = 11.6); ranged from 32-73	
Years as Home Health Aide	Mean = 12 (Median = 10); ranged from 1-32	

Home health aides in general as a workforce come from many different backgrounds, many are immigrants, and many are economically marginalized (PHI, n.d.). Therefore, serious consideration was taken to accommodate their schedule and availability, for which they were not compensated. Additionally, as an incentive to participate, all aides were entered in a lottery to win one out of four $25 Metro Cards. The lottery complies with the City University of New York Human Research Protection Program Policy on raffles as compensation for participation.

Recruitment

Agencies for this study were selected based on the researcher's professional contacts and met the criteria of having been in business for at least one full calendar year. Appendix 8 provides a list of agencies the researcher has had professional relationships and those that were initially identified with interest in participating. In order to ensure a sampling frame that was sufficiently diverse in terms of participant characteristics, the agency search was expanded via a snowball sampling approach, with agencies being encouraged to offer recommendations and contacts at other agencies. The researcher initially reached out via email to representatives of four agencies (Appendix 3: Agency Email Script). Three agencies expressed interest in learning more about the project. In the end the participants were recruited from these three LHCSAs.
To confirm the eligibility of agencies the researcher reviewed characteristics of each participating agency (listed on their websites), confirming that they are licensed, employing certified home health aides servicing older adults and have been in business for at least a year.

To obtain a comprehensive understanding of each agency, the researcher asked each agency's administrators about the size of the agency whether the agency is for-profit or non-profit, and a description of the services provided by the agency (Appendix 4: Agency Screening and Review Questions). All three of the agencies are not-for-profit.

Agency A, the smallest with approximately 95 employees, was established the mid 1980s and in addition to providing quarterly in-service classes, provides peer mentoring social work assistance and coordination of trainings with local organizations serving people with Alzheimer's Disease and related dementias (ADRD). The contact was one agency administrator who was able to answer questions and make decisions for the organization in a very direct and quick manner.

Agency B was also established in the mid 1980s and employs about 1,500 staff of mostly nurses and aides (including Personal Care Aides). The agency provides in-service classes once to twice per month and while it encourages aides to attend educational workshops outside of the organization, it does not offer them as part of their educational portfolio. To recruit the agency to promote the study to home health aides, the researcher emailed and spoke with several administrators, who had to follow up with other departments and contact other, "on the floor" administrators to coordinate each day of research. In other words, the larger the agency, the more complex organizational structure which therefore required multi-level reviews and approvals of the project.

Lastly, Agency C, a social service agency established in the late 1960s employs about 2,000 staff members who deliver over 50 programs and services for older adults. Professional staff includes social workers, case managers, nurses, and home health aides. In addition to monthly or quarterly (depending on the need) in-service classes, the aides may partake in any of the services and trainings offered by the agency, free of charge and with some accommodation to their schedules. Agency C has an elder abuse program and offers elder abuse training. Much like within the agency B, there were several levels of administrators involved in the decision to make the site available to the researcher and to coordinate the time and space for research interviews.

Technology made communication and coordination with this agency quite efficient as multiple people were included on emails and able to follow up with the researcher in a timely manner.

Once an agency agreed to be a study site, the researcher emailed flyers describing the project (IRB approved) with a request to distribute the flyers to the home health aides (Appendix 2). All three agencies agreed to print and distribute the flyers. One agency distributed the flyers with paychecks and all agencies made them available at in-service classes. The flyers were written in English for a sixth-grade reading level, which according to Rolf (2016) is the average reading level of home health aides. The flyer copy was checked against SMOG ("Simplified Measure of Gobbledygook") Readability Formula (Hunter.CUNY.edu, n.d.). The researcher's email address and cell phone number were on the flyer so that potential participants who had questions about the study could have their questions answered. The researcher received one email from a home health aide who was interested in taking a class about elder abuse, not participating in a study. The researcher received two phone calls from home health aides who expressed interest in the study. One of the two aides participated in an interview; the other aide did not participate due to scheduling challenges.

Data collection commenced in December 2018. The researcher scheduled seven visits to all three agencies over a period of three months (December, 2018 - February, 2019). During each agency visit, the researcher was available to conduct interviews with home health aides who were at the agency to attend in-service trainings. The agency visits were conducted on the following dates: December 14th (2 interviews), December 17th (5 interviews but 1 did not record and was not utilized), January 7, 2019 (1 interview), January 18th (2 interviews), February 4th (1 interview), February 8th (6 interviews) and February 11th (1 interview). The visits were scheduled to coincide with dates of in-service classes, on site at all three agencies during which the

researcher would briefly (in about five minutes) describe the project, be available to answer questions and interview interested participants. The in-service instructors allowed the researcher to address the room at various times, sometimes right before a break. The likelihood of the aides returning to the office for another in-service class within the timeline of the study was low because the HHA certification only requires two in-service courses per year. This reinforced the researcher's attempt to accommodate and interview as many interested aides as possible while they were in the office. The aides are paid for their in-service time and classes are offered free of charge by agencies; topics vary, and curricula are designed independently by each agency.

It is important to note that the in-service classes often last all day (from 9am-5pm; one agency held one half-day class) making them physically and mentally draining. While the instructors seem to understand that and provide frequent breaks (one agency provided light breakfast refreshments) not much can be done about aides being uncomfortable sitting on hard chairs all day in sometimes uncomfortable temperatures (researcher noted one room to be exceptionally hot). Having someone make yet another request upon them without compensation may have been too burdensome a request for some home health aides to consider. Therefore, not all aides attending in-service trainings participated in the study.

Two agencies allowed for the researcher to come back on multiple occasions and one of the agencies held multiple in-service classes at each one of the visits. Each agency provided a private space for the researcher to interact with aides (such as an office or a private corner of a large, mostly empty classroom). To accommodate walk-in questions, the researcher spent several hours at each agency even when not interviewing participants. When a potential participant expressed interest in participating in the study, they were screened via a conversation with researcher, to ensure that they meet the eligibility criteria (Appendix 1: Screening Questions). It

is not possible to know how many of those who expressed interest but did not stay to be screened were eligible to participate. Of the participants who called and were screened to be eligible, only one completed an interview.

Data Collection

Data collection was conducted via focused, semi-structured interviews with HHAs. These allowed for free flow of information, unrestricted by boxed inquiry of closed ended, leading or limiting questions. Over a period of 3 months (December 2018 - February 2019), the researcher conducted 18 in-person interviews, 17 of which are included in this study. Two participants were from Agency A, 13 from Agency B and two from Agency C. The average length of time the interviews took was 16.17 minutes, ranging from 9.28 minutes to the longest at 37.42 minutes. These reflect only recorded time and do not include prior explanatory conversations about the project or the screening time. The interview guide consisted of five questions, each with several prompts allowing for follow up (for example, asking to explain something in more detail).

The researcher screened and collected demographic information of each participant (Appendix 1). One interview participant was screened over the phone, all others in person. Most researcher interaction with potential participants took place during breaks from in-service classes, and in two instances, at the conclusion of the in-service class. This resulted in several aides approaching researcher at the same time, therefore making it impossible to maintain confidentiality of who participated and who did not. This also created a challenge as some aides lost interest in participation because they did not want to wait to be interviewed while others rushed to complete the process. Home health aides within all agencies were reluctant to wait or return later for an interview. Aides sometimes seemed to rush through questions or offer little

elaboration on their responses. Aside from knowing that their co-workers were waiting, other reasons for short answers during the interviews could be that aides may not have wanted to use up their entire break time, or that they felt uncomfortable during the interviews. The researcher expressed that she was open to all participants having their lunch during the interview, but none chose to do so. Most aides were not interested in staying after the in-service classes, which would only be possible if the classes ended early as all agencies closed or the spaces were no longer available after hours.

If an aide could not wait to be interviewed, the researcher encouraged them to call and schedule an appointment. The researcher did not receive any calls to schedule an appointment for an interview. Between interviews the researcher distributed flyers through the office, including to aides not attending the in-service classes (in waiting areas around the agency), and reminded the administrators that study recruitment was occurring. Such interactions often resulted in brief conversations about the project. One notable interaction occurred when an administrator, identifying himself as a “medical intern” but also a PCA, HHA and CNA who tutors students for their certifications, wanted it to be known to the researcher that “elder abuse is very common." He was not interviewed for the project because he never worked as an aide for a LHCSA. but went on to state that he believed that “aides don’t report it (EA) because they don’t want to lose their jobs.” He went on to state that the families are “the worst” in the way they treat clients . He added that he did not receive any information about elder abuse as part of the HHA training because “everyone does it differently” (this was not a recorded conversation, but a detailed memo was taken immediately after).

In one of the agencies, both the instructor of the in-service class and nurse administrator, in their way of trying to encourage the aides to participate, became quite demanding and abrasive

in their speech after researcher's presentation. It gave the impression that lack of participation would somehow reflect negatively on the administrators. This spoke to the power dynamics of an already seemingly disinterested room. Additionally, the instructor proceeded to speak about the project in Russian which seemed to further alienate about 50 percent of the aides who clearly did not speak that language. Some of the aides were saying "this is not for me, I don't know anyone who is abused". The researcher at this point stepped in and stressed the voluntary nature of the project, lighten the mood by smiling and joking with some of the aides and emphasizing the understanding of the difficulties and pressures home health aides endure. This resulted in seemingly more relaxed facial expressions among the home health aides. Two potential participants expressed interest, one of whom was interviewed.

Interviews

The interview with the first two participants served as orienting pilots to ensure that the questions and expectations are clear and understandable as well as appropriate and seamless. Two aides were interviewed after researcher's first in-service attendance, one immediately after the other, therefore both interviews were reviewed regarding the necessity for potential adjustments. For example, based on the participants' answers, some questions were asked out of the order listed in the Interview Guide. The pilot study interviews were included in the total count of the 17 interviews included in the analysis.

Participants were told that they may skip any question they wished not to answer, terminate their interview, or withdraw their participation in the study at any given time. All participants chose to answer all questions, even if the answer was "I don't know". No one responded with "I don't want to answer" and no one terminated the interview without concluding

it. The individual, face-to-face interviews involved only one interviewer, the researcher. Participants were interviewed one time only and all interviews were audio recorded.

Participants were asked to sign consent forms documenting that they have been sufficiently informed of the benefits and risks of participating in the study (Appendix 5). Once the consent forms were signed, researcher turned the recorder on and began the guided interview process. In accordance with grounded theory, the researcher followed the Interview Guide (Appendix 1) while also expanding the inquiry based on the answers provided, assuring the richness of data (Oktay, 2012; Rubin & Babbie, 2014). The guide was used to ensure uniformity of interviews, not to restrict the answers (Creswell, 2013; Ravitch & Carl, 2016).

To assist in keeping interviews organized, the researcher wrote a brief introductory memo that was read at the beginning of each recording. The memo read:

> This is an interview for the home care /elder abuse project with the participant number _____. Today is_____. Participant has been screened and a consent form has been reviewed and signed. As discussed, I will be recording this interview as well as taking notes. Welcome and thank you for your participation.

The researcher then asked the first question: "What do you think elder abuse is?"

During the interviews, the researcher took handwritten notes on sheets of paper prepared with guiding interview questions and space for post interview memos, to capture any and all impressions and non-verbal communication cues. These memos were kept with interview transcripts. Additionally, on a separate notepad, the researcher took handwritten field observation memos to include all agency and miscellaneous observations, such as any conversations with the researcher in the hallway.

The overall interview exchanges were flexible and interactive to allow for the aides' expressions of desired information, while the researcher stayed open-minded and curious. The interviewer encouraged aides to speak freely and genuinely, and strived to create judgment-free environment by employing relational components of social work practice, such as engagement, establishment of rapport and trust, expression of empathy, and active listening (Ravitch & Carl, 2016; Rubin & Babbie, 2014; Tosone, 2004).

Following each interview, or at the end of a series of interviews scheduled throughout the day, the researcher reviewed and expanded on the notes written during the interview. The audio recordings were sent to be transcribed by a professional service immediately after each agency visit. The transcripts were received within 3-7 business days and were reviewed, line by line, as they were received. During this first line-by-line review, initial analysis and further memo writing took place.

Safety Protocol

Upon completion of the interview, each participant was provided with a handout listing contact information for organizations combating elder abuse in NYC, such as Adult Protective Services. This resource could be used to obtain more information about elder abuse, discuss a questionable case or report abuse (Appendix 7).

In the event that an aide was to disclose a work situation which appeared to potentially put them or their clients in danger, the researcher, who is a mandated reporter, was prepared to break protocol of the interview to clarify the situation and ensure safety. If the situation was complex enough to warrant further intervention, the researcher was prepared to facilitate a conversation with a supervisor. The researcher was also prepared to conclude the interview and not utilize the data. This protocol was specified in the consent form.

One case required a lot of clarification as the participant out right stated that her client was “being abused”. The researcher concluded that client was not in imminent danger. As it turned out, the aide did not believe that a family member was taking the client to see his doctor frequently enough while he needed wound care. The researcher explored and discussed the case in depth and was prepared to assist the aide to speak with her supervisor about it (ultimately the aide decided to speak with a supervisor by herself). This was a particularly difficult interview as there appeared to be some comprehension limitations and therefore it was challenging to obtain a clear picture of what is happening. For instance, the aide would state that she does not speak to her supervisor, then that she would or does speak with her supervisor if she has an issue. The aide was very obviously compassionate and attuned to the nuances of her client’s emotional dispositions and was aware of the impact of emotional and verbal abuse. In the end, the aide stated to be very appreciative of the conversation with the researcher and that her participation was prompted by wanting to talk about this specific case.

None of the interviews raised to the level where the researcher believed that the participant, or current client, were in imminent danger. There was no instance in which a follow up required a report the aide’s supervisor.

Ethical Considerations and Human Subject Protections

The study was approved by the Institutional Review Board for the Protection of Human Participants (IRB) via the Hunter College Human Research Protection Program Office in November 2018. No recruitment or data collection took place prior to the approval (Oktay, 2012; Padgett, 2008). The IRB approval expires on November 18, 2021 (Appendix 12).

Cultural Sensitivity

The researcher made a point to be sensitive to the marginalized context in which the home health aides may operate. For example, during the project introduction at the in-service classes, the researcher stated an understanding of aides' busy and restricted schedules and expressed appreciation for their time, interest and willingness to participate in the study, despite not being paid outright for their participation.

The aides are often economically marginalized, earning minimum wage and relying on public assistance (U.S. Bureau of Labor Statistics, 2017; U.S. Department of Health and Human Services, 2017; Rolf, 2016). They are most often women, women of color and immigrants who may have very different personal and cultural experiences than their clients, their supervisors and the interviewer (Rolf, 2016; Stone, 2016). Most of the aides were welcoming of the study presentation and participation request. Even if they chose not to participate, they smiled, came up to the researcher to say that they think that it is important to talk about elder abuse and wished me luck. Other responses to participation requests included expressive body language such as rolling of the eyes, taking out phones while researcher was speaking, or walking out of the classroom. One aide made outright statements of "wasting their time" if they were not paid for their participation. On more than one occasion the researcher was approached by aides double checking if they could "get the MetroCard today" or "be guaranteed to receive it" in the near future. In one case, an aide stated that "it was the researcher's loss as I have a lot to say about elder abuse" accompanied by a facial expression suggesting disappointment. In each case the researcher attempted to explain her position as a student and thanked them for their time.

The researcher is aware that the aides in this study likely have experienced oppression, discrimination and devaluation, which the researcher made efforts to acknowledge and, as

appropriate and necessary, explore when the participants mentioned it or when a statement needed to be clarified. For example, researcher explored when aide spoke about supervisors "catching attitude" or being "spiteful" and "your check may not be right". This was important to incorporate as a means of acknowledging statistical facts regarding socio-economic and immigration status while consciously avoiding majority narrative assumptions (such as, for example, around behavior, when the aide said "do you understand?") and maintaining cultural sensitivity (Creswell, 2013; Rubin & Babbie, 2014; Padgett, 2008). Majority narrative refers to interpretations of experiences and making assumptions based on either widely accepted social norms or non-marginalized experiences promoted by privileged people with and in power (Creswell, 2013). Researcher kept stressing the fact that they, the aides, are the ones holding valuable knowledge informing this research therefore attempting to shift some of the power dynamic and attempting to empower the aides within their spheres.

Confidentiality

All collected data are strictly confidential and all personal identifiers have been removed from of the data. Participants were informed that their employers will not be notified about their participation in the study, and that their participation is completely voluntary.

Participants were only asked for their first names and telephone numbers. Their names were not used in the analysis of the study and their contact information was only necessary for the Metro Card lottery participation. Each participant was assigned an individual identification number in order to protect their identity from being revealed in the interview audio recordings and transcripts. This identifying information is kept on a separate document, locked and password protected in the researcher's files. The full consent forms, which required a full name and a signature, were kept separately and subsequently given to the advisor, Dr. Nancy Giunta,

to be kept in a locked file drawer in her office at the Silberman School of Social Work at Hunter College.

While the general findings of the study may be shared with the agency, individual, identifiable statements made by participants will not be shared. The audio-recordings, transcripts, and interviewer's notes will be kept in a locked file cabinet at the researcher's home office, where no one but the researcher will have access to them. Data will be kept for at least three years and may be used in new analysis, but the participants will not be contacted again. All participants were notified of these measures to ensure confidentiality.

Participant Risk

The expected risk of this study was minimal, in that some home health aides may have experienced discomfort or embarrassment discussing elder abuse and/or the circumstances of their clients. This did not appear to occur and was not specifically identified by any of the participants. However, in consideration of the fact that discussing elder abuse may be emotionally taxing, disturbing or triggering, all participants received a handout with free and confidential counseling services, such as the LifeNet program, offered in New York City (Appendix 6). The handout also included an online resource, Hitesite.org, which "connects New Yorkers with free or low-cost health and social services" which may be beneficial for aides.

Trustworthiness and Rigor

Most widely accepted threats impacting trustworthiness of qualitative research are bias of researcher and respondent, and reactivity (Padgett, 2008). This section reviews these factors as well as the role of the researcher, who has worked with older adults for over 18 years.

Role of the Researcher

Researcher's initial interest in the project stems from being a gerontological social worker with a background in home care and elder abuse services. This experience may be advantageous. However, the researcher's work as an in-office administrator in a home care program provided a different perspective of the work than that of a direct care provider, such as an aide. The researcher was conscious of being a "knowing outsider" and mindful of assumptions based on my knowledge and experiences (Creswell, 2013; Padgett, 2008; Rubin & Babbie, 2014). For example, the researcher made a conscious point not to have a response to every comment but rather to affirm statements or ask for clarification, particularly when participants complained or made disparaging statements. This was to avoid having a "supervisor-type" of a reaction that may come off subjective or judgmental as well as to avoid "trying to fix" participant described situations. When visiting the agencies, the researcher tried to stand physically alone as to appear neutral and not aligned with administration.

Ten years ago the researcher worked in one of the agencies participating in the study. The researcher has not worked in homecare for over six years. Despite high turnover rates within agencies, there are many HHAs who have been in the field for many years and the researcher anticipated potentially coming across aides who may know of the researcher or recognize me. This did not occur.

Having worked on the development of elder abuse outreach and educational programs, the researcher has a vested interest in knowing the impact of these programs in the professional community. Being aware of the potential bias, the researcher consciously used audit trails to enhance trustworthiness and objectivity of the study. The researcher kept field notes to further review any potential conscious or subconscious bias or influences that may arise based on the

researcher's professional experience in these fields. The memos provided a mindful reminder to be led by the data rather my own subjective, social justice-oriented, agenda (Creswell, 2013; Padgett, 2008).

Reactivity

Reactivity impact, that is the influence of the researcher on the environment studied, was of limited concern because while the researcher attended the in-service classes, the study did not include field interactions, such as during HHAs work with clients (Padgett, 2008). However, the researcher provided all participants with a handout of contact information for elder abuse reporting agencies which could have impact on future reporting Additionally, during the interviews when participants indicated a concern over a client, the researcher would indicate the "mandated reporter" status and further explore the situation. On one occasion the researcher had an extended discussion about client safety which resulted in the participant stating she would discuss the case with her supervisor.

Researcher Bias

The focus on objective process of a qualitative study is expected to increase its trustworthiness (Padgett, 2008). The researcher focused on maximizing objectivity by closely adhering to the Interview Guide. Participants were asked the same questions and followed a line of inquiry based strictly on answers provided. Interview transcripts and memos were also reviewed for objectivity in researcher's understanding of answers (Oktay, 2012).

Respondent Bias

The bias of the participants was addressed by encouraging open and honest communication. The researcher emphasized that answers do not have any impact on winning the Metro Cards or the logistics of their employment, including preference of scheduled hours or

client locations, both of which are a known and significant points of concerns for home health aides (Rolf, 2016).

Memos: Comprehension and Contradictions

While all participants spoke English, 13 participants spoke it as a second language. Language and comprehension of questions was at times a noticeable barrier to communication. There were several instances during the interview process where the answer provided was not quite matching the question asked. Such could be due to not understanding the question or, of course, avoiding answering the question.

Many of the participants chose to answer via examples of their experiences, which were at times difficult to follow and even contradictory. Some participants had difficulty finding the right words or being able to conceptualize an idea and therefore using examples to answer questions, which, although not always clear at the moment, actually made for an interesting process and provided richer data.

Whether based on language barriers and/or formulations of questions, cultural translations of meanings or even stress and discomfort of being interviewed, there were times where the researcher struggled to comprehend the meaning of participant's response. This was somewhat reoccurring when it came to the question of agency's role and supervision. More than on one occasion and aide indicated that they do not speak with the supervisor about their clients because they do not need to, and later state that they do in fact speak with them about client issues and would certainly do so in cases of elder abuse.

Another common contradiction was that while all aides agreed that they would absolutely report elder abuse if they saw it, few of them ever have reported it. At the same time the participants admitted to not reporting when they came across something questionable in the past,

and even fewer felt comfortable getting involved when they learned about abuse from a third party. This is, unfortunately, somewhat on par with available statistics of only about 1 in 24 cases of elder abuse being identified (NYCEAC, 2018).

Some other examples include misunderstanding questions, such as stating "domestic" to the questions about types of abuse (not entirely incorrect) or identifying other groups of abused individuals, such as "homeless people and women" when asked about who most often abuses older adults.

In most cases, eventually, some type of an understanding was accomplished. It does, however, bring up the question of the communication barriers that may come up for participants in other aspects of their work, with their clients and with their supervisors, contributing to the minimal communication. It may impact their feelings of competence and confidence.

Data Analysis

Codes, Concepts, and Themes

The researcher created a Codebook in a Microsoft Excel Spreadsheet to use direct quotes in the first step of the analysis. The researcher followed Oktay's (2012) guidelines for organizing data into "codes", "concepts" and "themes". Within that framework, "codes" are individual words or phrases that are the same or are relating to one specific topic or idea. Next, several "codes" were collapsed into a broader "concept" which could then be combined with other concepts to create a more general "theme" (Oktay, 2012). During the initial coding it was not unusual for a word or phrase to fall under several codes or categories.

Words were initially identified without analysis of the content, simply by reading and marking the transcripts, which has been noted to be helpful in "avoiding forcing of codes" (Oktay, 2012, p.56). This search for meaning was open to evolve along with information from

the data, which could not be fully initially predicted (Oktay, 2012; Padgett, 2008). For example, when all references to the words “supervisor” or “supervision” were identified their context split them into two codes: “relationship with supervisor” and “communication with supervisor”.

Saturation

In grounded theory, the continuous analysis determines the extent to which data saturation occurs, allowing the researcher to determine whether the sample size needs to continue to increase (Padgett, 2008). While it is expected that there is always a potential to discover new information, in the case of this study, repetition of answers and general points being made became evident after several interviews. For example, the understanding that there is more to the definition than just physical abuse was expressed by essentially all participants. Also, the implication that anything noted upon arriving at client’s home, even if not witnessed first-hand and not necessarily abuse, such as if a client fell or does not have enough medication, must be immediately reported to the agency. Many participants expressed frustration over the difficulty of getting in contact with their supervisors (“...sometimes I’m on hold for an hour, 40 minutes. It’s ridiculous”. Interview #8). While the participant’s use of examples continued to contribute to the richness of data, general themes and repetitive answers were clearly emerging. After completion of 18 interviews, the researcher made the determination that sufficient data were collected.

CHAPTER VI: RESULTS

This chapter will describe findings from the analysis of the interview data. Ultimately, the qualitative analysis used grounded theory methods to answer the research question, "What are the intrinsic and extrinsic facilitators and barriers to detecting and reporting elder abuse among home health aides in New York City?" Two predominant themes emerged from the data, each supported by related concepts. The first theme, the multidimensional nature of elder abuse, emerged from the following three concepts: (1) the definition and risk factors of elder abuse vary; (2) knowledge of elder abuse is attained from different sources; (3) abuse can be perpetrated directly or indirectly.

The second major theme is multi-level nature of factors that motivate home health aides to report elder abuse. Three concepts that support that theme are: (1) facilitators to reporting elder abuse are perceived as a personal obligation or responsibility; (2) barriers to reporting elder abuse are perceived as consequential; (3) quality of connection to the home care agency matters.

The themes that emerged from the data generated by the study participants are elucidated in this chapter by presenting the concepts and related codes drawn from the data. Direct quotes from interviews are used to tie together the codes, concepts and themes. Codes used in the analysis are indicated in <u>underlined</u> print throughout this chapter. Table 2 lists each theme with its corresponding concepts and codes. The codebook in Appendix 13 provides a synthesized version of all codes and corresponding participant quotes.

Table 2.

Themes, Concepts and Codes

THEMES	CONCEPTS	CODES
Elder abuse is multidimensional	1. Definition and risk factors of elder abuse vary	a. Physical abuse b. Neglect c. Deprivation d. Verbal abuse and disrespect e. Vulnerability and dependence
	2. Knowledge of elder abuse is attained from different sources	a. Agency based education b. Pursuit of self- education c. Personal experiences in caregiving d. The way we were taught
	3. Abuse can be perpetrated directly or indirectly	a. Family members b. Clients abuse home health aides c. Society
Personal, organizational, and economic drivers influence reporting	1. Facilitators to reporting elder abuse are perceived as a personal obligation or responsibility	a. It is important to report all known changes to client's condition b. Compassion or moral obligation c. Treat others the way you want to be treated. d. The work is not about the money e. Option to report abuse outside of agency
	2. Quality of connection to the home care agency matters	a. Communication with supervisor b. Relationship with supervisor
	3. Barriers to reporting elder abuse are perceived as consequential	a. Reporting process is burdensome. b. Negative experiences resulting from reporting.

Elder Abuse is Multidimensional

To effectively detect elder abuse, one must first understand what qualifies as such. As the data reflected, participants were aware of the many forms elder abuse may take. Participants also noted that elder abuse is complex to understand, define and identify, which may serve as a barrier to detection. For example, when asked if she thought elder abuse might go unidentified by a home health aide, one participant replied "Absolutely, if they don't know the warning signs, what to look for." (Interview #4).

Three underlying concepts are inherent in this theme of the multidimensional nature of elder abuse. First, the definition of elder abuse and its risk factors vary. Second, knowledge of elder abuse is attained from different sources. Third, elder abuse can be perpetrated directly or indirectly. This section presents the interview data to illustrate these emergent concepts.

Definition and Risk Factors of Elder Abuse Vary

In order to understand the participant's knowledge about elder abuse, the first question asked of participants was: "What do you think elder abuse is? (How would you define it?)". While all participants were able to identify several types of abuse, many doing so by speaking in examples, the overall definitions varied widely. All participants were able to identify at least two types of abuse with physical and verbal or "disrespect" as abuse, being the most common. Few alluded to financial mistreatment, "They take all the money for the family." (Interview #14) or emotional abuse related to money, "They could just, you know, try to manipulate the elderly person to getting [sic] their money." (Interview #4). Noticeably, only one participant mentioned sexual abuse (Interview #4). Three participants presented hoarding as a type of abuse, mainly because the family was neglectful by not stepping in to help, "It was so disgusting that I could not believe there were family members living in the home, and they

would allow… their mother to live in this type of dirty environment." (Interview #2). One aide described abuse as not reporting when a client falls down: "You're not a doctor so you have to call 911." (Interview #16). Another participant compared elder abuse to harassment at work, which was related to a video showed during in-service class that morning (Interview #13).

Physical harm was noted to be most unquestionably abusive and unacceptable behavior. Participants recognized that physical abuse may be easiest to spot as it may leave concrete marks, such as bruises, on skin. Examples of participant's statements about this type of abuse included: "You can squeeze them and, you know, beat them, you know." (Interview #1) and "... sometimes you could see bruises on them, you know" (Interview #5).

Neglect as abuse was another identified type. Some participants expressed: "... elder abuse is when you-you neglect them" (Interview #1) and "[abuse can be when one is] mistreating them, teasing them, neglecting them, abusing them."(Interview #16). One participant described "rejection" as a form of abuse (Interview #15). Neglect was also described as lack of "proper care", including not changing diapers frequently enough, not keeping people clean (person, clothes and home) or being "neglected of food" (Interview #7, #15, #17).

Neglect was also implied by participants who described families not visiting or not spending "quality time" with their clients, resulting in "starving for attention, starving for friendship" (Interview #8). Examples included situations of family members visiting but not paying attention to the older adult, as, for example, with some grandchildren: "they're teenagers", referring to other interests and generational gaps (Interview #11). Those generational gaps, such as with grandchildren who are ignoring their "elders" were also noted when discussing differences in understanding what abuse is, "[elder abuse is] common, especially [with] young children. They don't know how to talk to older people" (Interview #15). This

participant connected this to the way one was raised, which is further addressed under code "the way we were taught" (Concept 2: Knowledge of elder abuse is attained from different sources).

Active deprivation, such as when someone who has the capacity to control or withhold something from a person was another identified type abusive behavior. For example,

> I went to one person, and she was – she was bedridden, and she-she wanted to – she had lunch. Her husband limits her with the lunch and limit her with food. And he keep yelling at her, you know, because of her sickness. You know, she cannot move. And I can remember one day she wanted to eat a cookie so bad, and he did not give her. You know, that is depriving her from something, you know – depriving her from food, not something – from food. ... So you know, when we are not – when we don't get it I think that, you know, that's abuse because she's being deprived of, you know, something that she wanted. (Interview #5).

The participant was not clear about whether this client had dietary restrictions, but she was clearly distraught by the tone of these exchanges. Food was also mentioned in this example.

> She wouldn't let the mother have what she wanted to eat. 'You eat what we have,' but the mother would want this and that. I don't know if it was finances that she was depriving her of things that she really wanted to eat, and I'm like, 'Well, she's old. Let her eat what she wants.' (Interview #19).

Having the power to deprive a person of something implies their dependency and their vulnerability. Participants identified certain vulnerabilities of their clients as potential risk factors for abuse, particularly around being deeply dependent, such as in cases of dementia, physical limitation or being bed-bound (Interview # 7). As one participant stated: "*because of the*

challenges that [they] find themselves [in] because of their age... they end up being abused." (Interview #10). Other examples of vulnerability leading to abuse included,

> Because, you know, they keep asking one question over and over – over and over, you know. As I said, you know, people get tired, you know, answering the same question over and over, you know. A client has dementia it puts them at a higher risk to be abused because family members get tired.(Interview #5).

Dependency on others included exposure to abuse by those who were tasked with paid caregiving as well, as noted here.

> **...**Like a long time ago this lady I knew she was an aide. She told me she used to leave the patient – before she'd leave the patient would urinate, and-and, you know, go to the bathroom, number two on herself. She would leave them in it. That's what she told me. (Interview #7).

"Speaking down" to people, "teasing", not listening when they spoke, or threatening with a nursing home placement were coded as <u>verbal abuse and disrespect.</u> These could also be interpreted as a form of emotional abuse. One participant described how this content was taught during in-service classes: "...we were taught how to respect them, how not to often complete their sentences because it might make them feel inferior." (Interview #10). One participant offered the following description that incorporates the values of dignity and respect.

> … They also have verbal abuse, where you talk to them with no respect. You know, you strip them of any form of dignity because they're older. You know, they just talk to them any which way. That's verbal abuse. (Interview #19).

And another pointed to a behavior that may be perceived as both thoughtless and disrespectful.

> Sometimes you can witness another aide talking things in front of the patient that they shouldn't. You know, maybe a little too loud or maybe a little irrational or using curse words or anything of that nature. That's not a good thing. That's part of abuse, too. (Interview #16).

Being disrespectful and exhibiting power and control over a dependent older adult, for example not asking them about what type of food they want to eat or TV programs they want to watch, seemed to be particularly offensive to aides.

Knowledge of Elder Abuse is Attained from Different Sources

When participants were asked directly how they learned about elder abuse, their answers varied widely from abstract and vague references of inherently knowing about elder abuse to concrete sources from which they gained knowledge. Some participants expressed that abuse is obvious and one would "just know" and that "it is common sense" (Interview #16). Others learned about it from their homecare agencies, via personal experiences of being around older adults, or self-seeking information about the topic. Below are three participant-identified pathways to knowledge about elder abuse.

Although participants indicated that "some classes talked about" elder abuse, they were unable to identify specific elder abuse focused trainings in the agency-based education that was offered by the home care agencies. Still some did indicate that they learned about elder abuse from some form of agency training, such as an in-service or a home health aide certification course. There was a lack of uniformity in training and therefore potential (but unknown) gaps in training around elder abuse. As one participant indicated, "People out here don't have the same education as far as the training that they were supposed to have learned in their classes". (Interview #16).

One agency administrator stated that “sometimes an in-service class covers family violence”. One of the larger agencies offers trainings about elder abuse to staff from all programs (including case managers and social workers) and while aides are encouraged to take advantage of the offer, no one from this study has attended.

Several participants expressed interest about elder abuse when it came to knowledge building by self-education, whether formal such as college, or informal, such as watching television and reading books. This participant described learning about being vigilant from television, “I've watched all those shows and stuff like that, so that gives you clues for when you see something like that happening.” (Interview #17)

Additionally, one aide reported speaking with her doctor (Interview #9) another with a college professor (Interview #8) and yet another took a 50-hour class on dementia at the Alzheimer’s Association (Interview #19) all of which added to their knowledge on the subject.

Participants also indicated that they learned about elder abuse and overall needs of older adults because of their personal experiences in caregiving with family and friends. Participants indicated personally providing caregiving: “…my mother is almost 80 years old, so that's the experience of looking after an elderly person.” (Interview #16) Caregivers are also involved with providers, such as doctors and institutions, such as nursing homes, where they learned to watch for abusive behaviors.

“The way we were taught” pointed to another way of having obtained knowledge about what may be considered elder abuse. The direct question as to whether there were cultural aspects to identifying or understanding elder abuse, was frequently misunderstood and required further clarification, prompts, or examples (such as “would everyone see abuse the way you see it?”). The point of this question was to understand the different cultural reasons why aides may

not feel motivated to report abuse, such as, for example not perceiving is as abuse. One participant, an ambitious aide with about one year left on her college degree, pointed out that for many, abuse beyond physical continues to be invisible and non-existent.

> Definitely, I think that there are cultural variations because based on probably how you were raised and your background. You know, probably in my culture maybe abuse is just physical. But now people are beginning to understand it more from education and the internet and stuff. So people are understanding that it's just not just physical, but there are different aspects of it. But it definitely has to do with culture. (Interview #2).

Different backgrounds translate to the continuum of what people find as tolerable or acceptable. When asked whether aide even found herself in situations she perceived to be abusive and others did not, she described dirty living conditions.

> I saw it as abuse because I felt that it was – it's a way of life that being clean and being neat was a way of her also being healthy. Because how could you be healthy and be around filth. That's how I understood it, but maybe they didn't. (Interview #2).

By "they" the aide was referring to family members who seemed to believe that client was "just sloppy."

Some participants stated that older adults should be treated as if they were part of our own family. For example, **"**You know, as a person who took care of their own grandfather, I totally understood. So I totally get – I get very sensitive with my own patients. So I deal with them – I always go in with my patients thinking that they're my grandparent, and so this is how I handle my case." (Interview #2).

As one participant stated: “I think compassion and loving, and caring come[s] from home” (Interview #16) indicating the relational impact of families. Others pointed out that we now have more access to knowledge and therefore a raised awareness about abuse, which may be why it is easier for younger people to talk about it: “Older people weren’t exposed as much as the younger people now to internet and television and all these different technologies” (Interview #4). Access to technology is correlated with this generational shift of upbringing in that people are exposed to the world beyond theirs, have access not only to concrete information but also to virtual supportive environments. Use of technology dilutes secrecy and opens doors for questions and family conversations.

That difference in understanding elder abuse was also accredited to the general socio-cultural shifts, as this participant indicated: “….they don’t think it is abuse, but it is. Because that’s the way they were taught. But then - this is the 21st century, that is not acceptable right now” (Interview # 7). Participant spoke generally and did not refer to a specific abusive situation. Lastly, but importantly, the following participant stressed the power that comes with knowledge.

> When someone doesn’t understand how to go about something or do something, they’re going to be afraid to talk. …Another woman now, she may find the research, who to reach out to, who to talk to, and she’s going to stand up and do what she needs to do, regardless of what. (Interview #9).

Abuse Can Be Perpetrated Directly or Indirectly

In exploring how abuse is perpetrated, participants described clients experiencing intra-familial abuse as well as abuse occurring within other trusted relationships. They referred to the

possibility of an abuse situation being bi-directional in which there are cases of home health aides being subject to abuse by clients and their family members. Finally, participants described societal perceptions of older adults to be abusive, thus suggesting elder abuse being perpetrated indirectly.

Participants most frequently identified abusers as people closest to the older adult: their family members or close caregivers, including home health aides. For example, this participant indicated the power family members may have over dependent and/or vulnerable adults, “The people who are close to them, the family members I think are the number one [abusers]. Family members don't answer to anybody.” (Interview #19).

However, participants also expressed compassion for family members who were the primary caregivers, stating the importance of respite, “I think your family get tired [sic]. And you know, they just, you know, get tired with the person. And you know, they don’t speak to them in a nice way, you know. Like you know, they scream at them.” (Interview #5).

Some participants took pride on the fact that they could provide this respite, and even some education about medical conditions and resources, for family members (Interview #8, #10).

Some aides noted that elder abuse “goes both ways” and reported experiencing what they would consider abuse while at work. Examples included sexual advances, creating “extra work’ and theft. Home health aides are trained to work with clients diagnosed with dementia and other cognitive impairments which may manifest in behavioral issues such as physical or mental outbursts. Those behaviors, however, are not necessarily considered to be abusive by aides as they are understood to be due to illnesses. In such cases aides express compassion and forgiveness, as described by this participant.

> You know, have compassion for them. And when they're old, you know, sometimes when they have Alzheimer's or dementia, they're not doing things on purpose. You have to understand to put yourself in their skin when they do something. You have to forgive them and-and help them. You know, that way we direct them. Because sometimes they-they are very confused.(Interview #1).

On the other hand, there were behaviors described as unrelated to a client's impairments as well as conducted by family members. One participant reported being threatened with being fired if they do not comply with sexual advances by a client.

> Because many times – like three, four times – male try to, you know, [aide pointed to her genitals] and call you to touch their private part. There was two of them who tell me, 'We'll sign your paper and send you back home.' I said, 'I'm not here for that. I'm here to help you. But I'm not here for, you know, sentimental [sexual] position [sic]' So some of them are really – they get upset and, you know, screaming at you." (Interview #1).

The discomfort the aide felt making these statements was apparent in her body language, as she shifted in her chair and looked down. But she also seemed determined to make sure the researcher understood the hardships the aides may have to endure at work.

Some participants stated that a client, or their family, would expect aides to do work beyond their specific duties. Some clients would go as far as "creating work" so that the aide is "not sitting around." One participant described a situation where a client would take everything out of a drawer and tell aide to re-fold it (Interview #15). Participants also reported being yelled at, being threatened that their time sheets will not be signed, or that something false about them will be reported to the agency.

One aide reported a family member stealing from her, and later learned that her co-workers suffered the same fate. Neither one of them reported it to the agency until after the case was closed. She indicated her concern over losing the case, "She stole from me, the daughter, and I didn't report it. I just never left money in my bag again. I just put my money in my scrubs...I didn't want to ripple the waters because I needed my job." (Interview #17). While these examples were noted by only a few of the participants, they seem to be quite extreme and impactful and therefore deemed important to include.

Notably, the participants also spoke of the devaluation of older adults and a macro-level societal prejudice. While the word "ageism" was not stated outright, aides implied in their answers that it contributes to abuse when society does not accommodate older adults. For example, "When you get a certain age – they [society, others] watch your age. They want to identify you as you're like a piece of meat, you don't exist no more, and they just want to push you aside…. That's wrong." (Interview #9). Another participant noted an example of people complaining when an older adult is taking a longer time to board a public bus, "People don't understand [what it's like to be old] and disrespect… [for example] when they are accessing public transports."(Interview #10). These examples spoke to the participants varied experiences from not only work, but also from personal perspectives and insightful observations.

Personal, Organizational, and Economic Drivers Influence Reporting

To understand the details of navigating the day-to-day situations that participants face, the question: *"*What would motivate YOU to report elder abuse?" was followed by "Have you had a situation where you have reported elder abuse or where you thought about reporting it?" This was also one of the ways to try to learn about the motivating factors and the impact, if any, of the reporting resources available.

The theme clearly emerging from this line of questioning was that motivators or barriers can be driven by personal, organizational, or economic factors. The following sections examine this theme through the following three concepts: (1) facilitators are perceived as a personal obligation or responsibility (2) barriers to reporting are perceived as consequential (3) quality of connection to the home care agency matters.

Facilitators to Reporting Elder Abuse are Perceived as Personal Obligation or Responsibility

When determining what to do when suspecting elder abuse, the participants spoke of the many variables contributing to their decision making. As employees of homecare agencies, they are expected to abide by the policies as well as supervisory expectations. They are clear on the fact that the agency relies on them, as direct providers of care, to report any and all changes to client's conditions and functioning. The participants mostly referred to the importance of reporting "all known changes to client's condition" (i.e. not elder abuse specific) that are noticed when they begin each shift to ensure that even what has occurred outside of their scheduled hours is reported. As this participant stated, "Well, we are supposed to report everything that we see. If we came to work and saw a bruise that wasn't there when we left yesterday, we are supposed to report it. So you communicate as you see a need to. You communicate as needed."(Interview #19).

These reports may be as a result of something an aide observed, such as a bruise or a cut, or a result of something client says, such as that they fell the night before.

> "…when you call [the agency] you have to give them detail of what you see, what you observe. Sometimes when the client don't feel good or need to do something,

need something to be done, you have to call and give every detail to the – to the supervisor." (Interview #1).

Participants shared that clients sometimes ask them not to relate certain things to the agency that they had witnessed. Not reporting an issue, whether by family or another aide on shift, may be perceived as elder abuse, "I'm just as neglectful if I said nothing" (Interview #8). As this participant indicated, "For instance, some people cover up abuse. Some people would try to get them up off the floor without reporting it. Some people won't tell. Some people won't say anything, you know?" (Interview #16).

Given the strict mandates the aides are under to report all changes, these requests can cause a dilemma particularly as it has a potential to impact the aide-client relationship. One participant described her client's response, "She told me she fell, and she had a big bruise. I was like, 'Well, you know I have to call that in' 'Oh, no! Don't call, don't call, don't call!'" (Interview #19).

The aide attributed this request to the fear of being placed in a nursing home. . Some participants distinctly stated that they would only report abuse if they witnessed it first-hand ("see [them] personally"). One aide stated that in the more than 19 years she has been working as a home health aide she has never seen anything reportable.

For some of the participants the drive to report abuse was fueled by individual compassion or moral obligation and desire to ensure a good quality of life and care for their clients. Participants seemed to indicate that mistreatment, or lack of adequate treatment, was difficult to witness and they felt compelled to report it. As one participant stated, it is important to "have a clean mind", i.e. not be burdened by what's been witnessed (Interview #15). Another one stated: "You are saving someone. Regardless of whatever the situation is. It's not something

to put on a [scale], it's a human being."(Interview #9). This participant indicated the importance of reporting by further stating "How are you going to feel? [knowing that something happened to the person]". On the other hand, if the aide makes a decision not to report, despite in a case where "the agency is doing everything they can … it's probably an aide who doesn't really care". (Interview #19).

The aides expressed dedication to providing a safe environment for their clients. This seemed more rooted in personal experiences than in what was learned in agency trainings. For example, the expressed definition of elder abuse was linked to the experience aides had in caring for older adults in their personal lives and in the way, they would want to, or expected to be treated. As this participant stated, No one should feel that way or be mistreated ...Whether it's physically or mentally or whatever no human being have [sic] a right to be treated that way. not even animals have a right to be treated that way...Treat someone how you want to be treated."(Interview #7).

Another participant disclosed that she was in an abusive marriage for over 25 years and is now highly attuned to identifying abuse (Interview #5).

Being a home health aide is not a lucrative profession and the participants noted that it is not a job one takes to get rich. As employees, however, they are also aware of the financial consequences being removed from the case carry. The implication was that " this is not a job for everyone" and rather that the job is "not about the money" but rather "a calling" as the following participant stated:

> See I don't do this for the – for the money because when I did the job in 2003 the pay was $6.25. I don't – I never do this job for the money, because if it was for the money I would have commanded a – demanded a lot more. Because I feel I

> bring a lot to the table – and not only experience and skills but mental and emotional support. I just bring a lot to the table. You know, because I-I'm empathetic. I listen. I like to listen to people. Some people need to vent, you know. (Interview #8).

The participants were clear about the hardships of being an aide but making that distinction indicated the rewards, such as improving the lives of their clients, of the work as well.

Participants were aware that abuse can be reported through other channels outside of the home care agency, including to the police. Not all, however, could recall Adult Protective Services or any other specific resource to contact. Some participants stated they took the initiative to speak with client's family members or professionals, such as a physical therapist visiting clients, about concerns. One participant shared the following situation that occurred when she reported the abuse to the client's brother after making multiple attempts to report the abuse to her supervisor within the agency.

> And he [the client's brother] got upset and said that I was causing chaos and-and problems for the family. And that's when my supervisor was, 'Oh you could have taken this in a different direction. You didn't have to do that. You could have spoken to me.'…How many times am I gonna call your number and you don't pick up? (Interview #8).

As this situation illustrates, communicating with outside sources, despite the best intentions, may result in negative consequences for the aide, which will be discussed under the concept of barriers to reporting.

Quality of Connection to the Home Care Agency Matters

This concept focused on understanding the aides' relationships with their supervisors and their connection to the agency at large, as well as whether such has an impact on their motivation to report elder abuse.

One of the most frequent issues raised by the participants was that they had a difficult time getting a hold of their supervisors, which negatively impacted their communication. Examples included being placed on extensively long holds when calling the agency and/or having to wait a long time to hear back from their supervisor after leaving a voicemail. For example, this aide indicted that she doesn't speak to her supervisor much because "They don't answer their phone." (Interview #7). The aides are expected to make reports at the beginning of their shifts if they notice changes from their previous visits and in cases of an emergency, especially when it requires taking a client to the hospital. But in those instances, leaving a voicemail may be sufficient. Not getting a hold of a supervisor becomes problematic when one wants to discuss a case rather than just make a notification. One participant flat out stated that it is "very rare" that she speaks to the supervisor about her clients (Interview #2).

The supervisory relationship was described as tied to the unique personal characteristics of each supervisor, but it was clear that it impacted the way participants experienced their jobs and connection to the agency. For example, the difficulty with calling out sick was mentioned, not only because the supervisors are difficult to get a hold of but also because it may frustrate them and result in a reassignment or worse, "spitefully, your check may not be right" (Interview #16). For example,

> Sometimes you can't even take care of yourself. They tell us they give us sick days, but [they're] being spiteful – like I said, you have some supervisors where I've

actually heard aides talk about it that if you call out too many times, maybe twice a month you get sick, she's going to have an attitude that you're calling out because they've got to look for someone to put in your place.(Interview #16).

The aide noted that one cannot go to work while sick, but they are risking losing a case when they call out. Traveling between clients to ensure sufficient hours, working long hours or sleep-in shifts also makes it difficult to schedule and attend their own medical appointments. This results in frustration and expression of "isolation" while at work. One participant proudly admitted to helping other aides "with their rights" such as understanding payroll, to ensure that they are not exploited, particularly regarding overtime time pay (Interview #16).

The participants interact with multiple people at the agencies but did not express to develop significant relationships with their supervisors; it also appeared that sometimes their supervisors change based on their client assignments.

A sentiment about "the office" not understanding the complexities their jobs entail was expressed.

It's bad because they [supervisors] don't understand. They don't comprehend. They don't understand what it's like when you go to a home and a patient's like, 'I don't want you here because you're not the right person.' So I just traveled from lower east side, East Houston Street all the way to 152nd Street or wherever, and I'm not allowed to be here because no one told you I was coming? So now I'm on the phone with the supervisor, and the supervisor is taking forever to pick up. (Interview # 7).

One participant thoughtfully stated that it would be helpful for a nurse to make more frequent home visits or even to spend a shift with aides at a clients' home, as it would help the

supervisors understand what they actually experience on a day to day basis. Such as this participant noted in the difficulty with maintaining boundaries that everyone is comfortable with, while providing empathic care, sometimes resulting in termination:

> The daughter was looking for any reason to get rid of me because the mother was confiding in me. So, she called the agency and said I invaded her privacy because I took the pictures [aide took a picture of client's framed pictures on desk and made it into a mug as a holiday present].(Interview #19).

Barriers to Reporting Elder Abuse are Perceived as Consequential

Many of the participants chose not to fully engage in directly responding to the question as to whether they think that elder abuse may go unidentified or unreported, stating that they "don't know" or "can't speak for others". Others made it explicitly clear that they would "definitely, always" make a report but spoke to hypothetical reasons as to why others may not want to report elder abuse. The following illustrate the complexities around NOT reporting elder abuse, including the burdens and negative consequences.

Some participants stated that there is a perceived hardship or an actual inconvenience in the process of reporting abuse. For example, aides may have to come into the agency in person, which would require them to travel on their own, unpaid time. An aide may also be asked to complete a written report and be available to answer questions about the report as stated by this participant, "You'll have to write a report.... (some people don't want to be bothered). ....Yes. You have to write and come in too, bring the letter and come in, and then they will interview you and ask you questions about what happened, when it happened...." (Interview #12)

Furthermore, if potential elder abuse occurred outside of the agency or at a different agency, the aides may not feel like it is their place to report it or become involved. For example,

as this participant stated about a situation she heard about from someone, **"**I should have reported when the one told me she'd leave her like that (in dirty diapers) when she get off of work. But I never reported it." (Interview #7).

The expectation of negative consequences of reporting was indicated by some participants. Expectations may be based on aide's own previous negative experiences when a report was filed. The expectation of negative outcomes for those who have never reported abuse could be based on emotions (such as fear of the unknown) or experiences heard from others. This participant generalized why aides may not want to report abuse due to perceived negatives consequences, "They just don't wanna report it because they don't wanna lose their job, and that is because, you know, a family member might wanna remove them from the job if they find out that they informed the supervisor or the authorities. So yeah, the repercussion." (Interview #4).

Another participant spoke of being fired for reporting her client being subjected to abusive behavior by workers in a "day hab" (rehabilitation facility). This participant stated that she would still report cases in the future but would do so anonymously (Interview #7).

The fear of personal safety due to direct contact with the abuser was also a concern. One participant described a situation that occurred outside of the home care agency.

> One time I was in St. John's Hospital, right. And this – I don't know if she was a nurse's aide or a regular worker. She had a uniform. She had this guy with her, this Caucasian guy with her, and I guess he was like….he was getting on her nerves. So she was just throwing paper at him, throwing paper at him. And I said something. I was like, "If I knew where you worked I'd tell on you." ...She got up in my face, wanted to fight." (Interview #4).

And another participant noted that while she would always report abuse because "…I think it is wrong", others may not want to get involved because "what they say – snitches get stitches?" (Interview #7). That last comment seemed to have been an expression rather than an indication of an incident as the aide did not offer any follow up comments (although it should be noted that the interviewer did not follow up on the comment directly either).

The 17 aides participating in this study provided a rich account of the multiple dimensions of elder abuse as well as the facilitators and barriers of reporting it. These participants also offered a glimpse of the many challenges of this growing formal-caregiving profession. The review of motivational factors for reporting elder abuse must therefore occur within that complex environment in which the aides, and their clients, exist. This chapter aimed to synthesize the rich data obtained from the interviews and to present the findings of the data analysis in an attempt to answer the research question. These results are discussed, as are the overall implications of this study for practice, policy and research, in the following chapter.

CHAPTER VII: DISCUSSION & CONCLUSION

The goal of this exploratory study was to identify the experiences of home health aides and their perceptions around detecting and reporting elder abuse. Home health aides are often the first to learn about potential abuse by either witnessing it directly or hearing about it from their clients. There appears to be no research, however, on their knowledge and perceptions of elder abuse as the home care services literature seems to favor a focus on nursing professionals (Lo et al., 2010; Thobaben, 2017). This study aims to change that by shining a well deserved light on these often ignored front-line workers.

This study was guided by the following research question: What are the intrinsic and extrinsic facilitators and barriers to detecting and reporting elder abuse among home health aides in New York City? The conceptual framework used was the Theory of Self Determination (SDT), which explains the personal, or "intrinsic", and social, or "extrinsic" variables that play a role in human motivation. SDT incorporates the fulfillment of psychological needs, which may involve external controls, such as paycheck or a praise from a supervisor (Deci & Flaste, 1995; Ryan & Deci, 2017). The intrinsic and extrinsic variables, as understood in the Self Determination Theory (SDT), relate to three factors: autonomy, competence and relatedness. The aims of this study were to (1) describe home health aides' knowledge about elder abuse, and (2) to explore their motivational factors, or barriers, regarding its reporting. In this chapter, the findings will be discussed according to each aim, through the lens of SDT. Next, the implications for practice, policy, and research will be discussed. The chapter will end with a discussion of the strengths and limitations, followed by a conclusion.

Aim 1: Knowledge About Elder Abuse

The first aim of the study, learning about the aides' knowledge about elder abuse, pointed to the diverse conceptualization of what elder abuse means. All participants identified multiple types of abuse, most speaking about it terms of specific examples. All recognized abuse should be understood as more involved than one causing solely physical harm, with some participants describing "hoarding", "neglect" and "deprivation of desired food" as examples. Furthermore, participants noted that abuse can be direct and perpetrated by a family member or a client toward an aide, or indirect, such as by society, perpetrated by lack of respect towards older adults.

Despite lack of consensus as to whether elder abuse is in fact a commonly occurring experience, participants expressed interest in learning about the topic. As expected, their knowledge varied based on personal and professional experiences and education: some aides had been caregivers in their personal lives, all had different home care services exposure and eight have been educated outside of US. As the elder abuse literature supports, the need for more education was noted: "*some aides need a little extra work, a little extra learning and education*" (Interview #16) (Schmeidel et al., 2012; Truong et al., 2019). Although some participants were intrinsically driven to acquire more knowledge about abuse, others were not. Independent curiosity about the subject of abuse and purposeful knowledge seeking, such as speaking to a doctor, seems to have the potential to increase overall competence in analysis of the abusive signs observed at work. This, however, also has to be understood in the context of whether the aide has time and resources to accomplish it. That is, the aide may be curious and intrinsically motivated to learn more but does not have the time or money to do so.

Aim 2: Motivation

As one of the primary themes indicated in the findings chapter, reporting is influenced by personal, organizational and economic factors. Intrinsically, participants described it as a personal or moral obligation, "because it is the right thing to do" and extrinsically as an organizational norm, "because the agency expects us to report". Considering the economic burdens that homecare work comes with, it was important to consider the logistical implications of what reporting a case of abuse may result in, such as a client withdrawing from services or an aide being removed by the agency. Both scenarios result in loss of income, with implications to the way supervisors, coordinators (those who schedule cases) and an agency as a whole respond to potential cases of elder abuse.

The results of this study support what is known from the literature: that supervisory support is vital and increases competence and autonomy (Schmeidel et al., 2012). So, it follows that if the agency provides resources to improve aides' competency, exhibits trust in their skills and judgments as well as takes their concerns seriously creating a supportive and collaborative work environment, the outcome will be an increased satisfaction of the psychological needs. From the Self Determination Theory, we know that when psychological needs of a worker are met, a deeper integration of agency's values, and deeper commitment to work is likely to occur. In the field of homecare, this may lead to an increased consideration for clients' wellbeing and an increased attentiveness for signs of abuse, as well as its reporting (Ryan & Deci, 2017). The participants expressed that it is important, and expected by the agency, that all changes to client's condition are reported. Even in cases where clients themselves ask aides not to notify the agency, the aides express the intrinsic compassion or moral motivation to do so, indicating correlation of intrinsic and extrinsic motivational factors. Coupled with expressed desire to "treat others the

way I would want to be treated" if information about reporting is easily available and supervisors provide supports in terms of discussions and reporting procedures, the potential is integration of intrinsic and extrinsic values. Such integration would likely result in increased reporting of elder abuse.

When a home health aide perceives an agency's response to reporting as punitive, not only will there be less integration of agency's values but the intrinsic motivation to be more involved with clients may be compromised. While the participants expressed that one does not become a home health aide "for the money", they did note that a burdensome reporting process, such as having to come into the office on a day off or writing a report, may be a barrier. Participants also noted the impact of negative consequences of reporting, such as the potential of losing the case and therefore risking a paycheck. The agency's lack of support in the reporting process may therefore be detrimental to integration of motivational factors. Even in cases where negative consequences are inevitable, such as when an aide is removed from a case, support in a form of immediate case replacement for example, may be able to offset this barrier.

The significant role that the supervisory component of support plays, as expected, was noted by participants. Supervisors are in a position to create a positive and productive connection to the agency, representing the "relatedness" component of SDT. Access to supervisors was noted to be in need of improvement as participants noted that they are placed on hold for long periods of time when they call or are forced to leave voicemail messages that may or may not be returned. While the aides noted that they must report to supervisors, many only speak with them when absolutely necessary. This is a barrier as lack of easy communication prevents aides from speaking with their supervisors about cases they find to be challenging in terms of clearly identifiable abuse or discussing potential intervention options. In other words, the aides may feel

as if they do not have anyone to assist them or share their concerns. For example, one aide noted not feeling competent to make a determination about intervention and not knowing the steps to follow with the agency, including whether this was an issue she could discuss with the supervisor. This seemed to echo sentiments hinted at by others: it is difficult to report without proof (such as bruises) and aides do not necessarily feel comfortable or empowered enough to discuss the grey areas of potential abuse with their supervisors.

The way communication is experienced is connected to the way the aide identifies the relationships with their supervisor. Here the participants' experiences were on a continuum, ranging from having a good relationship, to having negative experiences such as in cases when supervisors are not understanding of requests for time off, to a neutral relationship. Research indicates that inadequate supervision impacts the way people experience their places of employment and negatively affects their motivation to be involved in elder abuse intervention (Cairns & Vreugdenhil, 2014; Killick & Taylor, 2009; Teresi et al., 2013). Both communication and the way aides perceive their relationships with their supervisor, is connected to the way the way they experience their place of employment.

Self-Determination Theory (SDT)

The Self-Determination Theory (SDT) posits that motivation is guided by attending to three psychological needs: autonomy, competence and relatedness. These needs are correlated in that they support one another and in that they can be achieved from an intrinsic and extrinsic perspective.

For example, autonomy indicates actions that correspond to ones' values. Being able to act in an autonomous way in a work environment may positively impact one's performance (Ryan & Deci, 2017). While the home health aides work in isolation, outside of the agency's

offices and inside the intimate spaces of their clients' homes, this alone does not indicate their autonomy. The aides are bound by Plans of Care (POC) which provide structure to their shifts and ensure that clients' needs are met. This takes away their autonomy. Still, they are navigating unique and often complex day to day situations. How their autonomous decisions are allowed and received by their supervisors would contribute to the extend in which this psychological need would be impacted. For example, the aides expressed to take pride in their work and in the experiences and knowledge they bring to it. If that knowledge is appreciated, such as in cases of bringing a concern to the supervisor's attention, versus admonished, such as in cases where the supervisor does not follow up on the concern or even tells aide not to get involved, would impact the fulfillment of that need. Participants also expressed seeing themselves as providing not only respite for family caregivers but also as educators, such as in cases of modeling behavior, particularly with clients who may have dementia. These clients have been identified by participants to be at risk for abuse as families may grow "tired" or do not understand the nature of the disease. Appreciating the support, the aides may provide outside of the Plan of Care has the potential to contribute to having the need of autonomy fulfilled, positively impacting motivation.

The range of experience and knowledge expressed by participants speaks to the second component of SDT: competence. For example, several participants stressed the significance of being patient and understanding of clients who have cognitive impairments, stating that such may be frustrating for family members (whether for logistical or emotional issues) resulting in some mistreatment. They expressed insight into clients' conditions: "...because they can't manage their own stuff, so they take it out on other people" and implied that one has to understand and "not take everything personally", including in cases of what may be seen as

discriminatory behavior. One aide was dismissed from a case "for praying" and while she was not clear as to what triggered the client, she stated to "understand" and left the case (Interview #13). The aides are also expected to maintain professional boundaries, which may prove to be challenging given the setting. Their capacity to understand and know how to act accordingly in these often delicate or sensitive situations likely varies among participants and home health aides in general. Providing tools to enhance that competence seems like an opportunity for supervisors and agencies at large. Furthermore, competence is correlated to autonomy in that it enhances self- efficacy. Navigation of these daily, moment-to-moment decisions indicate competence and should be looked to be continuously enhanced by supervisors and agencies.

Empowering aides' authority by trusting their judgements and, when possible, extending their capacity to make more independent decisions was an expressed desire. Such supervisory and organizational support could therefore have real impact on propelling both the autonomy and competence. A skilled home health aide who can be relied upon to conduct their work autonomously is an asset to the agency as a whole.

Relatedness, the third factor of SDT, indicates the general connection to the agency or a cause. The participants already know the policies referring to reporting all changes of their clients' functioning, however, also report that there are times when clients themselves ask them not to do so. Having high competency, in that they understand the potential harm that may come to client, as well as a connection to the agency where they are motivated not to disobey the polices, may increase their motivation to report elder abuse. Wanting to do well by the agency because of the integration of values would also increase the reporting rates. Supervisory and agency support has the potential to offset some of the hardships of the day-to-day work and improve the aides' relatedness to the agency and profession.

The idea of the importance of having good staff representing the agency was echoed in the sentiment of the importance of bringing the aides "in on the business" respecting their investment in the agency and its reputation (Interview #10). Aides should able to "cooperate and understand and to give hope and joy" (Interview #13). One could argue that training and further education about not only issues such as elder abuse but also about agency's policies and regulation would be helpful in building and promoting that reputation and increase aides' intrinsic connection to the agency.

When asked whether the participants are concerned about being removed from a case upon speaking with the supervisor about challenges or problems, most participants stated that they were not concerned. This may be correlated to their intrinsic motivation "to do the right thing". Often when an issue rose to the point of reporting, the aides themselves wanted to be removed from the case. An example of a situation dire enough for the aide to request removal was in an extreme hoarding situation (Interview #2) which was believed to be a health hazard for the aide. In such cases, unless the agency is able to persuade another aide or the responsible party to clean up, the case is dropped by the agency, sometimes without a referral, missing the opportunity for an intervention. In this example, as it often happens, the aide had no idea about the ultimate outcome. While this itself was not unusual as often the agency does not follow up with aides about their former clients, with no regard for tenure or the relationship between client and aide, doing so may provide an extrinsic motivation to reinforce motivation. Relationships are bound to develop, however unreciprocated and boundary driven may they may be (Buch, 2018). While the expectation for aides to move immediately onto another case may be business as usual for the agency, it seems to go against human nature and otherwise expected component of empathy. One may argue that this negatively impacts the relational development toward both

clients and agency. One participant explained these internal conflicts, saying that they are told by the agency "not to get attached" but "...how can't we? I think that's an unfair statement…" (Interview #8).

Not receiving feedback may also be perceived the agency not following up on a report of abuse. As one participant stated: "a lot of things get brushed under the rug here." With visible frustration, this participant explained that that she once wrote a letter [about a client] to the supervisor and never got any feedback (Participant # 16). Increasing the support around reported abuse, such as following up and notifying the aide of the outcome, could also increase the willingness and motivation to come forward with information.

Implications for Practice

Home health aides indicated that, as direct providers, they would like to be invited to collaborate with the agency for the benefit of their clients. This could decrease the negative or punitive perceptions of reporting of abuse. The key would be management's assurance of continuous work eliminating the risk of financial consequences. Collaborative efforts between administrative, supervisory, and direct care staff toward client safety and well-being would keep aides informed of a situation after they report potential abuse, particularly in cases where they have developed bonds with clients but are no longer working with them. Currently, it is a common occurrence for aides to not be informed of the outcomes of cases, particularly if the reporting aide is removed from a case.

Reporting abuse seems to be intrinsically motivated by the perceived "wrong and harm" and extrinsically motivated by agency's policies and rules. The home health aides interviewed for this study identified the supports they would like to receive additional education and training, enhanced supervision and easier communication with the agency and their supervisors (most

notably, shorter phone hold times). The already low wages and difficult parts of home care work could be offset by a more supportive and inclusive work environment. Studies indicate that supervisory support and enhancement of skills and perceived competence may increase job satisfaction while frustration with psychological needs such as autonomy and relatedness may lead to exhaustion, which in turn may lead to decreased motivation and overall job performance (Deci et al., 2017).

Few of the participants also noted that communication in English can at times be challenging. This was witnessed during the interviews, where only four of the 17 participants were native speakers of English. They may face challenges in comprehension and being able to find the right words to express themselves. Language barriers may also limit comprehension of policies, expectations and overall capacity and willingness in communication with the agency. It would be prudent for the agency to recognize and address these needs in a more comprehensive and inclusive manner, such as with providing translators in English classes.

Some participants noted the difference between what is provided in training and the unexpected circumstances they encounter in the real world, which would be helpful for their supervisors to observe. A participant articulated: "…it's one thing when you teach a class…When-when the aides go out there, in the – in the homes and the mentality is different". (Interview #15). The training curriculum and supervisory conversations could incorporate more elder abuse content.

Improving access to further instructional development, as well as easier and more frequent access to supervisors and smoother, more considerate of the aide's time and resources reporting process, such as by paying aides for their time was also noted. This perpetuates relatedness to the agency. The aide's commitment and dedication to clients, truly the key

component to this important job, is already there and is providing an opportunity to maximize the impact of detection and reporting of abuse.

Answers to the prompting question: "Do you speak with your supervisor about clients?" suggested a plurality of the understanding and expression of communication channels between the aides and supervisors. Participants would say that yes, they do speak with their supervisors but may only need to speak with them an issue arises, in other words, not to have discussions about cases or be mentored. Giving aides an opportunity to voice their ideas about what works and what does not work within the agency, as well as validating their ideas for improvement, was an important component of the research interviews. Yet, this seemed to be a challenge for many home health aides to identify, potentially because aides are not often asked to contribute in such ways.

Implications for Policy

It may be argued that there is a direct correlation between an overall societal devaluation of older adults that is commonly displayed in our society, and marginalization of elder abuse on the policy agenda (Bruhn & Rebach, 2014; Jackson & Hafemeister, 2013; North, 2015). Implementing anti-ageism policies in our workplaces and institutions as well as collectively working toward creating a more pro-aging society may reduce the prevalence of ageism and elder abuse for current and future generations.

Cultural values around aging need to be re-evaluated. Federal policies and financial support for older adults were on the policy agenda throughout the twentieth century. Elder Abuse was recognized to be a global public health issue by the United Nations in 2002 (Beaulieu et al., 2015; Marquand & York, 2016; WHO, n.d.). While elder abuse advocacy gained some momentum, most notably since 2012 declaration of the World Elder Abuse Awareness Day

(WEAAD; celebrated on June 15th) elder abuse policies and financial investments are inadequate (WHO, n.d.). For example, in 1991 the federal government allocated $3.80 per 18+ adult in protective services to $45.03 per child for protective services. Today, about $7 billion is annually allocated for child protective services while the Elder Justice Act (EJA) received only 10% of the allocated $777 million (Blancado, 2019; Dubble, 2006; NAPSA, 2016). The EJA funding impacts the collection and standardization of APS data, which in turn impacts standardized research.

Continuous funding for the Victims of Crime Act (VOCA), which was revised in 2015 to include support for victims of elder abuse, is also necessary (Justice.gov, n.d.). In fact, taking note from that inclusion, all policy and funding sources for adults and families should include a section identifying and supporting older adults and elder abuse.

The findings of this study suggest that home care agencies would benefit from policies calling for additional financial resources Additional funding could offset the educational and supervisory cost incurred by home care agencies providing more intense education and supervision around elder abuse. Such education and support should also be expanded to family caregivers. Much like offering parenting classes for new parents to reduce child abuse, providing resources for new caregivers of older adults could be empowering and ultimately reduce abuse.

Professional organizations, such as Home care Association of America and the National Adult Protective Services Association (NAPSA) continue to provide recommendations, guidelines and resources for professionals, however utilization of these is voluntary. Standardized reporting and reviewing criteria based on professional guidelines may better inform research, and therefore practice, mainly in that data will be comparable. Reporting of abuse may

be emotionally taxing even when one has all the necessary information and when mandatory reporting is in place, which in NYS it is not (Rodriguez et al., 2006).

Research Implications

The findings of this study offer several implications for future research. As this was an exploratory study of home health aides working in New York City, it would be prudent to repeat this study in both rural and metropolitan areas outside of New York. While the outcomes of this study may not be generalizable to all homecare providers, it will certainly serve as a foundation to building knowledge in an arena where it is sorely lacking. Further and repeated utilization of this design in future studies has the potential to build significant knowledge and enhance the environment in which home care services, and interventions, are provided for older adults.

Future research opportunities include exploratory inquiry of facilitators and barriers to identifying and reporting elder abuse through lenses of organizational theory or case study design. These would present an alternate perspective and allow for a discussion on potential organizational change as well as about individual needs and impact. Home health aides exist in an agency environment which includes other staff and multiple frameworks of caregiving responsibilities. To that end, there should also be some consideration to expand the study to include supervisors and even other relevant administrative staff, such as case coordinators.

Strengths and Limitations of the Study

This study is both timely and relevant, as majority of people wish to remain in their homes as they age (Blancato & Ponder, 2015; North & Friske, 2013). The rapidly expanding lifespans dictate the need for expansion of home care assistance: by 2050, the number of people aged 85 and older will reach close to 19 million (Administration on Aging, 2013, 2016; Center for Urban Future, 2013; Jackson & Hafemeister, 2013). The strain on already inadequate

resources and overburdened caregivers will likely increase the incidents of elder abuse in need of discovery and intervention. The purpose of this study was to fill the gap in information about home health aides' motivation and barriers to report elder abuse. This information not only contributes to the necessary knowledge about the growing field of home care services but also has direct applications in providing suggestions to practice. Most importantly, this study finally gives a voice to the front line workers that communities rely on to provide care for our aging populations.

Analysis of a self-reported data presents numerous problems including provision of inaccurate information. Such may occur for multiple reasons, from rushing to complete the interview, to poor memory, to potential desire to present favorably. The information provided may also be incomplete or insufficient to provide a comprehensive analysis (Rubin & Babbie, 2014; Oktay, 2012; Padgett, 2008). Furthermore, the home health aides' observations and involvement with clients may not accurately represent their knowledge and abilities, but rather the adaptability to the fast pace and highly demanding work environments. Cultural variation may have influenced the "conceptual equivalence" of what is "abuse" or the social norm expectation of caregiving or responsibility toward older adults (Killick et al., 2015). Variance of cultural backgrounds of the participants may also hinder willingness to provide certain information which may be perceived to be inappropriate, taboo or even offensive to discuss, such as respect for clients' privacy, discussing older adults or sexual abuse.

Some of the interview participants noted that being a home health aide is more than "just a job", that it is not "for everyone" and that they got into it because they desire to "help people". Notably no one has stated that it is an easy job, or the "best" job or that they enjoy being an aide. Rather the participants focused on ascribing meaning to their work, its importance, and often, the

extension of the caregiving they provided within their own families. While conceptually noble, it does not speak to the overall lack of employment opportunities aides may be experiencing. In fairness to understanding the totality of their experiences, future research should include a question this researcher wished was asked: "What job would you have if you were not a home health aide?".

An important limitation of this study is the fact that interviews were conducted only in the English language. The language barrier, even in cases where participants spoke English, was evident at times by participants displaying limited comprehension of nuanced questions and/or concepts, such as the cultural variations in understanding of elder abuse. This language limitation, as well as work, scheduling conflicts and transportation limitations may leave out a population of aides with significant, and varied, work experience.

A possible limitation of this study was limiting data collection to one-on-one interviews. A focus group format may have benefited those participants who felt uncomfortable in a one-on-one interview. While this was not outwardly stated by the participants (only one admitted to being nervous), some discussions regarding the supervisory relationship, for example, could lead to a more comprehensive data. Group format would also potentially include aides who were not willing or able to wait to be interviewed as well as aides who may be encouraged by the presence of others, particularly as aides discussed the study among themselves.

Conclusion

By year 2030, the older adult population is estimated to be at about 72 million, with close to 1.3 million residing in NYC (AoA, 2016, CUF, 2013). Current research indicates that up to 13 percent of older adults in US have experienced some type of elder abuse (Mariam et al., 2015; NYC Elder Abuse Center, 2009; National Council on Aging, 2014). As the population of older

adults grows, so will the numbers of those who are experiencing abuse. Unwillingness to report abuse is very real as over 90% of older adults prefer to live at home, and fear over removal of a caregiver who makes it possible may outweigh tolerance of mistreatment (Poo, 2016). Home health aides, a rapidly growing profession, provide direct and often intimate care, leading to development of trusting relationships, which may lead to disclosure of experienced abuse (Buch, 2018; Kelly, 2017; Lam & Garcia-Roman, 2017; Mathias & Benjamin, 2003). Increased necessity for home care services is therefore opportunity to increase potential interventions as currently only about 1 in 24 cases becomes known to the authorities (Buch, 2018; WHO Facts Sheet, n.d.).

Current research points to a gap in studies with home health aides as participants, limiting our understanding of their knowledge or motivation to report elder abuse. It does however indicate that professionals, such as nurses and doctors, are generally not sufficiently educated about elder abuse (Barker & Himchak, 2006; Dawson & Langston, 2016; Marquand & York, 2016; Schmeidel et al., 2012).

This study's research question was: What are the intrinsic and extrinsic facilitators and barriers to detecting and reporting elder abuse among home health aides in New York City? The two aims of the study were to learn about the extent of the aides' knowledge about elder abuse and to explore their motivational factors regarding its reporting.

The Self- Determination Theory (SDT) provided a theoretical orientation to this study. In SDT, motivation is presumed to be determined by personal (intrinsic) or social (extrinsic) factors. SDT further determines motivation based on presumed satisfaction of three psychological needs: autonomy, competence and relatedness (Deci & Flaste, 1995; Ryan & Deci, 2017). Learning about reasons behind participants motivation make a decision about reporting

abuse could be anchored around their psychological needs being met. SDT indicates that fulfillment of these needs leads to internalization of values and beliefs toward motivation that is sustained even without explicit rewards. Research of SDT indicates that there is potential for increasing of motivation by extrinsic methods, which has implications for practice.

This study was cross-sectional and exploratory in design and utilized the Grounded Theory method. The purposive sample consisted of 17 certified home health aides working with older adults in licensed home care agencies in New York City. Data was collected via semi-structured interviews of five questions, conducted in English. Interviews were audio recorded and transcribed, with researcher taking additional notes. The average length of interviews was about 16 minutes, with the longest one lasting almost 38 minutes. All but one participant were female with ages ranging from 32 to 73 years. The length of time working as an aide was between one and 32 years. Further demographic details are listed in Table 1. Given the sensitive nature of elder abuse, a safety protocol was put in place in case of an elder abuse in need of immediate response was disclosed; implementation, however, was not necessary.

Data collected was organized into "codes" which were based on words or phrases used by participants. Collectively they made up "concepts", which in turn collectively made up "themes" utilizing Oktay (2012) classifications. The two main identified themes were "Elder abuse is multidimensional" and "Personal, organizational and economic drivers influence reporting". The details corresponding concepts are organized in Table 2 and details of codes are provided in Appendix 11.

The participants indicated that there are many definitions of elder abuse as well as direct and indirect perpetrators, such as family members, clients who abuse aides and society at large. It is not surprising as there is a well-documented lack of a cohesive, universally utilized definition,

leaving most agencies, and individuals, to apply their own perceptions of the definition to all cases (CDC, 2016). The participants knowledge about elder abuse was stated to have been obtained from multiple sources, including expressed experiences of caregiving for family or friends.

The motivation to report abuse was expressed as a personal or moral obligation with the barrier described as potential negative consequences such as losing a case and experiencing a financial loss. The discussion of supervision and communication with the agency noted some barriers, such as difficulty with getting a hold of a supervisor. Interestingly, the aides were not quite as able to identify areas for improvement of the current trainings and educational programs. Such may be a result of their disconnect, or weak relational attachment to the agency, or more simply, lack of conversations with supervisors.

The facilitator to gaining knowledge about elder abuse, as well as motivation to report appear to be largely intrinsic in nature. The extrinsic motivator, the participant identified quality of connection to the home care agency, seems in turn to have the potential to be either the facilitator or a barrier. While the research question does make a distinction between the intrinsic and extrinsic motivational factors, one may argue that as long as there is motivation with positive outcomes of reporting it does not quite matter whether it is intrinsic or extrinsic. Where it does matter, however, is in the spaces where change can occur, which is in implementation of supports by supervisors and agencies. In the end, it is clear that field of home care services appears to have significant potential in enhancing the capacity for home health aides to become more involved in intervention therefore enhancing the quality of life for scores of older New Yorkers.

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Appendix 1. Interview Guide

Screening Questions:

- Are you a NY certified home health aide?
    - How long have you been a home health aide?
    - Are you also a Personal Care Aide?
    - When was the last time you had an "in-service" training?
    - When was the last time you worked for an agency (vs. hired privately)?
    - Do you work in all of the boroughs?
- How many of the clients that you are currently working with are over 60 years of age?
    - Is that usually the case?

Demographic Questions

- What is your identified gender?
- What is your identified race/ethnicity and place of birth?
- What is your age?
- What is your level of education?

Researcher's Guide to Opening Statements

- PURPOSE

  To learn how elder abuse is understood and addressed within homecare agencies.

  Estimated time of the interview is about 1 hour.

- VOLUNTARY

  Reminder that participation is voluntary and that the interview can be terminated by the participant at any time (and that participant can skip/not answer any question they choose not to answer)

- CONFIDENTIAL

  All efforts to ensure confidentiality will be taken and all participants will be assigned a number by which their interviews will be identified. All identifying information will be removed from data prior to analysis. Audio tapes will not include participant's name or identifying information.

  Information provided will be kept confidential and only shared with the agency in an aggregate, analyzed format that does not contain any identifying information of participants.

- INCENTIVE

  Each participant will be entered to win a $25 Metro Cards. A sealed envelope (containing the participant's ID number) will be provided for lottery entry.

  A separate sheet of paper connecting the names of aides with their assigned numbers will be kept for the purpose of the lottery and potential need to clarify the information provided.

- FOLLOW UP

  Would you be comfortable with a follow up phone call should there be a need for clarification - answering "no" will not exclude you from the study.

- CONSENT

  Permission to audiotape and signing of consent.

- MISCELLANEOUS NOTES
- Acknowledge the nature of aide's work- their time constraints, intimacy of the work and the difficulty of the work
- Ensure that they understand and do not have any questions.

- Ask if participants are comfortable and ready to proceed with the interview.

Guiding Interview Questions:

- What do you think elder abuse is? How would you define it?

Prompts

  - Types?
  - Common?
  - Who are the abusers?
  - Where did you learn this? (is it discussed in the agency?)
  - Do you think that is how it is understood by others? (any cultural aspect to abuse/ understanding it?)

- Please tell me about the types of elder abuse (situations) you think may be most commonly encountered?

Prompts:

  - Why?

- What would motivate you to report elder abuse? Have you had a situation where you have reported elder abuse or where you thought about reporting it?

Prompts

  - Only monitoring?
  - Safety?
  - Resources?
  - Supervisor's involvement?
    - Do you speak with your supervisor about clients?

    - Are you concerned about being removed from the case upon speaking with your supervisor about challenges and problems?
- Do you think elder abuse may go unidentified or unreported by a home health aide?
    - Why?
    - Do you think that happens often?
    - Agency's role?
    - What would be helpful?
- Is there anything else that you would like to add?

Appendix 2. Participation Request Flyer

Inviting

CERTIFIED HOME HEALTH AIDES (HHAs) to participate in a research interview about elder abuse

raffle to win $25 Metro Card*

contact: AGNES HALAREWICZ (doctoral student at the CUNY/Graduate Center) at [redacted] at ahalarewicz@gradcenter.cuny.edu

***participation in study for raffle entry not required**

Appendix 3. Agency Email Script

SUBJECT: Homecare & Elder Abuse study

Dear…

I hope this email finds you well.
I am a geriatric social worker and have been working with your agency (referring clients) for many years (I used to work for JASA, Next Stage Senior Care Services and Elder Care Solutions).

I'm currently a doctoral student at Hunter and am interested in interviewing home health aides for a study about elder abuse.

This study will not require identification of any clients; the agency and aides' names will be kept confidential. Below please see the agency screening questions.

I would interview the aides outside of their scheduled work times and as an incentive I will have a raffle to win $25 Metro Cards.

I would welcome the opportunity to discuss this with your further and answer any questions you may have.

For your convenience, I am also attaching the project flyer.

Thank you for your consideration,

Agnes Halarewicz, LMSW
[redacted]
ahalarewicz@gradcenter.cuny.edu

Appendix 4. Agency Screening Review and Questions

Agency Screening Review and Questions

1. When was this agency established as a Licensed Homecare Agency?
2. How many employees
    a. Agency as a whole (if part of a larger agency)
    b. In homecare services
3. What is the estimated percentage of clients over the age of 60?
4. Is this a non-profit or for-profit?
5. What resources/programs are available within the agency?

Appendix 5. Consent Forms

THE CITY UNIVERSITY OF NEW YORK

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Title of Research Study: Facilitators and Barriers for Home Health Aides Detecting and Reporting Elder Abuse in New York City.

Principal Investigator: A.K. Halarewicz, LMSW
Doctoral Student, Social Welfare

Faculty Advisor: Nancy Giunta, MSW, PhD
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You are being asked to participate in a research study because you are Certified Home Health Aide working with older adults in a Licensed Home Care Agency in New York City.

Purpose:
The purpose of this research study is to learn about reporting of elder abuse by aides. This study is part of a doctoral dissertation in Social Welfare.

Procedures:
If you volunteer to participate in this research study, we will ask you to do the following:

- Meet with the researcher for a face-to-face interview about elder abuse.
  - The interview will last up to 1 hour. The interview will be scheduled at a time convenient for you.
  - I will ask you about elder abuse and your work experience.

The researcher will take notes during and post the interview to enhance understanding and accuracy of statements. Notes will indicate items such as important themes, points of interests and questions about the information provided that can be clarified during the interview. These notes will be part of data collected during and with each interview.

Audio Recording

- The interview will be audio (voice) recorded. Audio recording will be done for the purpose of accuracy and to allow the researcher capacity to analyze the interview in details. It will later be transcribed by a professional service provider and reviewed by the researcher and potentially by the research team.
- The participants will not be able to edit, review or modify their audio recordings.
- You can still participate in this study if you do not consent to audio recording.

Time Commitment:
You will be interviewed only once, for about 1 hour.

Potential Risks or Discomforts:

- Elder abuse may be uncomfortable to talk about.
- I will give you a list of mental health resources should you want to talk about your feelings about the interview, or the issue of elder abuse, further.
- I will give you information about NYC organizations working with victims of elder abuse.
- You will have a chance to add or change your statement during and at the end of the interview.

Potential Benefits:

- You will not directly benefit from this study.
- You will contribute to the important knowledge about elder abuse. This may have an impact on the types of trainings and services that will be available in homecare agencies in the future.

Payment for Participation:
You will be entered in a lottery to win a $25 Metro Card.
The lottery will take place after all interviews.
You will only be eligible to win a Metro Card if you participate in the interview; you will continue to be eligible if decide not to answer some of the questions or if your interview is terminated due to the safety concerns over the content of your answers.
You will be notified only if your name has been picked as one of the winners.
As per CUNY raffle policy, Metro Cards will be available on the same day of the drawing .
Researcher will individually coordinate delivery of the won Metro Cards with participants.

New Information:
You will be notified about any new information about this study that may affect your willingness to participate in a timely manner.

Confidentiality:
We will make our best efforts to maintain confidentiality. There is a potential for a breach in confidentiality.
We will disclose your identifying information only with your permission or as required by law.

The licensed home care agencies (participant's employers) will not be informed about your participation in the study.

All protections will be taken to keep your privacy and confidentiality during the interview and analysis of the study. The notes will be stored in the researcher's home office, in a locked file cabinet. This consent form will be stored at CUNY.
All computerized notes will be password protected. The audio recording will be removed from the recording device and stored in a password protected cloud and/or researcher's password protected flash drive. The audio recording will be transcribed by a professional transcription service.

I will protect your confidentiality by asking for your fist name and telephone number only. You will be given an identification number. Only numbers, not your name, will be used in the analysis of the study. The document linking your name and contact information to the assigned number will be stored in a locked cabinet in the researcher's home office and/or on a password protected computer document. This document will be destroyed upon the conclusion of the study.

If an abusive situation is identified I, the researcher, will speak to you and your supervisor about it. I am a mandated reporter and may report it to appropriate authorities, such as Adult Protective Services. In such cases, the data from the interview will not be used in the study.

The research team, authorized CUNY staff, and government agencies that oversee this type of research may have access to research data and records in order to monitor the research. Research records provided to authorized, non-CUNY individuals will not contain identifiable information about you. Publications and/or presentations that result from this study will not identify you by name.

Future Use of Data:

Researcher's notes, audio transcription and audio recordings will be kept by the researcher. Anonymized data, identified only by a number, may be used in the future analysis for another study. Anonymized data may be requested by other researchers. Each request will be reviewed by the researcher and research advisors.

The participants will not be contacted again. The document linking your name and contact information to the assigned number will be destroyed upon the conclusion of the study.

Participants' Rights:

- Your participation in this research study is entirely **voluntary**. There will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled.
- Your participation or non-participation in this study will in no way affect your employment at the licensed homecare agency.

- You can decide to withdraw your consent and stop participating in the research at any time, without any penalty. In that case, the data collected during the interview will not be used in the study and will be destroyed.

Questions, Comments or Concerns:

If you have any questions, comments or concerns about the research, you may speak with the researcher: A.K. (Agnes) Halarewicz: cell phone: [redacted] or email: ahalarewicz@gradcenter.cuny.edu.

If you have questions about your rights as a research participant, or you have comments or concerns that you would like to discuss with someone other than the researchers, please call the CUNY Research Compliance Administrator at 646-664-8918 or email HRPP@cuny.edu. Alternately, you can write to:

CUNY Office of the Vice Chancellor for Research
Attn: Research Compliance Administrator
205 East 42nd Street
New York, NY 10017

Store and/or Share Data for Future Research

On the checklist below, please indicate if you would permit the researchers to store and/or share your transcribed and audiotaped interview answers for future research.

____ I agree to allow my interview answers to be stored for future research by the researchers for this study.

____ I agree to allow my interview answers to be shared with other researchers for future research.

____ I DO NOT agree to allow my interview answers to be stored or shared for future research.

Signature of Participant:

If you agree to be audiotaped, please indicate this below.

_____ I agree to be audiotaped

_____I do NOT agree to be audiotaped

If you agree to participate in this research study, please sign and date below. You will be given a copy of this consent form to keep.

_____

Printed Name of Participant

_____

Signature of Participant Date

Signature of Individual Obtaining Consent

_____

Printed Name of Individual Obtaining Consent

_____

Signature of Individual Obtaining Consent Date

THE CITY UNIVERSITY OF NEW YORK

ELIGIBILITY SCREENING SCRIPT

Title of Research Study: Facilitators and Barriers for Home Health Aides Detecting and Reporting Elder Abuse in New York City.

Principal Investigator: A.K. Halarewicz, LMSW
Doctoral Student, Social Welfare

Faculty Advisor: Nancy Giunta, MSW, PhD
Associate Professor
Director, Silberman Aging
Silberman School of Social Work at Hunter College, CUNY
Ngiunta@hunter.cuny.edu

Thank you for talking to me about our research. This research study will aim to identify what motivates identification and reporting of elder abuse by home health aides working with older adults in NYC. This study is part of a doctoral dissertation in Social Welfare.

I would like to ask you a few questions to determine whether you are eligible to participate in this research. Would you like to continue with the screening?

Instruction: If yes, continue with the screening. If no, thank the person and hang-up.

The screening will take about 5 minutes. In order to participate in the study, you must be a certified home health aide, working with older adults in a Licensed Home Care Services Agency in NYC.

I will ask you questions about your home health aide certification, the average age of your clients, your identified gender, race/ethnicity, place of birth, age and level of education.

You do not have to answer any questions you do not wish to answer or are uncomfortable answering, and you may stop at any time. Your participation in the screening is voluntary.

You may be entered in the MetroCard raffle even if you do not to participate in the study.

We will make our best efforts to keep your answers confidential. No one except for the research team will have access to your answers.

Each aide will be assigned a number. This will include all screened participants and all interviewed participants.
A separate document will list the number connected to aide's name and phone number.

The screening information may still be included in the study if you do not qualify for the study. Data may be utilized in the analysis.

The document connecting screened individuals and participants identifying information and research assigned numbers will be destroyed 2 years after the conclusion of the study.

If you do qualify for the study, decide to participate and sign the research informed consent form, the information will be kept by the researcher for the minimum of 2 years and may be utilized in the future analysis for another study. While data may be used for future analysis, the participants will not be contacted again.

Would you like to continue with the screening?

Instruction: If yes, continue with the screening. If no, thank the person and hang-up.

Screening Questions:

- Do you speak English?
- Are you at least 18 years of age?
- Do you reside in NYS?
- Are you a NY Certified Home Health Aide?
    - How long have you been a home health aide?
    - Are you also a Personal Care Aide?
    - When was the last time you had an "in-service" training?
    - When was the last time you worked for an agency (vs. hired privately)?
    - Do you work in all of the boroughs?
- How many of the clients that you are currently working with are over 60 years of age?
    - Is that usually the case?

Demographic Questions

- What is your identified gender?
- What is your identified race/ethnicity and place of birth?

- What is your age?
- What is your level of education?

Thank you for answering the screening questions.

Instruction: Indicate whether the person is eligible; requires additional screening; or is not eligible and explain why.

Do you have any questions about the screening or the research? I am going to give you a couple of telephone numbers to call if you have any questions later. Do you have a pen? If you have questions about the research screening, you may call me directly at [redacted].

If you have questions about your rights as a research participant, or if you wish to voice any problems or concerns to someone other than the researchers, please call CUNY Research Compliance Administrator at 646-664-8918.

Thank you again for your willingness to answer our questions.

Appendix 6: Counseling Resources

Please contact the following resource for mental health counseling and support:

- **NYCWell** –27/7. Free and confidential counseling and supportive services. Language interpreters are available.
    - nycwell.cityofnewyork.us
    - 1-888-692-9355

- **NYC LifeNet**- Free and confidential counseling and crisis services. Language interpreters are available.
    - Part of Mental Health Association of New York City: www.mhanys.org
    - 1-800-543-3638

- **HITE-SITE**-website for free or low-cost NYC programs and services.
    - Hitesite.org

Appendix 7. Elder Abuse Resources

Call 911 for immediate emergencies

For information about Elder Abuse, please visit the following:

- NYC Elder Abuse Center: www.nyceac.com
- National Center on Elder Abuse: www.ncea.aoa.gov
- National Committee for Prevention on Elder Abuse: www.preventelderabuse.org

For case specific inquires or to report Elder Abuse in New York City please contact one of the following:

- Weill Cornell Medicine: Vulnerable Elder Protection Team (available 24/7): 212-472-2222

MANHATTAN

NYC Adult Protective Services: Manhattan North Borough Office: 212-971-2727

- Manhattan South Borough Office: 212-279-5794
- JASA (below 59th street) 212-273-5200
- Carter Burden Center (above 59th Street) 212-879-7400

BROOKLYN

- NYC Adult Protective Services: Brooklyn Borough Office: 718-722-4830 | 4812
- JASA 718-943-7723

BRONX

- NYC Adult Protective Services: Bronx Borough Office: 718-620-8880

QUEENS

- NYC Adult Protective Services: Queens Borough Office: 718-883-8254
- JASA 718-286-1500

STATEN ISLAND

- NYC Adult Protective Services: Staten Island Borough Office: 718-556-5846

Appendix 8. Homecare Agencies

[redacted] is a non-profit based licensed homecare agency providing homecare and case management services for older adults residing in New York City since 1984.

[redacted] was established in 1983 and is a the privately paid homecare division of a large agency which also accepts health insurance. The agency covers five New York City boroughs and Nassau, Suffolk, Westchester and Rockland counties. The agency is accredited by community Health Accreditation Program (CHAP).

[redacted] is a large non-profit organization serving older adults in all five boroughs via multiple programs, including caregiving and elder abuse services since 1968.

Appendix 9. Key Federal Policies and Initiatives Related to Elder Abuse

1950	President Truman begins the process of evaluating policies put forth for older adults	Results in expansion of Social Security benefits
1958	President Eisenhower signs The White House Conference on Aging Act	
1961	First White House Conference on Aging	Conference is held every decade, with the most recent one in 2015
1965	Older Americans Act (passed House reauthorization in March 2016 and was presented to the President on April 13, 2016).	Administration on Aging (within Department of Health and Human Services) was created under Older Americans Act. Administration on Aging houses the National Center on Elder Abuse
1967	Age Discrimination in Employment Act (ADEA; Pub. L. 90-202)	Amended in 1986 to abolish the mandatory retirement age (except in certain professions)
1974	Title XX of the Social Security Act	Block Grant funding provides financial support for Adult Protective Service programs
1989	US wide survey of state health departments protocols on Elder Abuse (revealed knowledge of state laws with only 28% conducting awareness trainings)	2014 follow up survey revealed 67% of state health departments included elder abuse information on websites but continue to indicate gaps in trainings
2010	Elder Justice Act	Passed as part of the Patient Protection and Affordable Care Act (148 PPACA).
2013	Elder Abuse Victims Act (HR4963) (U.S. Department of Justice)	2016- reintroduced in Congress
2013	Fair Labor Standards Act (U.S. Department of Labor) revision	As of 2015 : minimum wage and overtime protection for domestic workers
2013	Elder Protection and Abuse Prevention Act (S.2747) is reintroduced to Congress	The bill calls for financial support of APS programs. This is the 3rd time this bill has been introduced. 2016-introducted in the House of Representatives
2014	Office of Elder Justice & Elder Justice Initiative website (U.S. Department of Justice)	2014- Elder Justice Roadmap. Report by the Department of Justice and Department of Health and Human Services.
2015	Victims of Crime Act (VOCA)	Revisions to include elder abuse (U.S. Department of Justice)
2017	Elder Abuse Prevention and Prosecution Act (P.L. 115-70)	Mandates Department of Justice to provide Elder Abuse trainings, provide resources for prosecutors and collect data on investigations

(Congress.gov, 2016; HHS.gov, 2016; Poo, 2015; Teaser & Hall, 2018)

Appendix 10. Glossary of Terms

- ADLs- Activities of Daily Living
- APS- Adult Protective Services
- CHHA- Certified Home Health Agency
- CNA- Certified Nursing Assistant
- CPS- Child Protective Services
- CRJ- Criminal Justice (systems)
- DOH- Department of Health (also NYSDOH in New York State)
- DV- Domestic Violence
- EA- Elder Abuse
- HHA - Home Health Aide, also referred to as “aide” or certified aide or a home care worker
- IPV- Inter-Personal Violence
- LHCSA- Licensed Home Care Services Agency
- LPN- Licensed Practical Nurses
- PCP- Primary Care Physician (also, MD: Medical Doctor)
- POC- Plan of Care
- RN- Registered Nurse
- SDT- Self-Determination Theory

Appendix 11. Codebook

Appendix 12. IRB Approval