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The Effects of Job Characteristics on Home Care Workers’ Well-being and Job Performance: Understanding the Psychosocial Effects of Relational Care

Emily C. Franzosa
The Graduate Center, City University of New York

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THE EFFECTS OF JOB CHARACTERISTICS ON
HOME CARE WORKERS’ WELL-BEING AND JOB PERFORMANCE:
UNDERSTANDING THE PSYCHOSOCIAL EFFECTS OF RELATIONAL CARE

by

EMILY C. FRANZOSA

A dissertation submitted to the Graduate Faculty in Public Health in partial fulfillment of the
requirements for the degree of Doctor of Public Health, The City University of New York
The Effects of Job Characteristics on Home Care Workers’ Well-being and Job Performance:
Understanding the Psychosocial Effects of Relational Care

by

Emily C. Franzosa

This manuscript has been read and accepted for the Graduate Faculty in Public Health in satisfaction of the dissertation requirement for the degree of Doctor of Public Health.

______________________  __________________________
Date                     Sherry Baron

Chair of Examining Committee

______________________  __________________________
Date                     Jim Stimpson

Executive Officer (Acting)

Supervisory Committee:

Emma K. Tsui

Steffie Woolhandler

Leslie Nickels

THE CITY UNIVERSITY OF NEW YORK
ABSTRACT

The Effects of Job Characteristics on Home Care Workers’ Well-being and Job Performance: Understanding the Psychosocial Effects of Relational Care

by

Emily C. Franzosa

Advisor: Emma K. Tsui

Home care workers are the lowest-paid and most precarious segment of the health care industry. Although these workers provide critical, non-medical support that allows elderly and disabled individuals to remain in their homes, the workforce is highly unstable, due to low wages, a lack of supportive benefits like health coverage, paid leave and retirement support, poor working conditions and a physically and emotionally demanding workload. But a lack of consensus around the nature and value of home care has made “quality”, in terms of both jobs and care provision, difficult to define, measure or improve. While home care is a physically and emotionally intimate job dependent on a trusting relationship between worker and client, the impact of providing this relational care is rarely considered. Instead, efforts to measure job quality do not consider the psychosocial impacts of caring work, and the caring labor workers perform is not reflected in quality indicators, which focus on task-oriented clinical measures.

This project addresses these gaps through a mixed methods approach. The first section draws on two national databases (the 2011 Medicare Home Health Compare (HHC) quality database and 2010 Medicare Home Health Agency Cost Reports) to examine whether agency characteristics (ownership status, agency size, chain status and geographic region) predict the level of benefits aides receive, and whether higher benefits are associated with better quality outcomes for patients. The analysis found that spending on aide benefits was well below national averages for the rest of the civilian workforce, with large agencies and non-profit and government agencies...
providing the highest level of benefits. While benefit level was not a significant predictor of quality measures, large size and chain status were strongly and consistently associated with higher quality ratings. However, it is unclear whether this reflects better quality care, or simply more capacity to complete these assessment tools. The second section uses data from four focus groups of unionized New York City home health aides to examine workers’ own perceptions of quality care and how providing high-quality, relational care affects their well-being. While aides felt that agencies considered “good care” to be completing the tasks on their care plan, their own definition of quality care also included a high degree of relational care. To perform this care, aides took conscious steps to build relationships with patients by employing communication, empathy, respect and love. However, these personal ties often meant setting boundaries with the client, client’s family and agency could be challenging, and aides largely felt unsupported by their agencies in negotiating these boundaries. While aides found their work emotionally satisfying and rewarding, they also experienced stress from balancing their professional and personal roles, and faced an additional strain of feeling undervalued both as individuals and as skilled professionals their agencies and at times their patients and patients’ families.

To improve the structure of home care jobs and care in the future, researchers should break down “silos” to more effectively link data on workers, patients and agencies; prioritize outcome measures over clinical processes; and investigate emerging trends such as for-profit franchises and new payment models. Policymakers must better align the definition of home care with the care clients need, invest in long-term care by providing living wages, benefits and paid time off, leverage home care workers’ expertise by elevating workers’ voices, integrating them into the care team and improving communication, and support workers’ emotional well-being with worker-focused training, mental health benefits, counseling and support groups.
ACKNOWLEDGEMENTS

Completing this dissertation would not have been possible without the support, expertise and generosity of so many. First, I want to acknowledge the 1199SEIU home health aides who so openly gave their time to this project, and who shared their experiences and expertise in such an honest and compelling way. You are the backbone of this industry, and your patients and their families are lucky to have you. I also want to thank Faith Wiggins, Maria Luisa Castaneda and Lourdes Rivera at the 1199SEIU Home Care Industry Education Fund, and teachers Caron Knauer and Cheryl Sutton, for generously opening your classrooms to me, and for your enthusiasm for this project and your dedication to improving home care workers’ lives.

I was lucky to have the support of an incredible, hands-on committee, who all went above and beyond for me, whether by poring over data sets or staffing focus groups, and whose ability to use research to inform social action is inspiring. Immeasurable thanks go to my sponsor and mentor Emma Tsui, a rigorous and thoughtful qualitative researcher whose knowledge of both the public health and social science literature is astounding, and who encouraged me to think broadly but write specifically. I will never understand how you managed to devote so much time out of your impossibly busy schedule to guiding this project and always being available, responsive, calm and positive, but I appreciate it more than I can say. I am also grateful to Steffie Woolhandler for asking me four years ago what I really cared about, and then steering my general frustration over the treatment of low-wage healthcare workers into a clear, cohesive, researchable project, and helping me build the skills I needed to answer my research questions. I thank Sherry Baron for your energy and insight, for so generously sharing your extensive knowledge about home care workers and qualitative research, for all the time spent refining and perfecting our instruments, and for helping me to keep this project focused and achievable.
Finally, I want to thank Leslie Nickels for your willingness to take on a new doctoral student, sight unseen, among all your other responsibilities, and for your enthusiasm for this project, your expertise, and your perceptive and invaluable feedback.

This dissertation also wouldn’t have been possible without my talented research colleagues who didn’t hesitate to take time from their own work, jumping in to moderate and take notes in focus groups, and talk through discussion guides and logistics. Janet Wiersema, Dr. Helen Cole, Dr. Gillian Dunn, Margrethe Hørlyck-Romanovsky and Pamela Vossenas, your skill, warmth and genuine investment in this project and these workers helped generate amazingly productive discussions, and I am forever grateful. I also would not have come this far without my amazingly supportive cohort, which includes the women above as well as Drs. Alka Dev and Anna Divney, Sara Flowers, Kafi Sanders, Amy Metroka and Linda McDowell. You have all made me a stronger researcher and a better collaborator, and I look forward to working together throughout our careers. I must also thank Sara Ingram, a tireless advocate for all of the public health doctoral students, including me, whose knowledge of the intricacies and unique challenges of the CUNY system and determination to move us forward through them, have been so invaluable to all of us.

Many people outside the CUNY system also helped me along the way. I want to acknowledge my professional mentor and boss, Stacey Millman, for supporting this project and for championing my career over the past 10 years, creating opportunities for my personal and professional growth (even if I didn’t think I was ready for them), and making me both more competent and more confident. I also benefited from the opportunity to bounce ideas (and frustrations) off the endlessly supportive Rebecca K. Givan and our morning discussion group.
And of course, I would be remiss to leave out the kind and patient staff of Healthy Nibbles and Joyce Bakeshop, where so much of this work actually happened.

My deepest thanks go to my parents, Dr. Susan D. Franzosa and Dr. John Franzosa, for instilling in both me and my sister a strong sense of justice and fairness, for encouraging us to advocate for ourselves and others, for always pushing us to ask questions and solve problems, and for setting a high bar for terminal degrees in our family. And, none of my work would be possible without Christopher Ozard, my toughest and most supportive reader, who asked hard questions and made me talk through the answers until my thinking was clear, and whose extraordinary physical and relational care over these six doctoral years (and the past fifteen) has kept me fed, healthy and sane. I am so very lucky to have you as my partner.

Finally, I want to thank Rose Adjei, whose skilled, compassionate and necessary care has made such a difference in my own grandparents’ safety, health and happiness. Our whole family is so grateful for you and all of the work that you do.
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Section I

Introduction, Conceptual Framework and Review of the Literature
Chapter 1: Introduction

Home care workers are the lowest-paid and most precarious segment of the health care industry. The nation’s 2.6 million Home Health and Personal Care Aides\(^1\text{-}^3\) – who make up 15\% of the U.S. healthcare workforce – provide critical, non-medical support that allows elderly and disabled individuals to remain in their homes and communities, a safer and less costly alternative to long-term nursing home care. Yet the workforce is highly unstable, due to low wages, a lack of supportive benefits like health coverage, paid leave and retirement support, poor working conditions and a physically and emotionally demanding workload. Turnover in the home care industry remains extremely high, with national estimates ranging from 40-75\% and even as high as 200\% per year.\(^4\text{-}^5\) As the population ages rapidly, the Bureau of Labor Statistics (BLS) predicts that home health aide jobs will be the fifth fastest-growing in the country between 2014 and 2024, with a projected growth rate of 38.1\%.\(^2\) Ensuring a healthy and stable workforce to meet this need is becoming a critical concern for families, employers and policymakers. But to date, incremental efforts adopted by government, foundation, and worker and consumer advocacy groups to meet this growing need have shown only limited gains.

The main barrier to addressing this issue in a systemic and meaningful way is a lack of consensus around the nature and value of home care, which has made “quality”, in terms of both jobs and care provision, difficult to define or measure. While home care is a physically and emotionally intimate job that depends on a trusting relationship between worker and client, the impact of providing this relational care is rarely considered. Instead, efforts to measure job quality focus on structural characteristics such as wages and benefits, without considering the psychosocial impacts – both positive and negative – of caring work. Similarly, the caring labor that workers perform is not reflected in current home care quality indicators, which focus on
task-oriented clinical process and outcome measures more applicable to acute care. To address these gaps in our understanding, this project employs a mixed methods approach that integrates existing, objective measures of home care quality with the more nuanced, lived experience of the people performing this work on the front lines of care.\(^6\) In the first part of this dissertation, I draw on two national Medicare data sources to gather descriptive information and examine the relationships between structural job characteristics and job quality. In the second, I use evidence collected directly from home care workers themselves to better understand how psychosocial job characteristics affect the well-being of workers and in turn, their ability to provide high-quality care - a connection that limited, aggregate measures alone cannot explain. By integrating multiple forms of data, this project describes what we know now about home care quality, and what we still need to investigate to better align jobs and care with our goals.\(^6\)

The three key aims of this project are:

- **AIM 1:** To determine whether Medicare-Certified Home Health Agencies (MCHHAs) providing more generous benefits to home health aides [measured as the ratio of benefit costs/wages] achieve higher standard quality scores than those providing less generous benefits using Medicare’s administrative and quality data.
  - Sub-aim 1: To determine whether organizational characteristics (including for-profit/nonprofit status, chain status, agency size, and geographic region) are a predictor of agencies’ benefit ratio, and in turn, quality outcomes.
- **AIM 2:** To conduct foundational research through focus groups with unionized New York City home care workers to better understand how psychosocial job characteristics support or undermine home care workers’ ability to provide what they perceive as “quality” care.

\(^6\)
• AIM 3: Through the same focus groups, to better understand the impact of psychosocial job characteristics on workers’ well-being and in turn, on patient care.

Chapters 1 and 2 lay out my analytical approach and provide background on the complex structure of the home care industry, describing how the lack of consensus about the nature and value of home care work, along with fractured funding streams and a lack of consistent oversight perpetuates bad jobs for workers and inconsistent care for clients.

In Chapter 3, I explore available quantitative data. This chapter examines the impact of structural job characteristics on care quality, using two administrative data sets on Medicare cost and quality to examine the connection between wages, benefits, and agency characteristics on existing home care quality measures.

Chapters 4-6 use qualitative focus group data to better understand home care workers’ own perceptions of quality care, and of their work. Chapter 4 explains the methodological and conceptual approach to this section. Chapter 5 focuses on the central construct of “good care”, and how aides define quality care. What does good care mean for workers, and how do they go about providing it? What skills do they use on the job? What support do they need to strengthen care for their patients, and themselves? Chapter 6 focuses on the effect that providing this care has on workers’ well-being, both positive and negative. What are the rewards of caring work? What are the challenges? How can we support aides’ well-being, both on and off the job?

Last, in Chapter 7, I draw on all of these findings to pose recommendations about how we can strengthen the home care system by more clearly defining home care. What is, or should be, the goal of home care? What data do we need to gather to better understand this work and the people who perform it? What do we want out of these services for our parents, our grandparents and our
society as a whole? How can we ensure the workers who provide this care have the support they need to do the job well, and stay healthy themselves?

A note about limitations

It should be noted here that the findings in this dissertation are not necessarily generalizable to all home care workers. Medicare cost and quality data, while nationally representative, do not include the many patients who receive long-term home care services through Medicaid or private-pay agencies, or independent providers. The experience of unionized, agency-based home health aides in New York City does not necessarily reflect the experience of personal care workers like home attendants and housekeepers; non-union workers; or independent providers, or the wide variation in home care services and programs between states. However, these factors further illustrate the concerns raised throughout this project about the ways our multi-layered home care delivery system makes defining and measuring home care in a systematic, rigorous manner nearly impossible. And, even with these limitations, certain themes and findings emerged so consistently in both this project and other researchers’ work – such as the need for higher wages, more comprehensive benefits, and more on the job support – that the findings build a strong case for the need to better acknowledge the emotional effects of providing and receiving care.

Finally, throughout this dissertation, I use many terms specific to the home care industry. A list of these commonly used terms and definitions is included as Appendix 1.A.
Chapter 2: Literature Review

What is Home Care? Who Pays, and Who Benefits?

Home care refers to the set of services that allow people who are elderly, disabled or ill to remain safely in their homes. Home care services can include skilled care provided by a visiting nurse or therapist, but the majority of home care visits provide what may be termed “custodial” care – tasks such as bathing and feeding patients, and keeping their environment safe, clean and clutter free. While the workers who provide this care go by many different titles, official US occupational codes recognize only two: Home Health Aides and Personal Care Aides. Home Health Aides (HHAs) may perform some clinical tasks for their clients, such as range-of-motion exercises and blood pressure readings. They also help with activities of daily living (ADLs) including eating, bathing, dressing and toileting and occasionally perform light housekeeping tasks like changing sheets or preparing food. Personal Care Aides (PCAs) are sometimes referred to as “homemakers”, and provide ADL assistance, housekeeping and meal preparation, and ensure their clients remain engaged in their communities by helping them prepare for work or accompanying them to the grocery store. Because the job structure and compensation for these positions are so similar, for purposes of this project I include both titles under the general term “home care workers.”

Home care is delivered through a variety of channels. Home care workers may be employed by Medicare and Medicaid-certified agencies that offer a range of in-home skilled nursing and personal care services; with for-profit chains or small providers that focus on non-medical care; or directly for a client, family or even their own family member. Thirty states support

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*a BLS Occupation Codes 31-1011 and 39-9021, respectively.*

*b Technically, aides perform this care under the supervision of a visiting nurse, but in practice, aide and nurse visits do not always coincide and aides often work on their own.*
“consumer directed” home care options, where clients may hire their own aides (often family members) either using money they receive from the state, or having the state pay the worker directly. The Paraprofessional Health Institute (PHI) estimates that in 2010, there were 839,000 HHAs and 985,000 PCAs employed by agencies nationally, while 800,000 independent caregivers were employed through consumer-directed programs and an estimated 500,000 were hired through the private-pay “grey market”. [See Figure 2.1] However, experts agree that these numbers, particularly those in the grey market, almost certainly underestimate the true size of the workforce.

Figure 2.1: Structure of the Home Care Industry

Over the past 40 years, the growth of disability advocates’ independent living movement, states’ efforts to reduce long-term care spending by shifting public dollars from institutional care to Home and Community Based Services (HCBS), and a growing need to care for a rapidly aging
population has created explosive growth in the home care sector.\textsuperscript{11,12} Between 2002 and 2012, the number of organizations providing home care services doubled from 15,000 to 30,000, and home care is currently the fastest-growing industry in the US, generating revenue of over $1 billion in 2012.\textsuperscript{13} Yet, as a recent report from the National Employment Law Project (NELP) found, the bewildering combination of multiple revenue streams from multiple sources at multiple levels in the home care system has created an industry with a troubling lack of accountability or oversight for how the considerable public dollars we invest in these services are used.\textsuperscript{c,14}

Public monies pay for approximately 80\% of all home care services.\textsuperscript{15} The largest payers are Medicare (42\%), whose home health benefit was initially created to cover short-term care following an illness, surgery or injury but has since expanded to reflect more “community-admitted” patients with long term care needs, and Medicaid (36\%), which funds long-term personal care services.\textsuperscript{15} A smaller share of public revenue comes from various funding streams including the Older Americans Act, Title XX Social Services Block Grants, the Veterans’ Administration, and the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) (which together make up less than 1\% of home care spending)\textsuperscript{d,15} With the exception of Medicare, these funding streams are released to states to use at their discretion to cover different populations, resulting in a multi-level system that is increasingly difficult for state health departments and Medicare-certified agencies to navigate in order to cover their costs.\textsuperscript{16} For instance, since states have sole discretion over their Medicaid design and spending, the US essentially has 50 separate Medicaid programs with different eligibility requirements, benefit

\textsuperscript{c} Total US home health spending in 2014 was $83.2b, with $34.7b provided by Medicare and $29.6b by Medicaid. 
\textsuperscript{d} The remainder is paid through private insurance (10\%), client out-of-pocket (9\%) and other sources (3\%).
plans, and payment structures for workers. In addition, even within individual states, Medicaid programs often contract out home care services to federally licensed or private agencies, funneling these public dollars through what NELP refers to as a “host of poorly regulated private companies” who hire and pay workers with state money. Further complicating these funding models is a shift toward so-called “value-based” care, as states increasingly seek to control their Medicaid spending by shifting participants into managed care plans. Twenty states have now implemented managed care models, where private insurers or non-profit managed care organizations receive a set monthly rate per patient to coordinate their care through a limited network of providers. Both clients and workers in many of these programs have expressed concern that since implementing managed care, worker hours and client visits have been reduced and in some cases, workers have had trouble getting paid. These multiple layers of administration also siphon off valuable dollars intended to pay for care; while private home care agencies charge consumers over $20 per hour for home health aide services, median wages for home care workers are only half of that amount.

Finally, one of the most dramatic shifts in home care services over the past decade has been the tremendous growth of private, for-profit franchises. The for-profit business model has proven extraordinarily successful for investors; in 2012, home care was one of the five most profitable franchise ventures in the country. But, many worry that this shift has also negatively impacted both workers and clients. Since many of these organizations are private-pay, and not certified by Medicare, there is little oversight over the quality of service they provide. And, in an effort to maximize profits, many private agencies evade labor protections with tactics such as requiring workers to agree to be labeled independent contractors instead of employees – which results in a higher tax burden for workers, and renders them ineligible for employer-sponsored benefits like
health coverage and paid time off. In 2015, despite achieving gross profit margins of nearly 40%, private-pay agencies spent only 50% of annual revenues on worker compensation. These trends may also be affecting workers’ job satisfaction; a recent study of a nationally representative survey of HHAs found that that aides working at for-profit chain-owned agencies were twice as likely to consider leaving their jobs as those working for non-profit agencies.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number/Percent</th>
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<td>Medicaid</td>
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<tr>
<td>Nutrition assistance</td>
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</tr>
<tr>
<td>Housing and energy assistance</td>
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</tr>
<tr>
<td>Any public benefits</td>
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<tr>
<td><strong>Work Hours</strong></td>
<td></td>
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<tr>
<td>Employed full-time, full year</td>
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<tr>
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Sources:

This complex structure has a cascading effect on both the quality of home care services, and the quality of home care jobs, creating multiple gaps that prevent both workers and clients from obtaining the support that they need.

*Who Provides Home Care?*

The demographics of the home care workforce are similar to those of other low-wage service jobs, and particularly jobs in the caring professions. Home care workers are overwhelmingly women (about 89%) in their mid-40s, and a disproportionate number are women of color. Forty percent of home care workers have children under 18, and about 23% are single mothers. This reflects longstanding government efforts to transition poor single mothers from welfare into health aide positions, as well as the unfortunate fact that these low-paying, low-quality jobs, which have few regulations or training requirements, are often the best options available for women who need to find work quickly, have a high school education, and who are minorities or immigrants. [See Table 2.1., Characteristics of the Home Care Workforce]

Home care is generally considered a “low-quality” job, which means more than simply “low wage”. A “high-quality” job provides adequate earnings with the opportunity to earn more over time; fringe benefits; autonomy and control over work activities; flexibility and control of scheduling and employment terms, and control over termination. Importantly, high quality jobs are stable; as workforce advocate Steve Dawson notes, a high-quality job provides a dependable, livable income “along with health and other benefits…in a safe working environment where you are trained well and supervised well, and most importantly, where both your work, and you, are genuinely respected.” Unfortunately, with the exception of autonomy (which can be both positive and negative), home care work meets none of these “high-quality” criteria.
In 2013, the median average hourly wage for home care workers was $9.61, which would leave most workers below the poverty line even if they worked full-time year-round – which fewer than half are able to do.\textsuperscript{20} Wages also do not increase significantly with job tenure; in one national survey, only 57\% of HHAs working for certified agencies reported receiving a raise in the past year.\textsuperscript{24,24} This is only half the story; since the Great Recession “officially” ended in 2009, the economic position of home care workers has grown worse. According to one PHI analysis, between 2009 and 2010, PCA wages experienced the first year-to-year decline on record.\textsuperscript{25} NELP similarly found that between 2009 and 2012, real median wages for home health aides and personal care attendants declined by 5\% and 5.5\% respectively (compared to an also troubling decline of 2.8\% for all low-wage workers).\textsuperscript{25} This decline in already extremely low wages means that approximately half of home care workers live in households earning below 200\% of the federal poverty income level, and rely on means-tested public benefits such as Medicaid, the Supplemental Nutrition Assistance Program (SNAP, formerly food stamps), Temporary Assistance for Needy Families (TANF), and housing subsidies.\textsuperscript{20} The most common explanation for the low home care wage structure is that Medicaid rate setting does not allow for building higher wages or benefits into reimbursement rates.\textsuperscript{7,16} However, this is a subject of some debate; some advocates have argued that more money would be available for wages if administrative overhead and manager salaries were lower; others note certified agencies may keep wages artificially low in order to win competitive state contracts.\textsuperscript{7,14}

The problem of low wages is compounded by scheduling practices that undermine workers’ stability through the number and consistency of their work hours. Only four in 10 home care workers are employed full-time, year round.\textsuperscript{20} Forty percent of part time workers are “involuntarily” part-time, meaning they would prefer more hours (this does not count those
“voluntary” part-time workers who are unable to work full-time due to a variety of reasons, such as lack of childcare). In addition, as Susan Lambert has found across the low-wage sector, since employers are not required to guarantee minimum hours, workers are often scheduled “to demand” on a per-diem, as-needed basis, leading to fluctuating daily and weekly hours and last minute schedule changes. Home care schedules in particular can be erratic because clients are frequently hospitalized, move in with family and require less or different care, or die. These unpredictable schedules make it difficult to arrange child care or the second jobs that many take on to make ends meet. Nonetheless, the number of workers who do work second and third jobs suggests that many are likely working full-time hours, but without the benefit of full-time status.

While wages are low, employer-sponsored benefits such as health coverage, sick leave and retirement support are often non-existent, and many workers rely on public coverage as an alternative. Close to 50% of home care workers were enrolled in Medicaid in 2013, and over a third were entirely uninsured. While some advocates hoped the Affordable Care Act’s expansion of Medicaid eligibility and new marketplaces for individual plans would make coverage more accessible to these workers, the refusal of 19 states to expand Medicaid, along with “affordable” premiums that can still cost workers nearly 10% of their already low earnings, have prevented many from accessing these options.

The lack of health coverage and paid time off for home care workers is particularly troubling considering the physical and emotional demands of the work. Home care workers are particularly susceptible to injuries en route to and in the workplace as they travel extensively to private homes which are not set up to provide care; lack access to safety-related equipment and assistive devices such as lifts or shower chairs and training in safety measures such as safe patient transfer; and, because many care for clients in poverty, work in unsafe neighborhoods and homes
that have pest infestations, mold, mildew and other hazards. In one study, Myers found that home health aides had three times the rate of lower-back injury of nursing aides. In 2010, HHAs took more days away from work due to injury compared to nursing home staff and all workers in general (a median of 12 compared to medians of 6 and 8, respectively), and stayed out of work longer, often with no pay. While these numbers are striking, they are also almost certainly underreported, considering the substantial number of workers in “grey market” employment. Home care workers are often also ineligible for workers’ compensation benefits because of worker misclassification, or are not aware of the coverage or their rights to it. Outside of workplace injuries, home care workers suffer from the same chronic health issues as the general population; the 1199SEIU Benefit Funds, which provide health benefits to 30,000 unionized home care workers in New York City, estimate that 53% of members require ongoing medications for conditions such as diabetes and high blood pressure. Finally, home care workers experience a number of psychosocial effects of both their physical and emotional labor. Workers report a high level of on-the-job stress, due to the emotional labor of caring for ill, dying, aggressive or disoriented clients, and an increasingly accelerated workload as more agencies and states seek to rein in costs by maximizing client visits. Research has also found that the structural characteristics of low-quality jobs, like job insecurity and constantly changing schedules, can negatively affect workers’ physical and emotional health.

**Recognizing and Valuing Home Care**

While the tasks that home care workers perform are largely non-medical, they nonetheless ensure a secure and hygienic environment for vulnerable elderly and disabled clients, which is a critical factor in allowing individuals to remain safely in their homes rather than entering a hospital or long-term residential facility. However, the historic perception and non-clinical nature of the job
has created a host of barriers to improving job quality. Like much of the caring and nurturing work traditionally associated with women’s unpaid labor, these jobs are often assumed to be low value, and to require “innate” skills rather than professional training.\textsuperscript{32,33} This is reflected in wages (home-based aides earn less than those who perform the same work in institutions); occupational coding (institutional nursing aides and HHAs are recognized as “Healthcare Support” positions, while PCAs are considered “Personal Care and Service” occupations); and training requirements (HHAs working for Medicare- or Medicaid- certified agencies must undergo 75 hours of training; there are no federal training standards for PCAs, although many states set their own training requirements).\textsuperscript{7,34,35}

Paula England suggests that two theories of care have shaped these perceptions. The first, devaluation, posits that decision makers in power undervalue jobs traditionally held by women, particularly women of color.\textsuperscript{32} Care workers in general experience a documented wage “penalty”; caring jobs pay less than others, even controlling for part-time status, worker education and other characteristics.\textsuperscript{35} This has certainly been the experience for home care workers, who provide services that have typically been codified not as needed health care, but as housework, family care, or charity care provided, usually unpaid, by women. The public good framework posits that this “women’s work” is also undervalued because the benefits are diffuse and hard to quantify – they accrue to society at large, rather than generating a visible economic return.\textsuperscript{32} However, labor advocates are quick to point out that even if it is difficult to put a dollar value on the benefit of home care services, we nonetheless owe a “social debt”\textsuperscript{12(p1)} to the workers who fill a critical role in our healthcare and social system by enabling the elderly and disabled to live independently, removing the full burden of caretaking from families, and supporting the work of clinical care teams.
In addition, undervaluing home care has led to an environment that falsely pits the needs of workers against the needs of those for whom they care. By marginalizing these services and the people who provide them, policymakers have for years effectively kept arguments around funding long-term services centered on keeping care affordable for state budgets and clients’ families rather than on assuring sustainable, quality jobs for workers. Low quality jobs for workers are justified in terms of the “paramount need” of clients, which, as Eileen Boris and Jennifer Klein argue, grants employers “additional moral license to expropriate [workers’] labor on the cheap” and implies that “denial and self-sacrifice are essential to the ethic of care”.36(p8) This is most evident in the historical exclusion of home care workers from the Fair Labor Standards Act’s minimum wage and overtime protections. In 1974, when Congress extended these protections to domestic workers, “companions for the aged and infirm” were exempted, including even those home care workers employed by a third-party agency rather than a private household.37 This effectively equated home care workers with casual babysitters, the other group exempt from the law. After years of contentious battles between worker advocates and home care employers, the companionship exemption was overturned by the US Department of Labor in 2015.13 However, home care employers appealed the ruling to the Supreme Court, claiming that the labor protections would be too costly and force them to reduce services to clients. Worker advocates countered that the industry was in fact thriving, with many home care companies reporting profit margins of 32% or higher. In June of 2016, the Court ultimately sided with workers and declined to hear the case.13,38

*Understanding Relational Care: Can We Provide Good Care Without Caring?*

This “false conflict” is particularly frustrating to both workers and clients because, in fact, they often care deeply about each other’s welfare.20,39 But, this relationship often goes unnoticed
because the nature and value of the care that home care workers provide to their clients has been the source of so much confusion and debate. What exactly is home care, and what are its goals? What value does home care provide to clients, families, the healthcare system, and our society? Are home care services just about keeping the elderly and disabled physically safe and comfortable, or are they about something more?

The complex public and private worlds that home care straddles – as a professional, paid, but intimate service performed in a client’s home with little outside supervision – has made it difficult to define expectations or desired outcomes of care. Home care workers provide physical support to their clients, but they also provide emotional support – relational care that can be just as important to client well-being. In his study of nursing homes, Tim Diamond found that the commodification of personal care, and the structure of industry funding and reimbursement, has encouraged LTC employers to discourage the relational care that institutional aides provide, discounting the emotional, “feminine” side of the work as wasted money, while prioritizing specific reimbursable tasks. Boris and Klein take this argument further, making the case that the system deliberately discounts relational care to disenfranchise the workforce and control public budgets, so that care “appears no longer as a labor of love, but becomes unskilled work that allegedly any woman could perform.” To do this, “social workers and agency supervisors have tried to reduce the job to household maintenance and bodily care in contrast to intangibles”, allowing them to measure and reimburse the work through “Taylorized” tasks that allot workers a specific number of minutes to bathe a client or help them in and out of bed. However, despite agencies’ efforts to disregard the emotional side of the work, home care still requires caring. Building a better understanding of home care and its goals requires us to consider several components of the relational care that is so central to the work.
First, relational care is necessary. HCBS programs support individuals’ right to live with autonomy and independence, in the least restrictive environment. Living with autonomy requires more than simply getting help showering and eating; it also takes what Arthur Kleinman describes as “cognitive, behavioral and emotional support.” When this relational side of home care is prioritized, both workers and clients benefit; aides and clients often cite close, trusting relationships as central to quality care. Over time, as home care workers gain specific knowledge about the individuals they care for through these relationships, they are not only better able to perform both intimate physical tasks like bathing and transferring, but also the emotional work of providing companionship and comfort that keeps their clients mentally healthy.

Second, relational care is challenging – and rewarding. Arlie Hochschild coined the term “emotional labor” to describe the relational work that service professionals must often “perform” in addition to their task-based labor. This work, which can require workers to demonstrate emotions that make clients or customers feel good while masking their own true feelings, can cause workers stress and make them feel disconnected from their own bodies and identities. MacDonald and Sirianni have referred to front-line service workers as the “emotional proletariat” because the personal, emotional labor they perform “creates value, affects productivity, and generates profit” for employers rather than the workers themselves. However, the unique, intimate nature of home care has caused some disagreement around using these terms to describe workers’ experience. Maria Ibarra, for instance, rejects the notion that home care workers are true “proletarians” because the emotional labor they perform is often authentic; workers genuinely care for many of the individuals with whom they work. But others argue that “even the authentic expression of emotion is work” and the effort needed to
“care about, manage and absorb the emotional reactions of…others on a daily basis can…have potentially negative consequences”\(^{46(p13)}\) and lead to emotional and physical exhaustion and stress.\(^{47,48}\) Performing emotional labor means that workers must often put their own worries to the side to provide good care to their clients, which can be difficult when juggling their own anxieties about family, finances, or even other clients.\(^{47}\) Workers also report that because of the genuine bonds they form, they are profoundly emotionally affected by patients’ deaths – a common occurrence when caring for an elderly or ill population.\(^{47,49}\) These effects of emotional labor are particularly important to consider in workforce development, since home care workers who are depressed and anxious are more likely to leave their jobs.\(^{47}\)

But, emotional labor can also be satisfying and rewarding, contributing to workers’ emotional well-being. Studies of both paid and unpaid caregivers’ mental health and job satisfaction tend to focus singularly on the negative effects of caregiving – exhaustion, burnout, and depression. But as Kleinman argues, caring relationships are also complex, rewarding and reciprocal; care is a “defining moral practice” that “makes caregivers, and at times even the care-receivers, more present and thereby fully human” and as such, it is “far more complex, uncertain and unbounded than professional medical and nursing models suggest.”\(^{42(p4)}\)

Sociologist Clare Stacey argues relational work in home care provides both rewards and challenges for worker and client. Workers maintain that the rewarding, mutual relationships with their clients are the part of the job they most value. In in-depth interviews with home care workers, Stacey found that workers actively construct an identity of a moral and “caring self” that allows them to find “genuine pride and meaning” in forming caring relationships with clients, prioritizing and valuing the relational work they perform over the “dirty”, and stigmatized, bodily work of the job.\(^{43}\)
But, while constructing a caring identity allows workers to find meaning and value in their work, it can also have a negative effect on aides’ economic and emotional well-being – outside of simple measures of stress or burnout. Close bonds with clients can create conflicts for aides who struggle over whether they are providing these services for “love or money.” As Boris and Klein argue, this view of workers as altruistic “carers” may ultimately keep them from advocating for themselves by perpetuating the idea that care is valuable “only when it is undertaken freely, and not for pecuniary reward,” pointing out that the very term “caregiving” suggests something that is given away. Stacey found the “caring” frame often translates into what she terms “surplus” care – spending extra time with clients, calling clients on days off, performing extra cleaning or shopping – for which workers are often not compensated. Aides consistently report that they provide this “surplus” care not because the tasks were assigned or requested, but because they felt clients needed them and no one else would take on these responsibilities. These blurred boundaries also make it difficult for aides to pursue fair wages and job protections, even when they have legitimate, legally recognized reason to do so. For example, a 2009 survey of home care workers in three large cities found that 90.4% had experienced an “off the clock” wage violation, where they worked before or after their shift without payment for that time. These caring bonds may also keep workers in low-quality work; one survey of independent California home care workers found aides’ emotional commitment to their clients often kept them in jobs they would otherwise leave.

Third, relational care is skilled. While home care work is often referred to as “low-skilled”, political scientist Beth Shulman has rejected this term, arguing that it further devalues care by trivializing the very real relational skills that the work entails. While the caring labor that women perform has been naturalized and essentialized as innate and gendered, Stacey argues
that home care requires a high emotional aptitude to anticipate and respond to the needs of another, and that aides must constantly and intentionally work to balance the relational care they provide with “professionalism, objectivity, and distance.”\textsuperscript{43(p9)} Annemarie Mol describes this careful process as “tinkering”, noting that “engaging in care is not an innate human capacity…it is infused with experience and expertise and depends on subtle skills that may be adapted and improved along the way when they are attended to and when there is room for experimentation.”\textsuperscript{54(p14)} In other words, there is no one “right” way to provide care; but those who provide it must constantly and intentionally make adjustments in the way they approach and combine technical tasks with emotional labor, depending on the “specificities” of both caregiver and care recipient and “the relations in which we make each other be.”\textsuperscript{54(p14)} Research on nurses, who perform similar emotional work, notes that emotional intelligence, or “the ability to identify, assess, manage and control self and reactions to others’ emotions” is also a critical skill for care workers, enabling them to be highly attuned to their patient’s emotional needs and fine-tune their care accordingly.\textsuperscript{55,56}

Finally, and of most importance to this project, relational care is invisible. While the physical custodial services home care workers perform may be undervalued and undercompensated, the relational care they provide – companionship, emotional support, compassion – is almost entirely unrecognized outside of the worker-client relationship.\textsuperscript{43,57} The industry does not formally acknowledge this work; it is not listed on any formal care plan, it is not reimbursed by healthcare payers, and it is not compensated by employers. Like many service jobs, emotional labor in home care is an “invisible” job requirement; while employers implicitly expect workers to have and use these relational skills and even advertise them to consumers, employees are not compensated for performing them well or for the considerable effort they require.\textsuperscript{46} Instead, as
Stacey has noted, home care workers are often instructed to keep a “professional distance” from their clients and avoid developing personal relationships, even though “by ignoring these relationships, agencies dismiss what is central to quality care and worker satisfaction.”

The invisibility of relational care is clearly evident in the way that the quality of home care is measured. The same fractured, multi-layered structure that plagues home care funding, along with the lack of a clear definition of the goals and desired outcomes of these services, make measuring quality of care challenging. Quality measures are inconsistent across the industry, and those that do exist generally measure only the bodily work that aides perform, and patients’ physical outcomes. Medicare, state Medicaid programs, and private payers all use different quality tools. Of these, Medicare’s quality measurements are the most robust and the only quality measurements available on a national level; however, these tools give the most weight to clinical indicators over which aides may have little control, such as ER visits. Early proposed home health quality indicators in New York State, when Medicaid long-term care was transitioning to a managed care model, included only one measure of aide service—whether the aide arrived on time. Some researchers and advocates have used turnover as a proxy for measuring continuous, relational care, and high turnover has been linked to lower quality of care and patient satisfaction in nursing homes, although not in the home care industry. However, turnover only describes workers leaving their employers or the industry, not continuity with the same client. One recent study did find that continuity with the same aide was associated with improvements in home care patients’ ADLs, but this research focused on acute patients requiring short term services (on average, less than 40 days of care), where ADLs would be expected to improve. To make this care visible, we will need to find ways to include it in measures of labor force statistics and quality outcomes.
Supporting Workers Supports Quality Care

The current model of home care, where we depend on an undercompensated workforce to fill in the care gaps that policymakers will not, is unsustainable. As policy analyst Laura Dresser writes, the very nature of caring work means that it is “human and local” and the problem is not going away, but growing as more and more aging individuals require care. “Technology will not massively displace these workers” she writes. “Globalization will not move these jobs overseas. Care work is with us and will be so in the future.”12(p8)

As Boris and Klein argue, this problem can be fixed by recognizing the work that home care workers are performing and supporting it within the system. Home care is not simply devalued because of the race, class and gender of those who provide it, they claim, but also because of the way the state has chosen to structure it.36 The reluctance by policymakers to acknowledge and value both the physical and emotional labor that home care workers perform, particularly in austere post-recession public budgets, underlies and, I would argue, undermines efforts to transform our understanding, quality measurement, and reimbursement for home care services. Supporting workers in providing the care that clients need will require us to clearly define the goals of home care, and what quality jobs and quality care mean within this industry – and then re-align our system to meet the needs of workers, clients and families.

Conceptual Approach

This project seeks to better define and understand the quality of both home care services and home care jobs. Through this project, I argue that the relational work that aides perform, while formally invisible, is critical to building caring, ongoing relationships with clients, which in turn
supports the well-being of both workers and clients. When we fail to support workers’ ability to provide this care, workers and clients both suffer.

As Figure 2.1 shows, home care services are situated within a complex web of funding sources and delivery models; aides might work for a non-profit or for-profit agency, or as independent providers; they may be paid with public dollars or privately by their patients; they may be unionized or not. Each of these factors has an impact on four structural job characteristics: wages, benefits, scheduling and the availability of training. Of these, wages and benefits have been most clearly linked to workers’ retention in the field; however, unpredictable, “just-in-time” scheduling or per-diem work can also impact aides’ well-being by making it difficult for workers to work enough hours to earn a living wage, qualify for or afford health coverage or retain continuity with the same client over time. Due to a lack of funding and the perception of the job as low-skilled, training requirements in the industry are minimal or non-existent; this leaves workers vulnerable to injury in the workplace, as well as unable to gain new skills and advance in their careers. Those training programs that do exist most often focus on task-based processes, such as safe patient handling, rather than navigating the emotional aspects of the job.

The industry structure also contributes to the psychosocial work environment, which speaks to the challenges and rewards of the relational work that aides provide, and the complex and often blurred line they often walk between personal and professional worlds. The psychosocial aspects of work include both the emotional labor and physical demands of caring work, including the “invisible” or “surplus” work that aides often perform outside of the specific plan of care. They also include the emotional and professional support that workers receive on the job from their clients, their employers and the clients’ families, and the level of control that home care workers feel they have in negotiating which physical and emotional tasks they perform, and how they
perform them. This model also considers the value of the work, and the meaning, satisfaction, and respect that workers derive from providing this care. Both structural and psychosocial domains have a direct effect on workers’ well-being, including their physical, mental, emotional and economic health, and ability and desire to stay in their job.

These issues all ultimately influence the core of caring work, the worker-patient relationship. The well-being of aides and their clients are closely connected; when aides’ well-being is high, they are happier on the job and more able to perform caring work. When it is poor, they may become burned out, stressed or disengaged from their work, which can translate into missed days of work, or leaving a case or the industry altogether. However, both aides’ and patients’ own individual characteristics are also critical factors in the relationship; home health agencies recognize these factors, and often make an effort to match aides and patients based on language, ethnicity and other factors to ensure a certain level of comfort and familiarity.

Taken as a whole, this model proposes that both structural and psychosocial job characteristics directly influence workers’ well-being, and in turn, their ability to build and maintain caring relationships with their client, and provide quality care. This project will investigate the impact of these domains on workers’ well-being and ability to deliver complex, holistic care.
Figure 2.2 Conceptual Framework

The Impact of Relational Care On Workers and Care Quality

Worker/client characteristics
SES, immigration status, language, cultural practices, race/ethnicity, mental health

Job Characteristics:
(Structural)
- Wages
- Benefits
- Scheduling
  - Client continuity
  - Covelored
- Training

Industry Structure
Funding Source:
- Public (Medicaid, Medicare, other)
- Private

Employment model:
- Agency
- Independent Provider

Labor Protections:
- Union
- Non-Union

Work Environment:
(Psychosocial)
- Job Demands
  - Physical ("Visible")
  - Emotional ("Invisible")
- Job Control
  - Care Plan
  - "Skewplus" care
- Job Support
  - Supervisor/agency
  - Co-workers
  - Client
  - Family caregivers
- Job Value
  - Meaning, respect, prestige

Worker Well-being
- Physical
- Emotional
- Economic

Worker/Client Relationship

Client Well-being
- Quality of Care
- Quality of Life
Section II

Quantitative Methods, Analysis and Findings:

Structural Measures of Home Care Job and Care Quality
Chapter 3: Do Employer-Provided Benefits Lead to Better Patient Outcomes?

In this chapter, I investigate the relationship between structural job characteristics – specifically wages and benefits - and home care quality outcomes. Both higher wages and supportive benefits such as health coverage and paid leave have been found to improve home care workers’ retention and job satisfaction.\textsuperscript{21,48,51,62} However, because data on workers and clients are largely “siloed” (i.e., investigated separately by researchers, and collected into separate databases), the connection between job characteristics, retention and job satisfaction, worker well-being, and the quality of patient care is far less understood. No previous analysis has been able to directly tie wages, benefits and/or hours worked directly to home care quality outcomes. This analysis links two administrative data sets on Medicare cost and quality to make this connection.

Defining and Measuring Quality in Home Health Care

The Centers for Medicare and Medicaid Services (CMS) is the largest payer of home health services in the United States. CMS payments accounted for approximately 80% of total U.S. home health spending in 2011, including 42% paid through Medicare, and 36% through Medicaid.\textsuperscript{63} As the demand and cost for home health services skyrockets, CMS has become more focused on ensuring the quality of publicly-paid home health services. In 2000, the agency mandated all large Medicare-certified Home Health Agencies (MCHHAs), and Medicaid agencies in states where they are required to meet Medicare’s conditions of participation, to complete the Outcome and Assessment Information Set (OASIS) for Medicare and Medicaid patients receiving skilled care.\textsuperscript{64} The full OASIS instrument, which includes more than 100 domains of care, must be completed for each patient when they are admitted to home care, at recertification for each 60-day episode of care (the unit by which Medicare buys these services), and upon discharge. In addition to demographic information, the OASIS indicators capture two
main types of quality measures: *processes of care*, such as timely initiation of services and pain screenings, and *outcomes of care*, such as whether patients improved in Activities of Daily Living (ADLs) like walking and bathing.\textsuperscript{58,59} OASIS has proven to be a controversial tool, in part because of the staff burden required to complete the lengthy assessment, and more importantly, because of questions about whether the instrument is a reliable or valid measure of quality.\textsuperscript{64,65}

In many ways, these questions reflect the ongoing lack of a clear definition of the nature and goals of home health care.\textsuperscript{66} OASIS was designed to align with Medicare’s home health benefit, which was originally intended to provide short-term, post-hospital recovery care for patients whose health was generally expected to improve. But in recent years, Medicare beneficiaries have begun requiring more non-clinical care, for longer periods of time. Between 2002 and 2013, the average number of 60-day episodes of care for Medicare home health patients increased by 19\%.\textsuperscript{67} Between 2001 and 2012, the total episodes of care not preceded by a hospitalization or post-acute care (PAC) increased by 116\%, while post-acute episodes increased by only 23\%. Over the same period, the share of episodes not preceded by a hospitalization or PAC rose from 53\% to 66\% of all Medicare home health episodes.\textsuperscript{67} The Medicare Payment Advisory Commission (MedPAC) notes that these “community-admitted” patients are a different population with different needs; they receive more aide services and fewer therapy visits as a share of total care than post-acute patients, and almost twice as many patients are dually eligible for Medicare and Medicaid.\textsuperscript{67}

Despite this shift, the OASIS measures still focus on task-oriented processes largely performed by agency staff and therapists rather than aides, such as administering vaccines, or clinical outcomes, such as improvements in breathing, that may not adequately reflect the non-clinical and caring labor of the aides who provide the majority of visits. The patient satisfaction data
collected through CMS’ Home Health CAHPS (Home Health Care Consumer Assessment of Healthcare Providers and Systems) survey may speak to more of the relational care that aides provide; however, it is not mandatory and few MCHHAs report these measures. At this time, OASIS remains the most comprehensive, standard measure of home health quality in the nation.

The Impact of Wages and Benefits on Home Care Quality

The nature of the supportive, relational work that home care workers perform suggests that a trusting, ongoing relationship between worker and patient is an important component of quality care. Low wages and lack of supportive benefits like health coverage and paid leave have been tied to high turnover among home care workers, which advocates assert may disrupt the consistency and quality of patient care; however, as mentioned in the previous chapter, there is little empirical data to support this claim.10,20,61

Even when aides stay in their positions, there is reason to believe that job performance and patient relationships suffer when workers are fatigued, stressed or emotionally overextended – all issues that can be exacerbated by low pay and lack of benefits. Though no studies have connected stress and burnout specifically to home care quality, both factors have been shown to be associated with nursing home workers’ ability to provide high-quality care.69,70

Wages and Benefits

In 2014, home health workers earned a mean wage of only $9.61, which translates to earnings of less than $20,000 per year for a full-time, year round worker (although the majority of home care workers do not work full-time schedules).1 These wages do not increase significantly with job tenure; in one national survey, only 57% of HHAs working for certified agencies reported receiving a raise in the past year.24 As the profession is currently structured, approximately half
of home care workers live in households earning less than 200% of the federal poverty income level and rely on means-tested public benefits. In addition to low wages, few home care workers receive health coverage, paid leave or other benefits through their jobs. In 2007, while 73% of workers reported working for agencies offering health insurance in 2007, only 37.5% had enrolled in their employers’ plan, suggesting they either did not work enough hours to be eligible or could not afford coverage. In 2009, only 32% of home care workers reported receiving employer-sponsored health coverage, compared to 52% of direct-care workers in nursing homes and 78% in hospitals. It is unlikely that the Affordable Care Act’s employer coverage requirements will substantially improve access for these workers. While the ACA now requires employers with more than 50 full-time workers to offer “affordable” coverage (meaning, premiums of no more than 9.66% of household income) to employees working 30 or more hours per week, even workers employed by large agencies may not meet the 30 hour threshold or be able to afford spending close to 10% of their earnings on coverage.

What Drives Wages and Benefits?

Scheduling. Wages and benefits are closely related to scheduling, since more hours allow workers to earn more money, reach health benefit eligibility thresholds, and afford premium contributions for health coverage. Providing consistent hours to workers can be a challenge for agencies because of the population they serve; clients’ needs and schedules can change constantly as they improve or become hospitalized, move to institutional care, or die. Since employers are not required to guarantee minimum hours, workers are often scheduled “to demand”, leading to fluctuating daily and weekly hours and last minute schedule changes.

31
result, only 40% of workers report working year-round, full-time schedules that would allow them to earn a “full-time” salary or qualify for benefits offered to full-time workers. Almost half of part-time home care workers are “involuntarily” part-time, meaning they would prefer to work full-time hours. Additionally, even aides who work enough hours to qualify for benefits like health coverage may not enroll because they cannot afford the required premiums and co-payments.

**Worker Misclassification.** Until June 2016, home care was categorized as “companionate” work and excluded from minimum wage and overtime protections under the Fair Labor Standards Act. This perception of home care work as informal care rather than formal employment has made these workers particularly vulnerable to misclassification as independent contractors, even when employed by an agency and not a private client. Independent contractors are not eligible for health and other benefits, unemployment, or workers’ compensation insurance. Misclassification also has serious consequences for workers’ economic stability, since independent contractors must pay quarterly estimated income taxes and the employer’s share of social security and Medicare (an additional 7.65% in payroll taxes), and are not protected by minimum wage and overtime protections.

Though workers have won court cases around misclassification in Maryland, North Carolina, California and Florida, there is concern that these employee classifications are not enforced and may be contributing to both lower wages and lower benefit levels for home care workers.

**Agency Characteristics.** The ownership status, size, and geographic location of home care agencies can also have an important influence on the benefits that employers are willing or able to offer workers.
• **The Growth of For-Profit Franchises:** Since 1980, when CMS removed a statutory provision against proprietary agencies’ participation in Medicare’s home care program, the for-profit home health sector has grown tremendously.73 As the US population continues to age and require more home health services, proprietary, for-profit home care franchises have become an increasingly promising and lucrative opportunity for investors. In 2012, the nation’s top home health franchises earned gross profit margins as high as 40%, making home care one of the five most profitable types of franchise in the country.17 By 2010, for-profit agencies had grown to 70% of free-standing home health agencies.74 Unfortunately, in the drive to maximize profits, for-profit agencies may seek to reduce compensation costs by offering fewer benefits to staff, limiting hours so that aides do not meet the threshold for benefit eligibility, or misclassifying workers, all of which could potentially affect both turnover and quality outcomes. One recent analysis found that for-profit agency status was associated with both higher net revenue and lower quality outcomes than non-profit status.18

• **Agency size:** There is tremendous variation in the size of home health agencies, which range from small “mom and pop” operations to multi-state chains employing thousands of workers. In 2011, the same time period as the data used in this analysis, 59% of employers with fewer than 200 workers across all industries offered health benefits, compared to 99% of employers with 200 workers or more.75 Employees of smaller organizations also shoulder a higher proportion of the cost of health coverage; workers in smaller firms pay a higher percentage of the premium for family health coverage, which may dissuade them from enrolling even if benefits are offered. In 2011, among workers whose employers offered health plans, 21% of workers were not eligible for coverage at
all, and 19% of those who were eligible did not enroll in their employer’s plan, likely due to high cost sharing. This proportion may begin to change as the Affordable Care Act requires more employers to offer “affordable” coverage to full-time employees or pay a penalty; however, as previously mentioned, access to that coverage will depend on whether agencies continue scheduling many workers at less-than full-time hours and whether workers can afford the cost of premiums.

- **Regional variation:** Almost half of MCHHAs are located in southern US states. With their large, rapidly aging populations, Texas and Florida in particular are home to both the largest numbers of home care workers and the fastest-growing demand for home care services, making quality of care and the stability of the workforce a particular concern – especially since many of the Southern states with the highest growth of MCHHAs have also experienced a significant number of fraud reports. Southern states have the lowest rates of employer-sponsored health coverage in the nation, a troubling trend when considering that nine out of 16 southern states, including Texas and Florida, have also refused to expand Medicaid eligibility under the Affordable Care Act, leaving many workers without access to insurance from either their employer or public programs. One recent PHI analysis estimates that nearly half a million direct care workers (a number that includes institutional workers as well as home care aides) would become eligible for coverage if all 50 states were to expand Medicaid. 78% of those workers are in the South.

To better understand the relationship between wages, benefits, and quality, this analysis used Medicare’s administrative and quality database to investigate whether agencies’ characteristics predict the level of benefits that MCHHAs provide, and whether, in turn, MCHHAs that provide
more generous benefits to home health aides achieve higher scores on standard process and outcome quality measures than those providing fewer benefits. Specifically, this analysis focuses on three questions:

1) Do characteristics of MCHHAs (ownership status, agency size, chain status and geographic region) predict the level of benefits that aides receive?

2) Are agencies’ benefit levels associated with better quality outcomes for patients?

3) Are MCHHAs’ characteristics directly associated with quality outcomes, and if so, do employer-provided benefits explain this association?

**Methods**

**Data Sources**

This analysis draws on two national Medicare databases: the 2011 Medicare Home Health Compare (HHC) quality database and 2010 Medicare Home Health Agency Cost Reports (“cost reports”). The HHC dataset includes information submitted by 9,128 Medicare-certified home health agencies between September 2010 and December 2011. This information is based on quarterly OASIS indicators, and includes 13 individual “process of care” quality indicators, and 10 “outcome” quality indicators, as well as five aggregate (i.e., combined) indicators. All data are adjusted for case mix by CMS. The current analysis uses the five aggregate indicators as the primary outcomes. [See Table 1] The 2011 cost reports include complete financial and actuarial information submitted by 7,165 agencies. Medicare-certified agencies are required to file these reports, which include spending on staff salaries, benefits and patient care, among other information, on an annual basis. Limiting these data to agencies that included information on
both aide salaries and benefits and reported employing 1 or more full-time equivalent (FTE) aides yielded a sample of 3,312 agencies.

It should be noted that these databases do not include all US home health agencies. The National Association for Home Care and Hospice estimates over 33,000 agencies, or approximately three times the number in the HHC dataset, provided home care services in 2010. However, small agencies receiving less than $200,000 annually in Medicare reimbursement and agencies that only accept Medicaid and/or private insurance are exempt from Medicare reporting requirements. In addition, the cost report data do not include hospital-based agencies, whose information is included in their hospital’s Medicare cost report.

Outcomes, Independent Variables and Control Variables

Outcomes

The primary dependent variables were the five aggregate measures calculated by CMS based on the 23 process and quality indicators in the HHC dataset. These include: 1) mean quality score across all indicators; 2) processes of care, such as timely initiation of care; 3) improvements in patient outcomes, for instance, activities of daily living (ADLs); 4) health care utilization (patients are free of hospital admissions); and 5) potentially avoidable events (patients do not experience an increase in bedsores). These outcomes were analyzed as continuous variables. To facilitate interpretation of the results, I reversed the scales for the healthcare utilization and potentially avoidable event variables so that higher scores indicated fewer adverse events, and were consistent with the other three measures. All variables are included in Table 3.a at the end of this chapter.
Of these groups, I hypothesized that *improvements in patient outcomes, prevented* hospitalizations, and *avoidance of bedsore* would be associated with generosity of benefits, since these indicators more closely reflect the work that aides perform, and areas where quality may decline if workers are not able to provide consistent and ongoing care due to high turnover, missed visits or burnout. For instance, the outcome improvement group of scores, which includes progress in walking, bed transfer and bathing, is closely related to the regular ADL assistance that aides provide; and safe client bathing and transferring may prove critical in helping to reduce or prevent bedsore. Similarly, hospitalizations may be avoided when an aide who knows her client well and visits regularly can detect changes in the client’s health status early and alert the care team before a deterioration in health requires hospitalization. An
association between quality and prevented hospitalizations, as the only objective clinical quality measure based on Medicare claims data, would be a particularly important finding. The process group of indicators, which largely reflect agency and clinical staff responsibilities, such as conducting regular depression screenings or initiating care in a timely manner, was not hypothesized to be as strongly connected to aide wages and benefits.

**Independent Variables**

The principle independent variable in this analysis was *benefit ratio*. While Medicare’s cost reports do not include individual salaries, benefit costs, and hours, they do include total annual costs of aide salaries and aide benefits (primarily health insurance and paid time off) for each agency. They also include the agencies’ number of full-time equivalent (FTE) home health aide employees, computed by dividing the total number of hours worked by all employees receiving a W2 form by 2,080 (the number of full-time work hours in a year as measured by the Bureau of Labor Statistics). This allows me to estimate both the average hourly wage and full-time, year-round earnings for home health aides at each agency.

*Benefit ratio* was defined as *Total Benefit Cost/Total Aide Wages* per agency. A benefit ratio closer to 1 represents an agency paying more generous benefits to workers, while a benefit ratio closer to 0 represents an agency paying few or no benefits. A home care agency’s benefit ratio can be affected by three factors:

1) *Benefit generosity*: Agencies with a higher benefit ratio (close to 1) provide more generous benefits to home health aides.

2) *Hours worked*: Agencies with a higher benefit ratio have more aides working sufficient hours to qualify for employer-sponsored benefits. (For instance, while an agency listing
10 FTEs may either be employing 10 aides at 40 hours per week, or 40 aides at 10 hours per week, it is unlikely that 10 hours per week would be sufficient for an aide to become eligible for health coverage. Most employers require aides to work a minimum eligibility threshold of 80-100 hours per month to be eligible for health coverage.

3) *Employee cost of coverage:* Agencies with a higher benefit ratio will have more aides electing employer-sponsored coverage, suggesting that out-of-pocket costs (e.g. premiums and deductibles) are not prohibitive.

As a point of reference, benefit costs in the U.S. during this time period represented 31.4% of total employee compensation (i.e., wages plus benefits) for civilian workers (a category which includes both private and public employees), or a benefit ratio of approximately 0.42. However, since this analysis uses agency-level and not individual-level data, the benefit ratio should be interpreted with caution. For instance, a high benefit ratio could mean that aides are receiving generous benefits, but could also mean that wages are extremely low and benefits assume a larger share of total compensation. (For this reason, per-employee wages are included as a control variable in the analyses.)

In addition to examining the association between the benefit ratio and the five aggregate quality indicators, this analysis also included several covariates of interest.

*Agency Characteristic Variables*

- *Agency type.* This analysis focused on three types of ownership: *proprietary* (for-profit, investor-owned agencies) *non-profit* (organizations such as Visiting Nurse Associations, as well as any agencies with a religious affiliation) and *government* (owned by state and county administrators). While government agencies represent only a small proportion of
total agencies (6%), I retained them in the analysis in light of several states’ shift away from providing home care services directly to contracting the services out to for-profit agencies – a potential concern for quality of care, if ownership and quality are related.

- **Agency size.** In addition to predicting benefit ratio, agency size may also confound the relationship between benefit ratio and quality outcomes, since small agencies that cannot afford benefits may have fewer resources available for training or support that could improve quality of care. For this analysis, agency size was operationalized as a categorical variable using the Centers for Disease Control reporting thresholds: agencies annually serving 1-100 patients (small), 101-300 patients (mid-size), or >300 patients (large). Nationally, in 2011, 40% of home care agencies were small, 27.6% mid-size, and 32.4% large.

- **Chain status.** Similar to agency size, agencies that are part of a chain of organizations may have more resources available for staff training and support, as well as system-wide protocols for employee policies and for collecting quality data. In addition, since a high proportion of chains are for-profit, many of these organizations will also face pressure to maximize profits for shareholders. Chain status was operationalized as a binary variable, with chains vs. independent agencies.

- **Geographic location.** Geographic location was operationalized as a categorical variable using the four Census-designated regions of the US: South, West, Midwest, and Northeast.

*Additional Aide Compensation Variables*
• **Annual Wages per Aide.** Wages were included as a potential mediator. While a high benefit ratio may mean that workers are receiving generous benefits, it also may mean that wages are extremely low and benefits represent a larger share of compensation. Low wages may also independently affect worker retention or quality of care. To test whether low wages were mediating or confounding the association between agency characteristics, benefit ratio, and quality outcomes, I constructed a per-aide annual wage variable for each agency by dividing total aide wages paid by the number of FTE aides reported.

• **Annual Benefits Paid per Aide.** To examine variability in benefits between agencies, I constructed a per-aide annual benefit measure for each agency by dividing total aide benefits paid by the number of FTE aides reported. This measure was used to compare differences in benefits paid by agency characteristics.

While annual wages and benefit variables are used in the analyses, it should be noted that hourly wages and benefits are a better representation of workers’ earnings, since few home care workers are employed full-time, year-round. For ease of interpretation and comparison, hourly wages and benefits are presented in Table 3.b.

**Analytic Strategy**

All analyses were conducted using SAS 9.4 statistical software.

*Univariate Analysis:* I first performed preliminary descriptive analyses to assess the distribution of the variables of interest, identify outliers and remove implausible values likely related to data
entry errors (for instance, numbers less than zero). Since agencies’ size range is so great, extreme
values above 0 (those more than 3 SD from the mean) were not removed from the dataset, but
flagged and tested in later sensitivity analyses.

I then created the benefit ratio variable and analyzed it to determine if there was sufficient inter-
agency variation to detect statistically significant differences. Since fewer than a third of home
care workers receive any employer-sponsored benefits, I expected that most agencies would fall
below the 2011 national mean benefit ratio of 0.42 for civilian workers. In fact, only 4% of
agencies in the sample had benefit ratios of 0.42 or higher. Because so many agencies fell below
this threshold, I examined the data by three categories: low (0.0–0.15), medium (0.16 – 0.30) and
high (>0.30). I considered there to be sufficient variation if at least 10% of the sample fell into
each of these categories. However, in the main analyses, benefit ratio was examined as a
continuous variable to give more robust results and avoid losing data.

Next, I used separate ANOVA tests to determine if there were statistically significant differences
in the means of the aide earnings, aide benefits and benefit ratio variables by agency
characteristic (ownership status, agency size, chain, and geographic region). Finally, I tested the
correlation between the agency characteristic variables using chi-square tests of independence,
with the intent of addressing any issues of collinearity. Agency characteristic variables
correlated at p<0.05 were retained in the analysis to investigate the influence of each category.
Variance inflation factors (VIF) were calculated for correlated characteristics, with the intent of
removing those with VIF > 5 in subsequent analysis; however, all VIFs fell below this threshold
and were retained in the final models.

Multivariable Analysis
I tested my research questions in three separate analyses. Since the benefit ratio variable was not normally distributed, I used PROC GLM to run general linear models for all analyses, which do not assume data are balanced or normally distributed, and allow for easier inclusion of categorical variables. In addition, I performed a log transformation on the benefit ratio and aide wages variables to adjust for non-normal distribution and reduce the effect of outliers. For each analysis, I first used scatterplots to determine if a linear association existed between the dependent variables and outcomes, and to identify any deviations due to outlying observations.

Research Question 1: Do characteristics of MCHHAs (ownership status, agency size and geographic region) predict the level of benefits that aides receive?

**Figure 3.2**

**Analysis 1: Relationship Between Agency Characteristics and Benefit Ratio**

For the first analysis, I ran separate linear models using each of the three agency characteristics as the independent variable, and benefit ratio as the dependent variable (See Figure 3.2). Agency characteristics significant at p<0.05 were included in a second, multivariable linear model, both alone and with aide wages included as a potential mediator. Finally, I ran a third model using
interaction terms to determine whether there were interaction effects between the three agency characteristics.

To test whether model fit was improved by a simpler analysis, I also ran an alternate multivariate model using the three agency characteristics as binary variables (large vs. small/medium; proprietary vs. non-profit, excluding government-owned agencies; chain vs. non-chain, and southern vs. non-southern), with the category containing the largest number of agencies as the referent.

Research Question 2: Are agencies’ benefit levels associated with better quality outcomes for patients?

Figure 3.3
Analysis 2: Relationship Between Benefit Ratio and Quality Outcomes

In the second analysis, I used benefit ratio as the independent variable, and each of the five quality measures as dependent variables in separate general linear models for each measure (See Figure 3.3). Results significant at p<0.05 were included in a second set of models that also
included *agency size* and *aide wages* as covariates, both separately and together, to determine if these variables affected the significance, magnitude or direction of the associations. Results in which agency size and aide wages were significant at p<0.05 were then tested again using interaction terms between the predictor variables.

*Research Question 3: Are MCHHAs’ characteristics associated with quality outcomes, and if so, does benefit level explain this association?*

**Figure 3.4**

*Analysis 3: Relationship Between Agency Characteristics and Quality Outcomes (with Benefit Ratio as Covariate)*

In the third analysis, I used *agency characteristics* as the independent variables, and each of the five *quality measures* as dependent variables in separate, multivariable general linear models for each measure (See Figure 3.4). Agency characteristics were added into each model one at a time to assess whether each set of characteristics changed the magnitude or significance of the results. Significant associations (p<0.05) were then included in an additional set of models including *benefit ratio* as a covariate, to test whether benefit generosity mediated these relationships.
Sensitivity Analysis

For all three analyses, I ran sensitivity analyses on all statistically significant final models by trimming the top and bottom 3% of observations to determine whether extreme values were distorting the parameter estimates and whether excluding these data altered the significance, direction or magnitude of the results. However, as general linear models have been shown to be valid for any distribution, provided the data set is sufficiently large, I did not anticipate these analyses would significantly change the results.\textsuperscript{81,82}

Results

Aide Compensation (Earnings, Benefits and Benefit Ratio)

The mean aide wages per FTE aide in the sample (n =3,312) were $12.46 (IQR=$6.89) per hour, or $25,918 (IQR=$14,328) per year. Mean aide benefits paid per FTE aide were $2.30 (IQR=$1.72) per hour, or $4,775 (IQR=$3,581) per year. Median annual wages and benefits per FTE ($11.49 per hour or $23,909 annually, and $1.82 per hour or $3,787 annually, respectively) were similar to the means, suggesting that although these variables had a wide range, the central tendency was not excessively influenced by outliers.

The 0.19 mean benefit ratio in the sample was substantially lower than the national average benefit ratio of 0.42 for civilian employees. [See Table 3.b] Close to 88% of agencies fell into either the “low” (<0.15) or “medium” (0.16-0.30) benefit ratio category (43.2% low, and 44.4% medium). Only 12.4% of agencies had a “high” (>0.30) benefit ratio.

Agency Characteristics
**Ownership Type.** As expected, the majority of agencies in the sample (80.5%) were proprietary. 13.9% of agencies were non-profit, and 6% were government agencies. One-way ANOVA showed significant differences between the three ownership types’ differences in benefit ratios, $F(2, 3102) = 563.1, p = <0.0001$. Post hoc comparisons using the Tukey HSD test indicated proprietary agencies had the lowest mean benefit ratio ($M = 0.16$, IQR=0.08), while government-owned agencies had the highest ($M = 0.41$, IQR=0.20).

**Agency Size.** The majority of agencies in the sample were large (67.3%). 22.8% of agencies were midsize, and 9.9% were small. One-way ANOVA again showed significant differences between the benefit ratios among the three ownership types, $F(2, 3309) = 47.0, p = <0.0001$. Post hoc comparisons using the Tukey HSD test indicated small agencies had the lowest mean benefit ratio ($M = 0.13$, IQR=0.07), while large agencies had the highest ($M = 0.20$, IQR=0.10).

**Chain Status.** Two thirds (66.6%) of agencies in the sample were independent agencies. T-tests showed that chain agencies’ mean benefit ratio of 0.20 was significantly higher than the 0.18 mean benefit ratio for independent agencies, $F(1, 3310) = 0.11, p = <0.0001$.

**Geographic Region.** Over half of the agencies in the sample (54.1%) were located in the South. The next largest group was located in the Midwest (22.3%), followed by the Northeast (12.0%) and West (11.3%). One-way ANOVA showed significant differences between the four regions, $F(3, 3260) = 46.8, p = <0.0001$. Post hoc comparisons using the Tukey HSD test indicated significant differences in mean benefit ratio between all regions, except between Northeastern and Western agencies. Agencies in Southern states had the lowest mean benefit ratio ($M = 0.13$, IQR=0.10), while Northeastern agencies had the highest ($M = 0.23$, IQR=0.11).
Quality Measures. The means of the five summary quality measures ranged from a low of 58.5% (IQR = 11.4) for the outcome improvement group to a high of 99.5% (IQR = 1.0) for avoidance of bedsores. The median for all groups was within 2 percentage points of the mean, suggesting that the data are relatively evenly distributed and the central tendency is not unduly influenced by outliers.

Full descriptive statistics for all variables are presented in Table 3.b.

Relationship between Aide Wages, Benefits, and Agency Characteristics. Mean aide wages did not vary significantly by ownership type, or geographic region. However, they did vary by agency size, $F(2, 3309) = 8.8, p < 0.001$, with large agencies ($M = \$13.12, IQR = \$5.67$) paying higher average wages than mid-sized ($M = \$11.54, IQR = \$8.77$) or small ($M = \$10.08, IQR = \$10.98$) agencies. They also varied by chain status, with chains paying significantly lower wages than independent agencies. However, mean aide benefits differed significantly by all four agency characteristics. Proprietary agencies, small agencies and agencies located in Southern states paid the lowest annual benefits per aide, while government-owned agencies, large agencies, chains, and agencies located in the Northeast paid the highest. [See Table 3.b]

Correlation between Covariates. All four agency characteristic variables (ownership status, agency size and geographic location) were highly correlated; ownership and agency size [$X^2 (4, n=3,105) =101.8, p<0.0001$], ownership type and geographic region [$X^2 (6, n = 3,085) =432.2, p<0.0001$], and agency size and geographic region [$X^2 (6, n = 3,264) =134.9, p<0.0001$]. However, to investigate the relationships between the characteristics, and agency characteristics as a whole, all four were retained in later models and tested for collinearity in the analysis.

Research Question 1: Agency Characteristics and Benefit Ratio
Preliminary analysis showed that all four agency characteristics were independently associated with benefit ratio, so all were included in the multivariable model. *Ownership type* was a significant predictor of *benefit ratio*. Non-profit (β 0.22 SE = 0.10, p<0.0001) and government-owned agencies (β 1.00, SE=0.07, p<0.0001) were likely to have a higher benefit ratio than proprietary agencies. Agency size was also a significant predictor of benefit ratio, with small (β -0.34, SE=0.04, p<0.0001) and medium-sized agencies (β -0.18, SE=0.03, p<0.0001) likely to have lower benefit ratios than large agencies. Finally, some, but not all geographic locations were associated with benefit ratio. Compared to Southern agencies, Northeastern (β 0.12, SE=0.03, p<0.01) and Western (β 0.09, SE=0.04, p<0.01) regions were likely to have higher benefit ratios. Overall, agency characteristics explained almost 30% of the variance in benefit ratio between agencies (Adj. R² = 0.30, F(8, 3076) = 166.5, p <0.001.)

*Impact of Aide Wages.* The next model included annual wages per FTE as a covariate. While annual wages were significant at p<0.05, the parameter estimates were almost null and the magnitude and significance of the estimates for other variables did not change, so results are not included here.

*Impact of Interactions.* Interaction terms between agency characteristics were largely insignificant, with the exception of small interactions between region and ownership status, and did not change the magnitude, direction or significance of the parameter estimates, so were not included in the final models. [See Table 3.c]

*Binary Agency Characteristic Model.* Agency size and ownership were still significantly associated with *benefit ratio* when using binary agency characteristics. Small/medium agencies were likely to have lower benefit ratios compared to large agencies (β -0.03, SE=0.03,
p<0.001). Non-profit agencies were more likely to have higher benefit ratios than proprietary agencies (β 0.20, SE = 0.05, p<0.001) In this model, however, there were not significant differences in the benefit ratio between Southern and non-Southern states. Since the binary categories reduced the adjusted $R^2$ of this model from 0.25 to 0.13, and obscured important differences between the characteristic variables, particularly between regions, this model proved less informative than the full multivariable model. [See Table 3.d]

*Sensitivity Analyses.* Trimming the top and bottom 3% of observations did not affect the magnitude, direction or significance of the results, suggesting that outliers were not distorting the parameter estimates.

**Research Question 2: Benefit Ratio and Quality Outcomes**

In all models, benefit ratio was a significant predictor of mean quality score, the improvement group, and avoided hospitalizations [See Table 3.e] Controlling for agency size and aide wages, both separately and together, affected the size of the parameter estimates, but did not change their direction or significance, nor did the interaction terms (size*wages). Variance inflation factors (VIF) for all agency characteristics were less than 1.14, suggesting any effects of collinearity were minimal. Since so few patients experienced an increase in or worsening of bedsores, I also tested this outcome separately using quantile analysis at the first, fifth, tenth and 25th quantile (Since the scale on this measure was reversed so that higher scores reflected positive outcomes, these could also be considered the 99th, 95th, 90th, and 75th quantile). While there was a significant association only at the first (99th) quantile, the estimate is likely unreliable due to the small number of events.

Full results for this analysis are shown in Tables 3.e – 3.h.
Sensitivity Analyses. Trimming the top and bottom 3% of observations did not affect the magnitude, direction or significance of the results, suggesting that outliers were not distorting the parameter estimates.

**Research Question 3: Agency Characteristics and Quality Outcomes**

**Model 1: Association of Ownership Type with Quality Outcomes.** Non-profit agencies had higher quality scores than proprietary agencies, with the exception of bedsore prevention. The strongest association was seen in prevented hospitalizations (β=4.28 SE=0.47, p=<0.001). However, government agency ownership was weakly associated with lower quality scores in the outcome improvement group scores (β=-1.80 SE=0.84, p=<0.05). [See Table 3.i]

**Model 2: Association of Ownership Type and Agency Size with Quality Outcomes.** When including agency size, the association between non-profit ownership and higher process measures was no longer significant, nor was the association between government ownership and the outcome improvement group. But, agency size was significantly associated with almost every quality measure at p<0.05 or less, with small and medium agencies likely to have lower quality outcomes than large agencies. For instance, small agency size was associated with lower mean quality outcomes (β= -2.55 SE=0.37, p=<0.001), process of care measures (β= -2.96 SE=0.45, p=<0.001), outcome improvement measures (β= -11.26 SE=0.79, p=<0.001), and prevented hospitalizations (β= -5.43 SE=0.56, p=<0.001) compared to large agencies. [See Table 3.j]

**Model 3: Association of Ownership Type, Agency Size and Chain Status with Quality Outcomes.** Chain status was significantly, positively associated with higher mean quality scores (β= 0.83 SE=0.23, p=<0.01), the outcome improvement group (β= 2.74 SE=0.40, p=<0.001), and prevented hospital admissions (β=1.44 SE=0.35, p=<0.001). When including chain status,
government ownership was again associated with prevented hospital admissions. Ownership type was also no longer associated with any quality measures except prevented hospital admissions, where nonprofit agencies were likely to have fewer admissions compared to proprietary agencies ($\beta=2.8$ SE=$0.48$, $p<0.001$). [See Table 3.k]

_Model 4: Effect of Ownership Type, Agency Size, Chain Status and Geographic Region on Quality Outcomes._ Compared to Southern agencies, all other regions had fewer hospital admissions. Agency size remained consistently associated with all measures, except for avoidance of bedsores. [See Table 3.l]

_Model 5: Effect of Ownership Type, Agency Size and Geographic Region on Quality Outcome, with Benefit Ratio as Covariate._ Benefit ratio was only significantly associated with one quality measure, the outcome improvement group, with higher benefit ratios predicting higher outcome improvement scores ($\beta=4.59$, SE=$1.77$, $p<0.05$). Including benefit ratio in the model did not change the significance or direction the agency size variables; however, the Northeastern region was no longer significantly associated with higher process or outcome measures. [See Table 3.m]

Variance inflation factors (VIF) for the agency characteristics in all models were less than 1.3, suggesting that any effects of collinearity were minimal.

Full results for this analysis are shown in Tables 3.i – 3.m.

*Sensitivity Analyses.* Trimming the top and bottom 3% of observations did not affect the magnitude, direction or significance of the results, suggesting that outliers are not distorting the parameter estimates. Since the bedsore variable was so skewed, I also tested this outcome separately using quantile analysis at the first, fifth, tenth and 25th quantile. There was a
significant association only with agency size at the first quantile (or 99th quantile, as noted above), but again, this estimate is likely unreliable due to the small number of events.

**Discussion**

This analysis is the first to tie together home care workers’ compensation with the quality of the care that home care agencies provide. Overall, there was wide variation in the level of benefits that agencies provided to their workers, which appeared to be largely driven by agencies’ ownership status, size and geographic location. It also appeared that these characteristics, and not the level of benefits that aides receive, affect patients’ quality outcomes. However, limitations in the available data make it difficult to fully assess the complex relationship between job quality and care quality.

*Research Question 1: Do characteristics of MCHHAs (ownership status, agency size and geographic region) predict the level of benefits that aides receive?*

Ownership type, agency size, chain status and some geographic regions were significant predictors of benefit ratio. As expected, proprietary agencies provided fewer benefits than non-profits and government agencies. Similarly, the smaller the agency, the fewer benefits provided to aides, and independent agencies provided fewer benefits than chains (although chains paid lower wages). And, agencies in the Northeast paid higher benefits than those in the South.

While wages were similar across agencies, there was significant variation in the benefits paid. But even taking this variation into account, the overall amount of benefits paid to aides remained quite low, with almost 96% of home health agencies paying benefits below the national mean benefit ratio of 0.42 for civilian workers. This supports the published literature showing that home care workers often receive few if any benefits from their employers. The fact that
proprietary agencies consistently paid fewer benefits than nonprofit and government agencies also suggests that advocates may be correct in asserting these agencies are deliberately keeping benefit costs low in order to maximize profits. This is particularly important in light of two recent policy changes that advocates hoped would expand workers’ access to employer-provided benefits: first, the elimination of the “companionship” exemption to the FLSA, meaning that home care agencies must now meet minimum wage and overtime pay rules for aides, and second, the extension of the ACA’s employer mandate to smaller organizations, requiring employers with more than 50 FTE workers to offer health coverage to full-time employees.  

But, if home health agencies continue employing strategies such as limiting schedules to part-time hours or misclassifying workers as independent contractors, aides may not see the benefits of these new protections. In addition, shifts toward so called “value-based” payment strategies in Medicare and Medicaid reimbursement may incentivize agencies of all types to limit workers’ hours and benefits to manage costs.

*Research Question 2: Are agencies’ benefit ratios associated with better quality outcomes for patients?*

As expected, benefit ratio was significantly associated with improvements in outcomes and prevented hospitalizations, the quality measures which most closely reflect the care that aides provide. However, agency size may be confounding this association, affecting the level of benefits that agencies provide, and independently affecting measured quality. Avoidance of bedsores was not significant in the multivariable models, and even when using quantile regression, was only significantly associated with benefit ratio at the first quantile. However, because the number of patients who experienced new bedsores or whose bedsores worsened was so small, these estimates may not be reliable.
Research Question 3: Are MCHHAs’ characteristics associated with quality outcomes, and if so, does benefit level explain this association?

When including agency characteristics in this analysis, the association between benefit ratio and quality outcomes all but disappeared, suggesting that ownership, chain status, size, and to some extent, geographic region, were the driving factors.

Of the four agency characteristics, agency size and chain status were most strongly and consistently associated with quality outcomes. As agencies increase in size and capacity, so do their quality scores. This suggests a few possibilities; first, small agencies may not have the resources to provide training and support to aides that may improve quality of care, and second, small, independent agencies may not have the resources to focus on completing the lengthy and time-consuming OASIS instrument and leveraging agency-reported measures to their advantage.

As value-based purchasing for home care services becomes more widespread (20 states, including New York, have already transitioned their Medicaid home care recipients to managed care plans\(^86\)), the agencies with the resources to do so will have even more incentive to inflate their OASIS quality measures, which may increase the perceived quality gap between large and small providers. Since smaller agencies may already be at a disadvantage, efforts to improve quality indicators and metrics to better reflect the desired goals of home care should carefully consider agency and staff capacity.

Limitations

There were several limitations to this study. First, Medicare’s cost reports include only aggregate data, which did not allow me to look at the wages and benefits of individual workers. Since the cost reports include only W2 employees, the data also do not capture employees who have
potentially been misclassified as independent contractors. Agencies that provide only Medicaid or private-pay services, as well as small MCHHAs, are not represented in the data, nor are clients who are only receiving personal care services without therapy visits – a growing share of home health patients. Finally, many of the OASIS quality indicators are “soft” measures (for instance, “patient got better at walking”) that agencies could potentially inflate to improve their quality scores. However, as the only available national data sets that could potentially link job characteristics to quality of care, these data still provide important insight into these issues and critical research gaps.

Ultimately, this analysis was not able to satisfactorily answer the question of whether job characteristics like higher wages and benefits lead to higher quality care. This highlights two major issues. First, the fractured reimbursement system for home care services means that the available data on both workers and clients is both limited and siloed. Even when using the most comprehensive publicly available data on aide compensation, Medicare’s cost reports, I was only able to investigate aggregate data on workers at the agency level. The fact that all models in this analysis had very low coefficients of determination (the highest in any model was an adjusted R² of 0.13) suggests that there were many unmeasured variables that may have helped to explain these connections and pathways more fully. Data at the level of the individual worker, or data that capture information about both caregivers and care recipients, could help address these questions.

Second, the quality measures captured in OASIS, the most widely used and standard home care quality instrument, poorly reflect the services that aides are actually performing. Instead of prioritizing clinical domains like efficiency, safety and timeliness, home care quality measures might be made more valid and informative if they captured non-clinical factors like quality of
life, community or social engagement, or self-advocacy.\textsuperscript{65} This shift is already occurring in the nursing home industry. Over the past two decades, nursing homes have made efforts to transition to a person-centered approach that values workers for their relational skills as well as the technical care they provide.\textsuperscript{87,88} In many institutions, caregiver-patient relationships are built into staff competencies and outcome measures.\textsuperscript{89,90} Yet similar measures have not been applied to the home care industry, even though the patient-centered approach suggests these relational measures may be central to home care quality precisely \textit{because} the care is non-clinical.

These findings make it even more critical to more clearly define quality in both home care jobs and care. The following chapters will explore these issues through the experience of home care workers themselves, to better understand the connection between home care jobs, workers and clients.
Table 3.a. Variable measurement descriptions. All variables from 2011 Medicare Home Health Compare (HHC) quality data (quality measures) and 2010 home health cost reports (all other covariates)

<table>
<thead>
<tr>
<th>Outcome (Dependent) Variables</th>
<th>Type</th>
<th>Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary Home Care Quality Measures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean Quality Score</td>
<td>Continuous</td>
<td>Agency report, mean of 22 items (scale reversed for hospital admission and bedsores)</td>
</tr>
<tr>
<td>Processes of Care (e.g., patient screened for depression or pain)</td>
<td>Continuous</td>
<td>Agency report, mean of 13 process of care measures</td>
</tr>
<tr>
<td>Improvements in Patient Outcomes (e.g., patient got better at walking)</td>
<td>Continuous</td>
<td>Agency report, mean of 7 outcome of care measures</td>
</tr>
<tr>
<td>Avoidance of Hospitalization</td>
<td>Continuous</td>
<td>Medicare claims data, percentage of patients free of hospital admissions (scale reversed)</td>
</tr>
<tr>
<td>Avoidance of Bedsores</td>
<td>Continuous</td>
<td>Agency report, percentage of patients with an increase in bedsores (scale reversed)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Covariates</th>
<th>Type</th>
<th>Measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aide Compensation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefit Ratio (per agency)</td>
<td>Continuous</td>
<td>Total Aide Benefits paid per agency/Total Aide Wages paid per agency</td>
</tr>
<tr>
<td>Aide Wages (per FTE)</td>
<td>Continuous</td>
<td>Total Aide Wages paid per agency/FTE per agency</td>
</tr>
<tr>
<td>Aide Benefits (per FTE)</td>
<td>Continuous</td>
<td>Total Aide Benefits paid per agency/FTE per agency</td>
</tr>
<tr>
<td>Agency Characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ownership Type</td>
<td>Categorical</td>
<td>Proprietary, Nonprofit, Government</td>
</tr>
<tr>
<td>Agency Size</td>
<td>Categorical</td>
<td>CDC classification (Small: &lt;=100 patients, Mid-size: 101-300 patients, Large: &gt;300 patients)</td>
</tr>
<tr>
<td>Geographic Region</td>
<td>Categorical</td>
<td>Census region (Northeast, Midwest, South, West)</td>
</tr>
<tr>
<td>Chain Status</td>
<td>Categorical</td>
<td>Chain, Independent</td>
</tr>
</tbody>
</table>
Table 3.b: Descriptive Statistics of Aide Compensation, Agency Characteristic, and Quality Outcome Variables
Includes agencies reporting both aide wages and benefits, and employing 1+ FTE aides (n = 3312)

<table>
<thead>
<tr>
<th>Wages, Benefits and Benefit Ratio</th>
<th>Mean</th>
<th>Median</th>
<th>IQR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hourly wages per worker</td>
<td>$12.46</td>
<td>$11.49</td>
<td>$6.89</td>
</tr>
<tr>
<td>Hourly benefits per worker</td>
<td>$2.30</td>
<td>$1.82</td>
<td>$1.72</td>
</tr>
<tr>
<td>Annual earnings per worker</td>
<td>$25,918</td>
<td>$23,909</td>
<td>$14,328</td>
</tr>
<tr>
<td>Annual benefits per worker</td>
<td>$4,775</td>
<td>$3,787</td>
<td>$3,581</td>
</tr>
<tr>
<td>Benefit Ratio</td>
<td>0.19</td>
<td>0.16</td>
<td>0.13</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Agency Characteristics</th>
<th>n (%)</th>
<th>Mean Hourly Wage Per Worker (IQR)</th>
<th>Mean Hourly Benefits Per Worker (IQR)</th>
<th>Mean Benefit Ratio (IQR)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ownership Type</td>
<td>3105  (100)</td>
<td>12.73 (7.15)</td>
<td>1.96 (1.40)</td>
<td>0.16 (0.08)*</td>
</tr>
<tr>
<td>Proprietary</td>
<td>2489  (80.5)</td>
<td>11.79 (6.20)</td>
<td>2.90 (2.52)</td>
<td>0.25 (0.13)*</td>
</tr>
<tr>
<td>Private non-profit</td>
<td>430   (13.9)</td>
<td>11.59 (6.51)</td>
<td>4.70 (4.37)</td>
<td>0.41 (0.20)*</td>
</tr>
<tr>
<td>Government</td>
<td>186   (6)</td>
<td>11.47 (6.89)</td>
<td>0.19 (0.16)</td>
<td>0.13 (0.13)*</td>
</tr>
</tbody>
</table>

| Agency Size             | 3312  (100) | 10.08 (10.98) | 1.28 (1.43) | 0.13 (0.07)* |
| Small (1-100 patients)  | 328    (9.9) | 11.54 (8.77)  | 1.90 (1.58) | 0.18 (0.12)* |
| Mid-sized (101-300 patients) | 754 (22.8)  | 13.12 (5.67)  | 2.58 (1.69) | 0.20 (0.10)* |
| Large (>300 patients)   | 2230   (67.3) | 12.60 (6.73) | 0.17 (0.10)* |

| Geographic Region       | 3264  (100) | 12.33 (6.76) | 1.99 (1.45) | 0.17 (0.10)* |
| South                  | 1776   (54.1) | 12.42 (6.34) | 3.09 (2.33) | 0.23 (0.11)* |
| Northeast              | 391    (12.0) | 12.19 (6.85) | 2.39 (1.88) | 0.21 (0.13)* |
| Midwest                | 728    (22.3) | 14.18 (7.17) | 2.79 (2.06) | 0.21 (0.11)* |
| West                   | 369    (11.3) | 11.98 (4.27) | 2.41 (1.46) | 0.20 (0.08)* |

| Chain Status            | 3312  (100) | 12.80 (7.97) | 2.24 (1.84) | 0.18 (0.11)* |
| Independent agency      | 2207   (66.6) | 11.78 (4.75) | 2.41 (1.46) | 0.20 (0.08)* |
| Chain                  | 1105   (33.4) | 11.78 (4.27) | 2.41 (1.46) | 0.20 (0.08)* |

| Benefit Ratio (Total Benefits/Total Wages) | 3312  (100) | 12.80 (7.97) | 2.24 (1.84) | 0.18 (0.11)* |
| Low (<0.15)            | 1432   (43.2) | 12.24 (6.34) | 3.09 (2.33) | 0.23 (0.11)* |
| Medium (0.16 - 0.30)   | 1469   (44.4) | 12.19 (6.85) | 2.39 (1.88) | 0.21 (0.13)* |
| High (>0.30)           | 411    (12.4) | 14.18 (7.17) | 2.79 (2.06) | 0.21 (0.11)* |

* = significant at p<0.05; no significant difference between West and Midwest/Northeast benefit ratio, and small and medium sized agencies' wages per worker

- Based on total aide benefits/wages per agency
- n = agencies reporting
- Percentages may not total 100 due to rounding

<table>
<thead>
<tr>
<th>Quality Measures</th>
<th>n</th>
<th>Median</th>
<th>Mean</th>
<th>IQR</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean quality score (summary of all measures)</td>
<td>3217</td>
<td>78.9</td>
<td>78.0</td>
<td>6.7</td>
<td>34.1 - 95.7</td>
</tr>
<tr>
<td>Process of Care</td>
<td>3208</td>
<td>88.5</td>
<td>87.0</td>
<td>7.8</td>
<td>29.5 - 99.1</td>
</tr>
<tr>
<td>Outcome of Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improvement</td>
<td>3064</td>
<td>60.6</td>
<td>58.5</td>
<td>11.4</td>
<td>0 - 96.6</td>
</tr>
<tr>
<td>Healthcare Utilization</td>
<td>3217</td>
<td>72.0</td>
<td>70.1</td>
<td>11.0</td>
<td>26 - 100</td>
</tr>
<tr>
<td>(patient free of hospital admission)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potentially Avoidable Event</td>
<td>3074</td>
<td>100.0</td>
<td>99.5</td>
<td>1.0</td>
<td>90 - 100</td>
</tr>
<tr>
<td>(no increase in bedsores)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

n = agencies reporting
- Mean of twenty-two individual quality indicators.
- Mean of thirteen individual process indicators, such as timely initiation of care.
- Mean of seven individual functional-outcome-of-care indicators, such as ADLs.
### Table 3.c: Predictors of Benefit Ratio (log) (Adj. $R^2 = 0.27$)

*Parameter estimates, standard errors and p-values from multivariable linear models*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parameter Estimate</th>
<th>SE</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ownership Type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proprietary</td>
<td>ref</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private non-profit</td>
<td>0.22</td>
<td>0.10</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Government</td>
<td>1.00</td>
<td>0.07</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td><strong>Agency Size</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Large</td>
<td>ref</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small</td>
<td>-0.34</td>
<td>0.04</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Medium</td>
<td>-0.18</td>
<td>0.03</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td><strong>Geographic Region</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>South</td>
<td>ref</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>0.12</td>
<td>0.04</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Midwest</td>
<td>0.01</td>
<td>0.03</td>
<td>0.73</td>
</tr>
<tr>
<td>West</td>
<td>0.09</td>
<td>0.04</td>
<td>&lt;.01</td>
</tr>
<tr>
<td><strong>Chain</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent agency</td>
<td>ref</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chain</td>
<td>0.20</td>
<td>0.02</td>
<td>0.001</td>
</tr>
</tbody>
</table>

*Bold = significant at p<.001*

### Table 3.d: Predictors of Benefit Ratio (log) Using Binary Agency Characteristic Variables (Adj. $R^2 = 0.15$)

*Parameter estimates, standard errors and p-values from multivariable linear models*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Parameter Estimate</th>
<th>SE</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small/Medium Agency (v. Large)</td>
<td>-0.03</td>
<td>0.03</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Private non-Profit (v. Proprietary)</td>
<td>0.20</td>
<td>0.05</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Non-Southern State (v. Southern State)</td>
<td>0.01</td>
<td>0.02</td>
<td>0.538</td>
</tr>
</tbody>
</table>
Table 3.e. Benefit Ratio (log) as a Predictor of Quality Outcomes
Parameter estimates, standard errors and p-values from general linear models

<table>
<thead>
<tr>
<th>Quality Indicators</th>
<th>Parameter Estimate</th>
<th>SE</th>
<th>p</th>
<th>Adj. R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean quality score (summary of all measures)</td>
<td>0.88</td>
<td>0.18</td>
<td>&lt;.0001</td>
<td>0.01</td>
</tr>
<tr>
<td>Process of Care</td>
<td>0.47</td>
<td>0.21</td>
<td>0.027</td>
<td>0.00</td>
</tr>
<tr>
<td>Outcome of Care - Improvement</td>
<td>2.69</td>
<td>1.49</td>
<td>&lt;.0001</td>
<td>0.02</td>
</tr>
<tr>
<td>Outcome of Care - Health Care Utilization (patient free of hospital admission)</td>
<td>1.84</td>
<td>0.27</td>
<td>&lt;.0001</td>
<td>0.01</td>
</tr>
<tr>
<td>Outcome of Care - Potentially Avoidable Event (no increase in bed sores)</td>
<td>0.00</td>
<td>0.02</td>
<td>0.866</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**bold** = significant at p<.05

---

Table 3.f. Benefit Ratio (log) as a Predictor of Quality Outcomes, Including Agency Size as Covariate

<table>
<thead>
<tr>
<th>Quality Indicators</th>
<th>Parameter Estimate</th>
<th>SE</th>
<th>p</th>
<th>Adj. R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean quality score (summary of all measures)</td>
<td>0.46</td>
<td>0.18</td>
<td>0.009</td>
<td>0.04</td>
</tr>
<tr>
<td>Process of Care</td>
<td>0.11</td>
<td>0.22</td>
<td>0.5913</td>
<td>0.02</td>
</tr>
<tr>
<td>Outcome of Care - Improvement</td>
<td>1.49</td>
<td>0.31</td>
<td>&lt;.0001</td>
<td>0.13</td>
</tr>
<tr>
<td>Outcome of Care - Health Care Utilization (patient free of hospital admission)</td>
<td>1.84</td>
<td>0.27</td>
<td>&lt;.0001</td>
<td>0.07</td>
</tr>
<tr>
<td>Outcome of Care - Potentially Avoidable Event (no increase in bed sores)</td>
<td>-0.01</td>
<td>0.02</td>
<td>0.9297</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**bold** = significant at p<.05

---

Table 3.g. Benefit Ratio (log) as a Predictor of Quality Outcomes, Including Wages (log) as Covariate

<table>
<thead>
<tr>
<th>Quality Indicators</th>
<th>Parameter Estimate</th>
<th>SE</th>
<th>p</th>
<th>Adj. R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean quality score (summary of all measures)</td>
<td>0.92</td>
<td>0.18</td>
<td>&lt;0.0001</td>
<td>0.01</td>
</tr>
<tr>
<td>Process of Care</td>
<td>0.51</td>
<td>0.21</td>
<td>0.02</td>
<td>0.00</td>
</tr>
<tr>
<td>Outcome of Care - Improvement</td>
<td>2.71</td>
<td>0.15</td>
<td>0.474</td>
<td>0.02</td>
</tr>
<tr>
<td>Outcome of Care - Health Care Utilization (patient free of hospital admission)</td>
<td>2.00</td>
<td>0.27</td>
<td>&lt;0.0001</td>
<td>0.03</td>
</tr>
<tr>
<td>Outcome of Care - Potentially Avoidable Event (no increase in bed sores)</td>
<td>0.01</td>
<td>0.02</td>
<td>0.827</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**bold** = significant at p<.05

---

Table 3.h. Benefit Ratio (log) as a Predictor of Quality Outcomes, Including Wages (log) and Agency Size as Covariates

<table>
<thead>
<tr>
<th>Quality Indicators</th>
<th>Parameter Estimate</th>
<th>SE</th>
<th>p</th>
<th>Adj. R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean quality score (summary of all measures)</td>
<td>0.48</td>
<td>0.08</td>
<td>0.007</td>
<td>0.05</td>
</tr>
<tr>
<td>Process of Care</td>
<td>0.13</td>
<td>0.22</td>
<td>0.555</td>
<td>0.02</td>
</tr>
<tr>
<td>Outcome of Care - Improvement</td>
<td>1.53</td>
<td>0.31</td>
<td>&lt;0.0001</td>
<td>0.14</td>
</tr>
<tr>
<td>Outcome of Care - Health Care Utilization (patient free of hospital admission)</td>
<td>1.08</td>
<td>0.27</td>
<td>&lt;0.0001</td>
<td>0.10</td>
</tr>
<tr>
<td>Outcome of Care - Potentially Avoidable Event (no increase in bed sores)</td>
<td>-0.01</td>
<td>0.02</td>
<td>0.655</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**bold** = significant at p<.05
### Table 3.i. Bivariate Association of Ownership Type with Quality Outcomes (excluding Benefit Ratio and controlling for Aide Wages)
Parameter Estimates, Standard Errors and p-values for general linear models

<table>
<thead>
<tr>
<th>Agency Characteristic</th>
<th>Mean Quality</th>
<th>Process of Care</th>
<th>Outcome Improvement</th>
<th>Free of Hospital Admission</th>
<th>No increase in bedsores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address R²</td>
<td>Adj. R² = 0.00</td>
<td>Adj. R² = 0.00</td>
<td>Adj. R² = 0.01</td>
<td>Adj. R² = 0.03</td>
<td>Adj. R² = 0.00</td>
</tr>
<tr>
<td>Ownership Type</td>
<td>Parameter estimate (SE)</td>
<td>Parameter estimate (SE)</td>
<td>Parameter estimate (SE)</td>
<td>Parameter estimate (SE)</td>
<td>Parameter estimate (SE)</td>
</tr>
<tr>
<td>Proprietary</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Private non-profit</td>
<td>1.2 (0.31) **</td>
<td>0.74 (0.37) *</td>
<td>2.63 (0.56) **</td>
<td>4.28 (0.47) **</td>
<td>0.01 (0.04)</td>
</tr>
<tr>
<td>Government</td>
<td>-0.61 (0.44)</td>
<td>-0.01 (0.53)</td>
<td>-1.80 (0.84) *</td>
<td>0.56 (0.69)</td>
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</tbody>
</table>

* = p < 0.05, ** = p < 0.001

### Table 3.j. Multivariable Association of Ownership Type and Agency Size with Quality Outcomes (excluding Benefit Ratio and controlling for Aide Wages)
Parameter Estimates, Standard Errors and p-values for general linear models

<table>
<thead>
<tr>
<th>Agency Characteristic</th>
<th>Mean Quality</th>
<th>Process of Care</th>
<th>Outcome Improvement</th>
<th>Free of Hospital Admission</th>
<th>No increase in bedsores</th>
</tr>
</thead>
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<td>Adj. R² = 0.01</td>
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<td>Adj. R² = 0.08</td>
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<td>Parameter estimate (SE)</td>
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<td>Parameter estimate (SE)</td>
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<td>ref</td>
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<td>3.43 (0.46) **</td>
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</tr>
<tr>
<td>Government</td>
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<td>1.24 (0.67)</td>
<td>0.09 (0.06)</td>
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<tr>
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<td>Parameter estimate (SE)</td>
<td>Parameter estimate (SE)</td>
<td>Parameter estimate (SE)</td>
<td>Parameter estimate (SE)</td>
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<td>-0.13 (0.08) **</td>
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</tbody>
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* = p < 0.05, ** = p < 0.001
<table>
<thead>
<tr>
<th>Agency Characteristic</th>
<th>Mean Quality</th>
<th>Process of Care</th>
<th>Outcome Improvement</th>
<th>Free of Hospital Admission</th>
<th>No increase in bedsores</th>
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</thead>
<tbody>
<tr>
<td></td>
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<td>Adj. $R^2 = 0.01$</td>
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### Ownership Type
- **Proprietary**
  - Ref
- **Private non-profit**
  - 0.70 (0.30) *
  - 0.46 (0.37) *
  - 1.29 (0.52) *
  - 3.41 (0.46) **
  - -0.01 (0.04)
- **Government**
  - 0.01 (0.45)
  - 0.12 (0.54)
  - 0.13 (0.79)
  - 1.63 (0.68) *
  - 0.07 (0.06)

### Agency Size
- **Large**
  - Ref
- **Small**
  - -2.24 (0.38) **
  - -2.94 (0.46) **
  - -10.32 (0.79) **
  - -4.91 (0.58) **
  - -0.09 (0.06)
- **Medium**
  - -2.04 (0.36) **
  - -0.80 (0.33) *
  - -6.13 (0.46) **
  - -3.68 (0.39) **
  - -0.15 (0.04) **

### Chain
- **Independent**
  - Ref
- **Chain**
  - 0.83 (0.23) *
  - 0.06 (0.28)
  - 2.74 (0.40) **
  - 1.44 (0.35) **
  - -0.06 (0.03)

* = p < 0.05, ** = p < 0.01
Table 3.1. Multivariable Association of All Agency Characteristics with Quality Outcomes (excluding Benefit Ratio and controlling for Wages)

Parameter Estimates, Standard Errors and p-values for general linear models

<table>
<thead>
<tr>
<th>Ownership Type</th>
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<th>Process of Care Adj. R² = 0.02</th>
<th>Outcome - Improvement Adj. R² = 0.15</th>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
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<td>-4.15 (0.57) **</td>
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<td>-0.14 (0.04) **</td>
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<tr>
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<td>5.80 (0.51) **</td>
<td>-0.03 (0.05)</td>
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</tbody>
</table>

* = p < 0.05, ** = p < 0.001
Table 3.m. Multivariable Association of All Agency Characteristics with Quality Outcomes (including Benefit Ratio and controlling for Wages)

Parameter Estimates, Standard Errors and p-values for general linear models

<table>
<thead>
<tr>
<th>Agency Characteristic</th>
<th>Outcome (Improvement)</th>
<th>Free of Hospital Admission</th>
<th>No increase in bedsores</th>
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<td>Adj. $R^2 = 0.12$</td>
<td>Adj. $R^2 = 0.01$</td>
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<td><strong>Ownership Type</strong></td>
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<td>Parameter estimate (SE)</td>
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</tr>
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<td>0.08 (0.57)</td>
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<td>Government</td>
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<td><strong>Agency Size</strong></td>
<td>Parameter estimate (SE)</td>
<td>Parameter estimate (SE)</td>
<td>Parameter estimate (SE)</td>
</tr>
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<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Small</td>
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<td>0.18 (0.29)</td>
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<td>0.05 (0.03)</td>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Northeast</td>
<td>1.30 (0.37) *</td>
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</tr>
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<tr>
<td>West</td>
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<td>3.14 (0.59) **</td>
<td>3.81 (0.51) **</td>
</tr>
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<td>1.22 (0.38) *</td>
<td>-0.15 (0.32)</td>
</tr>
</tbody>
</table>

* = p < 0.05, ** = p < 0.01
Section III:

Qualitative Methods and Findings:

Aides’ Perceptions of Home Care Quality and Worker Well-Being
Chapter 4: Qualitative Methods

While the previous section examined the connection between structural job characteristics and quality care, this section explores the psychosocial effects of providing relational care on both care quality and aides’ own well-being. Since there is little existing data that investigates workers’ own perceptions of quality care and the effect on their well-being, these concepts are explored through focus groups with aides themselves. However, since this analysis, like much qualitative work, draws on existing ideas to interrogate these ideas, I begin this section by presenting some of the theories that inform this analysis.

Theoretical Orientation

In an effort to cut costs in the face of a growing long-term care (LTC) population, the past few decades have seen states “rebalancing” their LTC systems by shifting spending away from costly institutional care toward HCBS.11 These programs are not only attractive to states and families struggling with the cost of care but also to patients, many of whom express a strong desire to continue living independently in their own homes.11 Agency and policy descriptions of these services often focus on the physical care provided by HCBS that allows elderly, frail and disabled individuals to live independently, such as bathing, preparing meals and safely transferring the client.11 But the ability to live independently is about more than just physical comfort and safety. As with any caring work, quality home care services require relational care—the work that helps aides to meet their patients’ emotional, cognitive and mental needs.

Relational Work and Quality of Care
As the demand and cost for home health care skyrockets, home care agencies, healthcare payers, families and policymakers have turned their focus to ensuring the quality of services. But efforts to define and measure quality are undermined by a lack of consensus around the nature and goals of home care. As discussed in the previous section, MCHHAs often define quality care as their ability to deliver certain processes of care, such as timely initiation of services and pain screenings, and achieve specific outcomes of care, such as whether patients improved in performing ADLs. This is understandable, since these are the factors that determine the agencies’ reimbursements and public quality ratings. But, since an increasing share of home care services are now being delivered to long-term clients rather than those recovering from short-term illnesses or surgeries, many of these task-based, clinical measures of care may not be appropriate to the current and future home care population.

Those closest to the care – home care workers and their patients – often have a broader view of what good quality home care looks like. To workers and patients, it is impossible to provide good care without caring, and both consistently report that companionship and emotional support are an important part of the care they provide or receive. But because relational care is not included in agency brochures or reimbursed by healthcare payers, these services are largely invisible and unrecognized outside the aide-patient relationship. However, scholars such as Maria Ibarra argue that relational care is not only integral to quality care, but also as “difficult and skilled” as the task-based care for which agencies are reimbursed, and it “does not come naturally, and requires forethought, physical dexterity and a broad range of emotional labors.” Sociologist Clare Stacey terms this skill “high emotional aptitude,” while studies of nursing refer to it as “emotional intelligence”; either way, these terms refer to aides’
ability to be attuned to patients’ emotions, and understand how to express emotions appropriately depending on the setting.

While the home care industry has yet to recognize the importance of aides’ relational care, many sectors of the long-term care industry are now making efforts to acknowledge the centrality of the caregiver-patient relationship to quality care, and build these relationships into staff competencies and outcome measures. As noted in the previous chapter, nursing homes have recently made efforts to incorporate person-centered care that acknowledges workers’ relational skills as well as the technical care they provide. These relationships are central to both nursing home workers and residents; residents report that social and informal interactions are as important as the clinical care they receive (although these domains have proven difficult to quantify or connect to health outcomes). Yet similar measures have not been applied to the home care industry, even though the patient-centered approach suggests relational skills may be central to home care quality precisely because the care is non-clinical. Aides spend considerably more time than doctors, nurses or physical therapists with their clients, helping them to dress, bathe and eat – deeply personal interactions that depend on building trust. In addition, strong aide-patient relationships could lead to improvements in patients’ quality of life (including security, comfort, individuality and enjoyment). A draft set of competencies from the Centers for Medicare and Medicaid Services (CMS) for direct service workers (primarily aimed at those working in developmental disability) suggests that in addition to clinical domains, workers should support clients in community engagement, empowerment and self-advocacy. In Canada and several European countries, researchers and practitioners have used a home care assessment strategy developed by an international consortium (interRAI), which includes social indicators,
such as feelings of loneliness and isolation, as well as clinical quality indicators. To date, these measures are almost entirely absent from US home care competencies and quality measures.

**Emotional Labor and Workers’ Well-Being**

In *The Managed Heart*, Arlie Hochschild described the tensions service professionals face when required to “perform emotion” as part of their job while concealing their true feelings and identities. While this performance benefits employers’ bottom lines by making customers feel valued and cared for, it creates tension for workers, who can become alienated from their own emotions and bodies, leading to burnout. Unlike institutional workers, who are part of a formal and visible care team, home care workers work alone with patients, in private homes, with little supervision or support from a physician, nurse or therapist. These workers provide 70-80% of patient care, and as a result, shoulder the bulk of the emotional labor their patients require. Unsurprisingly, home care workers consistently report prioritizing their patients’ needs and happiness above their own, and experiencing a high level of on-the-job stress due to the emotional labor of caring for ill, dying, aggressive or disoriented clients, and working erratic and often uncompensated hours. However, it is also important to understand that the care relationship is by nature dyadic, and home care workers may receive benefits from these relationships as well, although the positives of these emotional connections are understudied across the field of care. As Lyons and Zarit argue in a study of family caregiver health, studies too often tend to focus on burden and burnout, without considering what caregivers receive back from the relationship. This is likely true in home care as well, where workers often report their relationships with their clients are the most rewarding part of their job.

Some researchers have attempted to explore where emotional labor fits within standard measures of the psychosocial work environment. But these frameworks, which were developed for
institutional workers in standard employment, may not adequately reflect home care workers’ experience. Because of the intimate nature of home care – a service provided in a private home to a client who effectively serves as both patient and supervisor – accepted measures based on the experience of institutional workers in more standard employment may not be relevant. For instance, the Job Demand-Control-Support (JDCS) model, which is frequently used as a psychosocial job satisfaction measure, posits that workers experience stress from jobs with high demands but low control and support in the workplace, while additional support, either from employers through supervision and training opportunities or from co-workers, may “buffer” these effects (some scholars have argued that the JDCS model should be extended to include emotional labor as an additional job “demand”). But, while helpful as a starting framework, the model does not take into account the unique relational dimensions of home care work. One study examining the relevance of the JDCS model to home care found that the personal, intimate nature of the job affected workers’ perceptions of these domains. For instance, workers perceived two types of “control” over their tasks – individual control, and the “joint” control they shared with their client in negotiating tasks. Similarly, the client, and not an outside supervisor or coworker, served as the most important source of “support” workers received on the job. In addition, employees’ sense of self in care work in general is often tied to the value and quality of their relationship to their patient, suggesting that these relationships may strongly influence the emotional reward and meaning that home care workers gain from their jobs - factors which psychological research has found to be critical to job satisfaction and workers’ emotional health.

A better approach to understanding the effect of emotional labor on home care workers is to consider the broader concept of workers’ well-being. Since agencies tend to focus on the
physical tasks that aides perform rather than their relational work, job satisfaction and turnover are often used as proxies for well-being. Even in studying institutional workers, well-being is a concept that is often defined by its absence. As Hupport and So note, we tend to pathologize well-being by focusing on what is wrong (depression or anxiety) rather than what makes an individual well. Hupport and So suggest that in addition to considering the objective factors that influence workers’ physical and emotional health, like the structure of jobs, we consider the broader concept of “flourishing”, or as they succinctly describe it, “the combination of feeling good and functioning effectively.” While this definition is quite broad, it nonetheless captures the many domains, including the physical, emotional, and economic, that affect workers’ emotional health and their ability to perform their jobs.

The significant body of research on unpaid family caregivers may provide more insight into the emotional demands and rewards that affect workers’ well-being. Like family caregivers, home care workers may have difficulty balancing their work and home lives; many aides report feeling a responsibility to put their clients’ needs before their own, and working additional unpaid hours to make sure those needs are met. In addition, navigating the thin line between paid caregiver and “friend” or “family”, as some workers and clients describe each other, may present a significant emotional and psychological challenge. However, while family caregivers have access to resources such as training, counseling and support to help them manage fatigue, stress and depression, paid caregivers must often work through these emotional challenges on their own. Taken as a whole, evidence suggests that the intimate and relational nature of home care directly influences workers’ understanding of their jobs, ability to build and maintain caring relationships with their client and provide quality care, as well as their own health and well-
being. This analysis explores aides’ perceptions of their emotional labor through three guiding questions:

4) How do home care workers define good care, and how does this differ from the agency’s definition?

5) How do the psychosocial demands of home care work affect workers’ ability to provide what they see as good care?

6) How do the psychosocial demands of home care work affect home care workers’ own emotional health and well-being?

Methods

The data in this analysis are drawn from four focus groups with unionized New York City-area home health aides, conducted in April 2016. The research was made possible through a collaboration with the labor-management funds that provide health and education benefits to members of 1199SEIU United Healthcare Workers East, the union representing home attendants and home health aides working for Licensed Home Care Services Agencies (LHCSAs) in New York City which primarily serve a Medicaid population.

Sampling Strategy and Recruitment

To explore these concepts, and ensure sufficient and high-quality data, I initially planned to hold 3-5 focus groups of 5-11 workers each. Experts generally recommend using 3-5 groups, depending on the group composition, to reach saturation, and note that groups with fewer than five participants may limit insights and interaction between group members, while more than 12 may prevent all group members from participating fully.108-111 To explore whether the quality of
the aide-client relationship changed aides’ perception of their work experience, I also aimed to stratify the groups using length of time with the same client as a proxy for relationship strength (assuming that if there was not a strong, high-quality relationship, aides would either leave the case or clients would request a different match). Since Medicaid long-term care clients must be evaluated and recertified twice per year, my goal was to separate aides into groups who had ever worked with a client for 6 months or more, and those who had only worked with clients for fewer than 6 months.

In order to be included in the study, workers were required to have at least six months of experience as an aide and to have worked with more than one client, to ensure they knew the job well enough to understand what it entails and to have formed ideas about the work and client care. Aides also needed to be at least 18 years old. To more closely investigate the aide-client relationship, participants were also required to work for a long-term client (rather than those recovering from illness or surgery), and currently be caring for a non-family client, since there are likely additional and complex psychosocial effects associated with caring for a relative. Finally, due to the time and resource constraints associated with holding groups in multiple languages, participants needed to be proficient in English. This limited my ability to draw from the many immigrant home care workers with limited English skills in New York City, particularly the large population of Russian and Chinese workers. However, the intent of this recruitment strategy was not to develop an empirically representative sample, but to uncover meaningful contextual patterns and themes around home care work and the emotional impact of providing this care.6,112,113 While not a specific inclusion criteria, I anticipated that the focus groups would be largely or entirely composed of women since the workforce is overwhelmingly
female. (This was indeed the case; only 2 out of the 27 participants were men, which roughly reflects the gender demographics of the industry\textsuperscript{10}.) [See Figure 4.1: Study Sample]

Recruiting home care workers for focus groups presents a number of logistical challenges because aides are not a centralized or standard workforce. Aides work long and erratic hours, at all times of the day and night, in private homes across New York City. They may spend hours

**Figure 4.1 Study Sample**

![Figure 4.1 Study Sample](image_url)

**Inclusion Criteria:**
- 18+
- 6 months+ experience as an aide
- English proficiency
- Has worked with 2+ clients
- Caring for non-family client
- Providing long-term (non-acute) care

33 aides enrolled in 1199SEIU Home Care Education Fund English classes

Class I
11 students attending class

11 students eligible; all attended focus group

Group 1
6 aides
*Mixed client continuity*

Group 2
5 aides
*Mixed client continuity*

Class 2
17 students attending class

17 students eligible; 16 attended focus group*

Group 3
8 aides
<1 year with same client

Group 4
8 aides
1+ year with same client*

*1 aide absent from class

**Included 1 aide with <1 year with same client**
traveling between multiple clients and their own homes. Once hired, aides rarely visit their agencies in person, unless they need to pick up a paycheck or resolve a problem. These barriers make it difficult to bring together a group at a single, easily accessible location. With these challenges in mind, I looked for an opportunity to reach aides in a place where they were already gathered. In New York City, agency-based home care workers are represented by 1199SEIU, the nation’s largest healthcare union, which covers over 400,000 healthcare industry workers throughout New York, Massachusetts, New Jersey, Washington, D.C. and Florida. 1199SEIU represents approximately 66,000 home health aides, home attendants and housekeepers working for the city’s Licensed Home Care Services Agencies (LHCSAs). Historically, the state contracted with Certified Home Health Agencies (CHHAs) to provide services to Medicare and Medicaid patients, and the CHHAs in turn contracted services out to LHCSAs, with public monies flowing through the agencies to pay workers’ wages and contribute to three labor-management funds that provide their health, pension and education benefits (the 1199SEIU Home Care Benefit Fund, Pension Fund, and Education Fund, respectively). 115 (With the introduction of Medicaid Managed Care, the state now contracts directly with managed care organizations, who contract all long-term care services to nursing homes and home care providers.) My long-standing relationship with the Benefit and Pension Funds (BPF), where I have worked for over 10 years, provided an ideal opportunity to reach these workers. Both the Benefit and Education Funds were enthusiastic about the project, since it dovetailed well with their own missions and priorities. The Benefit Fund recently expanded efforts to support workers’ mental and emotional health and encourage them to use their mental health coverage, and the Education Fund is strongly committed to empowering the home care workers they serve and providing them with opportunities to make their voices heard.
However, even these organizations, which were strongly connected to the workforce, often had trouble reaching workers. In early planning conversations, we heard that the Funds had been unable to fill focus groups to discuss workers’ health benefits even when the participant incentive was raised far above the norm. Collaboratively, we decided the best approach would be to hold the groups during one of the Home Care Industry Education Fund’s classes. The Education Fund provides 16,000 home care workers each year with courses that help them build their English language skills, pass the Test Assessing Secondary Completion (TASC) exam required for a high school equivalency diploma, prepare for college entrance exams, attend college, take professional development courses and learn specific caregiving skills. The Fund also tailors programs around members’ schedules, offering multiple education paths and weeknight and Saturday classes at locations throughout New York City. Classes follow the academic calendar and generally meet once or twice a week for 12 weeks. The Fund’s Assistant Director of Education and Coordinator for Adult Education proposed holding the groups with two advanced English classes. Drawing from these classes ensured that several of the eligibility criteria were already met; aides need to meet a certain number of work hours over a certain period of time to be eligible for classes, agencies employing the workers only serve non-family clients; and all the students were proficient in English. In addition, the class size (11 and 22 students, respectively) allowed me to hold four optimally sized focus groups. However, this approach also resulted in a more homogeneous sample. All workers in these classes were home health aides that provide some clinical care, who may have a different perception of their job than the home attendants who are limited to ADL assistance and housekeeping. In addition, likely because of the Fund’s eligibility requirements, this group was highly experienced, and
most had been in the workforce for over three years – a significant length of time in an industry with annual turnover of 60% or even higher.⁴,⁵

Some experts caution against interviewing groups that know each other well, since this group history can prevent open discussion, or influence the conversation.¹⁰⁸,¹¹³ To avoid this, the focus group moderators made an effort to be conscious of pre-existing group dynamics, and probe implied norms and assumed group consensus.¹¹¹ However, since the discussion explored workers’ shared experience, I felt these prior relationships would ultimately benefit the discussion, drawing out similarities and differences in work experience and “triggering” memories of shared experience.¹¹¹ This proved to be the case; overall, the group participants did not appear to be inhibited. Many were relieved to hear that others had similar experiences with their clients, clients’ families, and agencies, and were eager to discuss them. Workers also commented during and after the focus groups that they were rarely able to talk with other aides about their work, and that they welcomed this opportunity to share with each other. The class instructors later told us that the students had so much to say about the topics raised in the groups that the conversations continued into the next class, and even became the basis for a writing assignment.

**Ethical Considerations**

Since this low-wage workforce often feels vulnerable and marginalized, I was committed to engaging the participants in the research process and helping them to feel comfortable, valued and respected. I used Graham’s map of research ethics as a guide to ensure that participants knew and fully understood the purpose of the research, did not feel pressure to participate or answer questions, and that results were reported accurately and with as little bias as possible.¹¹⁷ Past nursing home research suggests that care aides may be reluctant to participate in research
studies due to feelings of vulnerability, so we took several steps to establish trust and assure
participants of confidentiality before, during and after the focus groups.\textsuperscript{118,119} First, the aides both
know and trust their 1199SEIU Benefit Fund and Education Fund, and collaborating with the
Funds assured participants that the study was being conducted on their behalf, to listen to their
needs and understand how to better support them on and off the job. Second, the focus groups
were held in the students’ regular classrooms at the Funds’ offices, a neutral and familiar
location that is not connected to the aides’ employers or clients, which helped to reduce power
differentials and make participants feel safe, comfortable and in control.\textsuperscript{120,121} The instructors,
who are also trusted and well-known by the workers, remained in the classroom during the initial
introduction and screening to make sure that any of the participants’ concerns and questions were
voiced and answered. We also emphasized throughout the recruitment, screening and focus
group process that participation in the project was completely voluntary, and declining to
participate would not affect the workers’ class grades, benefits, or jobs. To allow students to
unobtrusively opt-out, we deliberately held the groups during the second half of each class, with
a week’s advance warning, so students could leave after the class break or choose not to attend
class that night if they did not want to participate. While we informed participants that complete
confidentiality cannot be assured in a focus group setting, we began each focus group by asking
the participants not to share details of the discussion outside of the group, and gaining the
participants’ verbal agreement to keep the conversation private. Finally, one month after the
focus groups, I visited each class to present my initial findings and ensure they accurately
reflected what the participants had shared, and solicit their feedback. [The summary of findings
presented to the classes is included as Appendix B]. To ensure the protection of the research
subjects, all research activities received prior approval from the Lehman College Institutional
Review Board. [All IRB-approved documents and project approvals are included in the Appendix.]

**Data Collection**

Recruitment, eligibility screening, and the focus groups took place over a period of two weeks in April 2016. During the first week, I visited each class to introduce the project, invite the students to participate, and administer a brief eligibility screening questionnaire [see Appendix C and D]. All students who attended the classes (n = 27) agreed to participate. The focus groups were then held the following week, during the second half of the class. Each class was broken into two groups in separate classrooms, and I moderated one group while an additional moderator led the second. Assistant moderators also attended each group to record observations, which were then included in the analysis and used to verify the accuracy of the transcripts and the research findings. At the beginning of each focus group, participants provided informed consent, and completed a brief written survey to collect basic demographic information, as well as data on length of employment, income and job characteristics [See Appendix E and F].

The demographic questionnaires were developed using standard demographic questions from national surveys, including the Behavioral Risk Factor Surveillance System and U.S. Census. All materials were reviewed by the dissertation committee as well as the Education Fund’s Assistant Director and the Coordinator of Adult Education to ensure that participants, most of whom had a high school education or less, would be able to understand and respond appropriately to the questions. The moderators and assistant moderators also met the week prior to the focus groups to collaboratively review and finalize the structure of the discussion guide, and clarify the key concepts and questions to ensure uniformity across the groups.
Study participants were assigned to focus groups using the data collected in the screening phase to keep the groups as homogeneous as possible. Since the participants were more experienced than initially anticipated, it was not possible to stratify all the groups by length of time with the same client. Only one aide had worked with her clients for less than six months. By increasing the cut point to one year, I was able to stratify one class by aides who had primarily worked with a client for less than a year (Group 3), and those working with a client for more than a year (Group 4). However, there was some crossover, since, at the request of the instructor, one of the less experienced aides with more limited English skills was assigned to Group 4 with a more experienced friend to help her feel more comfortable and participate fully.

Each focus group began with the moderator welcoming the participants, explaining the goals of the study and how confidentiality would be maintained throughout, and assuring participants that the research aimed only to reflect their own experience and knowledge and had no repercussion on their jobs, their Union status, or their course grade. The discussions consisted of approximately 60-90 minutes of guided inquiry around the aides’ perceptions of what constituted “good” care, challenges and facilitators to providing good care, and how the provision of care affected their emotional health, using the interaction within each group to elicit rich data about workers’ perceptions.108 [The full discussion guide is included as Appendix F.]

I anticipated that participants would primarily want to focus on structural job characteristics such as wages and benefits, since these issues are top of mind for many workers.4,5,20,62 Even during the introductory/recruitment session, workers brought up these issues several times. In order to keep the discussion focused on the psychosocial aspects of providing care, the moderators specifically instructed participants that, “things like how much money you earn and health coverage are obviously big issues. But for tonight, we want to put these issues to the side, and
focus on your day-to-day work and how it makes you feel.” To ensure that these topics did not dominate the discussion, but that aides’ concerns around these issues were addressed, the Benefit Fund provided Outreach Coordinators who were on site both nights to answer any questions around wages, health coverage or other job issues after the focus groups concluded. Regardless, wages and benefits still came up repeatedly in the discussion, which speaks to the importance of these issues to workers.

Upon completing the focus groups, each participant received $25 and a round-trip Metrocard as compensation for their time and travel, which is consistent and within the range of current norms of compensating focus group participants. Each focus group was digitally recorded as an audio file, and the files were transferred to my computer the same day and backed up to a removable hard drive. Recordings were submitted to a professional transcription service via the company’s secure server, and transcribed verbatim. All identifying information was removed and replaced with each participant’s unique, random 4-digit code before the transcripts were uploaded for analysis. Unique identifiers were also used when compiling the demographic data. In addition to the focus group audio files and transcripts, I also kept a field notebook to record specifics immediately following each group, including the date, time and location, and initial observations and reactions, for instance, sensitive issues that arose, points of agreement and disagreement within the group and participants’ body language, expressions and level of engagement. These notes were used during analysis, along with the other moderators’ and assistant moderators’ notes, to cross-check and validate the transcripts and the research findings. The digital files, including transcripts, memos and related documents, were stored on a password protected computer, while paper transcripts, field notes and back-up drives were stored in a locked file cabinet in my office.
Analytic Strategy

The analysis was conducted using Dedoose, a qualitative software package that enables the researcher to assign specific codes to text and audio and track the number and combination of codes used. All data were analyzed using a modified grounded theory approach and discourse analysis.

Grounded theory is traditionally an emic, or “bottom up” approach that uses participants’ perspectives as the starting point, where the researcher allows concepts to emerge from the data and then refines them until a core category is created. I took a more etic, or “top down” approach to the analysis by starting with existing concepts and theories. My research questions, hypotheses based on existing literature and theory served as the basis for analysis and allowed for generating new theories through the views of the study participants. I began by listening repeatedly to the audio and reading the transcript of each group, and then coding the transcripts by sorting, organizing and indexing the data. I initially sorted the data by the main constructs central to my inquiry, quality of care and workers’ emotional health, with particular attention to how the psychosocial domains of job demands, support and control related to these concepts. These broad opening categories were ultimately revised based on the patterns and themes that emerged during analysis as most salient and important to the aides. Throughout the process, I examined my emerging theories about content, returning to the data looking for evidence, incidents, and events that supported or refuted the questions to verify my understanding of the data.

Data were coded in three steps, using open, axial and selective coding. In the open coding phase, I used constant comparison to break the data into discrete “incidents” and code them to categories based on both my project focus and on participants’ own language. I then used axial
coding to make connections between categories and their broader contexts, and develop major themes and concepts. Finally, I used selective coding to refine and specify each theme and develop a codebook to apply to each focus group transcript. This process was particularly helpful in understanding workers’ relationships with their clients. I started by examining all incidents where aides described “good care”, and looking for the tasks and processes that aides identified as part of good care. As I examined incidents across the four groups, categories emerged around providing good care: communicating with patients; treating them with empathy (the “golden rule”), respecting them as individuals, and assuming family roles. As I compared similarities across these categories, these all hung together as components of a “special bond” between aide and patients which aides identified as necessary to providing good care, and fell under the broader imperative to “make [patients] happy.” (See Table 4.1 for sample categories, themes and concepts.)

**Table 4.1. Sample Categories, Themes and Concepts**

<table>
<thead>
<tr>
<th>Category</th>
<th>Theme</th>
<th>Concept</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Building “special bond” between aide and patient</td>
<td>Good Care</td>
</tr>
<tr>
<td>Empathy (the “Golden Rule”)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respect (for patient’s independence/personhood)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kinship (Love)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plan of Care</td>
<td>Physical care</td>
<td></td>
</tr>
<tr>
<td>Respect</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Value</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appreciation</td>
<td>Emotional well-being</td>
<td>Well-being</td>
</tr>
<tr>
<td>Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Safety</td>
<td>Physical well-being</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>Economic well-being</td>
<td></td>
</tr>
</tbody>
</table>

To explore the deeper meaning under the surface of the conversation, I also drew on discourse analysis. Discourse analysis posits that language both shapes and is shaped by the social context in which it occurs; in essence, discourse helps to “structure the way a thing is thought, and the
way we act on the basis of that thinking”. In other words, it is not just the language that participants use that is meaningful, but the way that they use and understand this language. During the coding process, I looked for themes and patterns of association and variation in language, examining similarities and contradictions across speech acts, and what appeared to be missing or unsaid in the data. For instance, the preferred term for care recipients in the long-term care industry is “client” rather than “patient”, which reflects efforts in so-called “consumer-directed care” to position the client as an independent customer. On the surface, participants agreed with this terminology; when one moderator specifically asked participants which term they used, the group agreed on “client”, noting that “patient is for hospital” (Aide 1962, Group 2) and “they don’t like when you call them patient” (Aide 1485, Group 2). Yet throughout all four discussions, aides consistently used the term “patient” far more than “client”, even those who had specifically expressed a preference for the latter. The fact that aides used this terminology when speaking to each other about their professional roles suggests that they perceive their clients as patients for whom they are responsible rather than as more impersonal “consumers”, and that their own identity is that of a healthcare professional, not simply a service provider. (Because of this, I use the term “patient” when describing the findings.)

Validity of the Findings

There is some debate over the meaning of validity in qualitative research; some researchers argue that qualitative researchers should attempt to adapt and apply quantitative principles to their work, while others reject the concept of validity and argue that instead, qualitative research should strive for authenticity. For this project, I was primarily concerned that the findings accurately represented the views and experience of the participants, since these are workers whose voices often go unheard. Memos and field notes were used as evidence of my own
values, attitude and agenda to cross-check the internal validity of the findings. As the analysis was constructed, I also continually reviewed the classification systems and cross-validated findings to ensure that the categories and subcategories were inclusive and reflected all the data collected, and that the resulting findings were plausible. As an extra measure of validity, the two additional moderators used the codebook to cross-check the transcripts of the groups they had facilitated, and we then met to discuss these discrepancies until we reached consensus. This discussion was then used to further clarify the codes. Finally, to ensure the credibility and trustworthiness of the findings, I visited each class one month after the focus groups to share the initial findings and solicit the aides’ feedback and impressions. Overall, the aides agreed that the findings captured what they had shared with us, particularly around issues of trust, respect and communication (or lack thereof) from their clients, client’s family members, and the agency coordinators. This input was then used to further refine the themes and concepts.

However, it is also important to note that the very structure of a group discussion may introduce bias through the manner in which participants choose to represent themselves to others in the group. Despite the guidance of the moderator, groups have a tendency to polarize around specific topics and participants may either express opinions that they think are socially desirable, or take an opposing view to be contradictory. For instance, aides in these groups may have felt an obligation to overstate their concern for their patients and dedication to their work to represent themselves as ethical, conscientious professionals in front of their classmates. However, while I remained aware of these issues throughout the analysis, particularly since there was such strong agreement around issues like agency support and patient care, the fact that the findings were largely consistent with the home care literature led me to conclude that the data generally reflected aides’ honest opinions.
Study Population: Participant Demographics and Work Experience

In total, we held four focus groups of 27 workers (n = 6, n = 5, n = 8, and n = 8).

Demographically, the participants were roughly representative of the larger home care workforce; workers were primarily female, middle-aged, and foreign-born. 25, or 93% of participants were female, and 21 (78%) were born outside the U.S., primarily in the Caribbean and West Indies. 23 (85%) had a high school diploma/GED or less, and 4 (15%) had taken college courses or had an Associate’s degree. 12 (44%) lived with a spouse or partner, and 11 (41%) had children under age 18 living in the household.

Workers’ household income was also quite low, as anticipated. The current 1199SEIU contracted rate for home health aides is $10 per hour, which translates to annual earnings of $20,800 for a full-time, year-round worker who takes no vacation or other leave. 4 (11%) of workers reported annual household income below $20,000, 9 (33%) reported household income between $20,000 and $35,000, and 4 (15%) reported household income of $35,000-$50,000. However, this was also the question that participants declined to answer the most - 10 participants left this information blank on the demographic survey. 9 (33%) participants were the sole earners in their household. 2 (7%) also reported working an additional paid job outside of home care. [See Table 4.2, Participant Demographics]
<table>
<thead>
<tr>
<th>Table 4.2: Participant Demographics (n=27)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>n</strong></td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>18-24</td>
</tr>
<tr>
<td>25-39</td>
</tr>
<tr>
<td>40-59</td>
</tr>
<tr>
<td>60+</td>
</tr>
<tr>
<td><strong>Nativity</strong></td>
</tr>
<tr>
<td>US-born</td>
</tr>
<tr>
<td>Foreign-born*</td>
</tr>
<tr>
<td><strong>Country of Origin</strong></td>
</tr>
<tr>
<td>Dominican Republic</td>
</tr>
<tr>
<td>Grenada</td>
</tr>
<tr>
<td>Guinea</td>
</tr>
<tr>
<td>Guyana</td>
</tr>
<tr>
<td>Haiti</td>
</tr>
<tr>
<td>Ivory Coast</td>
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<tr>
<td>Jamaica</td>
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<tr>
<td>Nigeria</td>
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<tr>
<td>Peru</td>
</tr>
<tr>
<td>Puerto Rico</td>
</tr>
<tr>
<td>St Lucia</td>
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<tr>
<td>St. Maarten</td>
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<tr>
<td>St. Vincent</td>
</tr>
<tr>
<td>Trinidad</td>
</tr>
<tr>
<td>US</td>
</tr>
<tr>
<td><strong>Language spoken at home</strong></td>
</tr>
<tr>
<td>English</td>
</tr>
<tr>
<td>French/Creole</td>
</tr>
<tr>
<td>Spanish</td>
</tr>
<tr>
<td><strong>Education</strong></td>
</tr>
<tr>
<td>Less than high school diploma</td>
</tr>
<tr>
<td>High school graduate/GED</td>
</tr>
<tr>
<td>Some college/associate degree</td>
</tr>
<tr>
<td><strong>Household demographics</strong></td>
</tr>
<tr>
<td>Living with spouse/partner</td>
</tr>
<tr>
<td>Living with children &lt;18</td>
</tr>
<tr>
<td>Living with children &gt;18</td>
</tr>
<tr>
<td>Living with others (parent, roommate, sib)</td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
</tr>
<tr>
<td>$5,000 - $20,000</td>
</tr>
<tr>
<td>$20,000 - $35,000</td>
</tr>
<tr>
<td>$35,000 - $50,000</td>
</tr>
<tr>
<td>Don't know/didn't answer</td>
</tr>
<tr>
<td>Working paid job outside of home care</td>
</tr>
<tr>
<td>Only person in HH working for pay</td>
</tr>
</tbody>
</table>

*1999SEIU contracted HHA wage is a minimum of $10/hour, or $20,800 for a full-time, year-round worker with no vacation time.
Likely due to the Education Fund’s eligibility requirements, the participants were an experienced group of aides (see Figures 4.2 – 4.4). In an industry where an estimated 60% of workers leave the industry within a year, 15 (56%) of the aides had been working in the field for more than three years. 13 (48%) had worked with more than ten clients over the course of their career, and 8 (30%) had worked with 6-9 clients; only 6 (23%) had worked with 5 clients or fewer. The aides also tended to stay with their clients long-term. 7 (26%) had worked with a single client for more than three years, 41% (11) for one to three years, and 8 (30%) for six months to a year. Two aides had cared for their clients for over 10 years. Only one aide had worked with clients for less than six months. Most worked regularly with a few, long-term clients; 25 (92%) worked with 1-3 clients each month. Unusually for this workforce, many participants also reported working more than full-time hours on average. 11 (41%) reported working up to 50 hours per week. 8 (30%) reported working between 25-38 hours per week, and only 5 (19%) worked fewer than 25 hours per week. This may be due to eligibility requirements for 1199SEIU benefits.\footnote{To account for irregular schedules, the demographic survey asked participants how many hours they normally worked over a month, rather than a week. Some participants struggled with this question and may have overestimated their monthly hours.}

While these work characteristics set them apart from the broader workforce, this wide range of experience and perspective made them an ideal group for this project. [See Table 4.3, Participant Work Experience]
Figure 4.2. Years in Field

- <1: 3
- 1-3: 9
- >3: 15

Figure 4.3. Total Career Clients

- 1: 1
- 3-5: 5
- 6-9: 8
- 10+: 13

Figure 4.4. Longest Tenure with a Client

- Less than 6 months: 1
- 6 months - 1 year: 8
- 1 - 3 years: 11
- >3 years: 7
Table 4.3: Participant Work Experience (n=27)

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Job Title</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Health Aide</td>
<td>25</td>
<td>93%</td>
</tr>
<tr>
<td>Both Home Health Aide and Home Attendant</td>
<td>2</td>
<td>7%</td>
</tr>
<tr>
<td><strong>Years in field</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1</td>
<td>3</td>
<td>11%</td>
</tr>
<tr>
<td>1-3</td>
<td>9</td>
<td>33%</td>
</tr>
<tr>
<td>&gt;3</td>
<td>15</td>
<td>56%</td>
</tr>
<tr>
<td><strong>Total clients (career total)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>3-5</td>
<td>5</td>
<td>19%</td>
</tr>
<tr>
<td>6-9</td>
<td>8</td>
<td>30%</td>
</tr>
<tr>
<td>10+</td>
<td>13</td>
<td>48%</td>
</tr>
<tr>
<td><strong>Average monthly clients</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>13</td>
<td>48%</td>
</tr>
<tr>
<td>2-3</td>
<td>12</td>
<td>44%</td>
</tr>
<tr>
<td>4+</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td><strong>Average monthly hours worked</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;100 (under 25 hours/week)</td>
<td>5</td>
<td>19%</td>
</tr>
<tr>
<td>100-120 (25-30 hours/week)</td>
<td>4</td>
<td>15%</td>
</tr>
<tr>
<td>121-150 (31-37.5 hours/week)</td>
<td>4</td>
<td>15%</td>
</tr>
<tr>
<td>151-199 (38-50 hours/week)</td>
<td>11</td>
<td>41%</td>
</tr>
<tr>
<td>200+ (over 50 hours/week)</td>
<td>2</td>
<td>7%</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td><strong>Longest tenure with a client</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 6 months</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>6 months - 1 year</td>
<td>8</td>
<td>30%</td>
</tr>
<tr>
<td>1 - 3 years</td>
<td>11</td>
<td>41%</td>
</tr>
<tr>
<td>&gt;3 years</td>
<td>7</td>
<td>26%</td>
</tr>
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Chapter 5: Quality of Care: What is “Good Care”? 

While the quantitative section of this project analyzed existing measures of home care quality, this chapter explores aides’ own perceptions of quality care, and the skills they employ to provide it. Agencies primarily assess quality of care through specific tasks outlined on a care plan, and patients’ physical clinical outcomes. But aides often report a more holistic understanding of care quality that also includes relational care – or the companionship and emotional and cognitive assistance that supports patients’ overall well-being. This relational care allows workers to both better perform their assigned physical tasks, and to support their patients’ emotional and cognitive health. For instance, as one PHI report notes, bathing a patient with dementia who fears the shower requires more than physical strength; workers must also draw on their emotional intelligence, compassion and patience to get the job done.

In these focus groups, aides not only had specific ideas about what constituted quality care, they also took deliberate, conscious steps to deliver it. Most importantly, quality care required building strong, trusting relationships with patients which allowed them to better perform the tasks on the POC and support patients’ emotional health. Aides worked hard to grow and maintain these relationships, namely by employing communication, empathy, respect and love. However, the tension between these trusting personal relationships and aides’ professional roles also meant that setting and negotiating boundaries of care with the client, client’s family and agency could be challenging.

The Structure of Agency-Based Home Health Services

When an individual needs home care services, she or he is first assessed by a nurse or social worker, who then works with the agency to develop a list of specific services the patient will
receive at certain times (the Plan of Care, or POC). The POC may include “intermittent” visits from clinical staff, such as visiting nurses or occupational and physical therapists, as well as “custodial” care provided by paraprofessional home health aides or personal care attendants. Formally, aides are not allowed to deviate from the POC, either by performing fewer tasks or more. Medicaid and Medicare also require patients to be assessed regularly (every 60 days for Medicare benefits, and every six months for Medicaid long-term care). While some aides in these focus groups cared for private-pay clients, it appeared that the vast majority of their patients were enrolled in Medicaid, which reflected a common dynamic in home care of low-income women (often women of color) caring for other, older low-income women.

The home health care team is generally understood to include a group of individuals inside and outside the home health agency who coordinate the patient’s care. This team can include the patient’s physician, an agency nurse or social worker, therapists, an agency coordinator who is responsible for scheduling care and is the point of contact for the patient and their family, the patient’s family, the patient herself, and the home care workers (some patients receive services from both home health aides and personal care attendants, depending on the level of service they require). In some agencies, all patient care is coordinated under a single unit. However, in others, “skilled” care such as nursing and therapy visits are siloed, with “skilled” care coordinated by a Director of Nursing or clinical manager, and paraprofessional services scheduled through an administrative coordinator. Home health aides like those participating in these focus groups technically work under the supervision of a nurse, but supervision visits are infrequent. Under the current New York State Medicaid plan, for instance, nurse supervision visits are required only twice per year, although they may occur more frequently if there are concerns about the aide adhering to the POC, patient complaints about the aide, or if the POC needs to be updated.
because of a change in the patient’s condition. Many of the aides in this study reported that they rarely, if ever, saw the nurse assigned to their patient.

**Aides’ Perceptions of Quality Care**

**Physical Care: The Plan of Care**

Consistent with the home care literature, aides in our focus groups told us that their agencies defined good care by the POC. As one aide put it, the agency “just wants to know that we are following the plan of care, making sure that the patient is meeting their needs. You’re getting everything done; everything is on point” (Aide 1732, Group 1). The POC generally included assistance with ADLs, such as bathing, eating and dressing, cooking meals, accompanying the patient to doctors’ appointments, and light cleaning, which one aide explained as “when you clean when you did something to the client. Maybe if you bathe the client, and the bathtub or the bathroom is dirty – keep it clean. When you cook, you have to clean” (Aide 1094, Group 3). In other words, aides are responsible for cleaning related to patient care, but not for cleaning the entire home. Aides also performed some basic clinical tasks, such as helping a patient with medication or administering diabetic foot care. The tasks on the POC were frequently characterized as doing “everything”: “I help her with all her needs”; (Aide 1807, Group 1) ”I cook for her, I clean for her, I do everything you can think about” (Aide 1202, Group 1); “Everything she ask, I do (Aide 1125, Group 2). In fact, one aide told the group that she received special training and permission from her agency to test her patient’s blood sugar, since she was concerned that family members were not performing this task.

**Emotional Care: “Make them happy is the most important thing to me”**
Studies of home care workers consistently find that aides prioritize their patients’ happiness and view it as an essential part of care.\textsuperscript{21,51} This was true across all four groups; while aides acknowledged the importance of the POC, they felt that their most important work was supporting their patients’ emotional well-being – a job responsibility conspicuously absent from the care plan. Aides also viewed emotional and physical health as strongly connected; for instance, as one aide noted, “just keeping them happy…keep their blood pressure from rising” (Aide 1620, Group 4).
For aides, keeping patients happy meant ensuring that they felt safe, respected and not lonely, which aides accomplished by taking thoughtful and intentional steps to build trusting, ongoing relationships.

**“That Special Bond”: Building Trusting Relationships**

“Emotionally, it’s not always about, you are doing your job and you are following everything that’s there. Sometimes patients just want companionship. They want someone to talk to. Maybe they just want a best friend. Maybe they feel lonely – their own family doesn’t pay attention to them. You’re the only person there for them, so they want a connection with you, and that helps them emotionally, physically, and mentally.” (Aide 1732, Group 1)

Communication: “I listen to my patient”

Aides were very aware that many patients felt lonely and isolated, and often just needed to know that someone heard their concerns and cared. Overwhelmingly, aides said that “just listening” to their patients, asking them questions, and responding genuinely to their concerns was critical to establishing the mutual respect and trust that allowed them to provide good care. As one participant noted, “My client – especially she needs somebody to listen to her when she talks. She likes to talk. By just sitting there and listening to her – paying attention – makes her very happy” (Aide 1507, Group 4). When asked how they knew they were providing good care to their patients, aides frequently cited communication, and thoughtfully described the specific steps they took, and questions they asked, to show concern for their patients and better understand their moods and needs:

You talk to them. Always – sometimes when you see them sad. So, you could talk to them, and sometimes you will ask them what happened? How are you today? Sometimes they’re happy, and one day when you come they might be sad. Once you see them sad, so you then want to talk to them and make them comfortable, and ask them why. What happened today? Why are you so sad? Once they open to you, they will let you know what’s going on. What’s eating them inside – they will. If you don’t talk to them, they’re not going to say nothing. But when you talk to them and ask them or you show them you really worry about them. Like you want to know what’s going on, if something’s bothering you. Sometimes you say am I doing something wrong to you, and they say, “No, not you.” And they started to talk – what’s going on, what happened. (Aide 1125, Group 2)

Some people, they don’t say nothing. If you don’t say nothing to someone, she’s not going to know what you are or what you want to do for her. (Aide 1939, Group 3)
Aides felt that communicating and engaging with patients was particularly important for patients who were isolated in their homes or had limited mobility. As one aide who worked overnight shifts with bedbound patients shared:

Sometimes [the patient is] up until 11 o’clock. Sometimes we’re up until two o’clock talking because she’s alone. Sometimes I put her in bed three o’clock. So, we have good times. I listen to her mainly. That’s the main thing. A good night is when we sit and watch TV. She has a word game that we play...I’ve been working at this one for three years. The other one for 12 years. She was bedridden too. I have to turn her every two hours...she just talk, talk, talk. The discussions I enjoy. I listen to her when I’m leaving in the morning. She’ll let me feel so good. (Aide 1350, Group 4)

These open lines of communication and understanding helped aides stay attuned to their patients’ moods and better support their emotional health. For instance, one aide described using her knowledge of her patient’s love of music to cheer her up:

She loves music. Then, I saw her sitting so sad or crying. I say, why don't you open the stereo? She says, why don't you come and help me? Then I go and help her put the CD on and then she starts dancing on the bed. Okay, while she's dancing I was doing mopping or doing something for her. Then she says, why don't you give me a shot [at dancing]? I come dancing through the room and she keep laughing and laughing. She said, that's my girl. I see her happy, then I am happy. (Aide 1304, Group 1)

**Empathy: The Golden Rule**

All four groups frequently invoked the golden rule to “do unto others as you would have them do unto you” when describing how they cared for their patients. Aides described putting themselves or their own family in the patients’ shoes, noting that ”I try to treat my patient the way I treat my mother”, (Aide 1304, Group 1) or “I treat her just like I would want to be treated if I’m like that someday” (Aide 1350, Group 4). This approach made aides particularly attuned to and concerned about their patients’ emotional, physical and even financial vulnerabilities. In fact, several aides quite literally saw themselves in their patients, since they cared for individuals who were retired home care workers themselves. As one aide noted, “the lady I’m taking care of in the morning.
She said she’d been working for the agency for 31 years. Now she retired. She’s 65 years old. She said she retired without nothing. They give her nothing…Thirty-one years – nothing” (Aide 1854, Group 2).

These aides were extremely conscious of their patients’ precarious financial status and dependence on Medicaid to pay for their care, and described steps they took to protect their patients, from checking in to make sure the patients’ other aides were “keeping the place clean” to buying toilet paper or other household goods on sale when they were doing their own shopping. Aides also saw themselves as protectors of their patients, who they often felt were marginalized. For instance, when asked about nursing visits, one group felt that the frequency of nursing visits “depended on the patient” and that “high-class patients” who “live in a nice place” and are “not depending on the government” (Aides 1854 and 1065, Group 1) received frequent nursing visits, while for “some of the patient [on Medicaid] – it could be six months, no one is coming to see them” (Aide 1065, Group 1).

Respect: Supporting Patients’ Independence and Personhood

A central tenet of home and community-based services is ensuring the patient retains as much independence as possible. Aides in all four focus groups emphasized that they were primarily in the home to “assist” clients where they could, rather than take over their daily tasks, explaining that “if a patient can do for himself, we just assist. You know, we let them be independent” (Aide 1485, Group 4) and when possible, aides “don’t take the task from them, just assist” (Aide 1548, Group 4).

However, while the agency was primarily focused on physical independence, aides felt their patients’ cognitive and emotional independence was just as important. Aides took specific steps
to maintain this independence through what anthropologist Elana Buch refers to as acts of “social recognition” that increase personhood. Several aides talked about sharing crossword puzzles or playing word games with their patients to keep their minds active, and one even described the “homework” she assigned to a patient who was beginning to struggle with dementia:

I make her write. I say, write today’s date for me. Because she’s shaking, and I’m trying to keep her hands still. I think good care is keeping your patient mobile. Keeping them aware of everything. And especially when they’re forgetting a lot, you don’t want them to totally forget. You want them to still know what’s going on in the world. You know? She don’t like to watch TV, but I put her TV on. Say, “come on,” I call her grandma. Listen to the news. You have to know what’s going on. Even though she can’t understand, she will keep asking something over and over. But I explain it to her as much as possible. I keep telling her over and over, and she say “Oh, okay, I got it.” But the next few minutes she will come back again and ask again some of the things. (Aide 1485, Group 4)

Aides also supported their patients’ independence by encouraging them to pursue activities they enjoyed outside of the home. Many aides related stories of how happy patients were when they could take time for themselves, spend the day out in the community, or stay connected to friends:

My client – we celebrated her birthday at a restaurant. There was a jukebox. She liked playing the song Just a Gigolo [Laughter]. It reminded her of her days when she used to sing that to her boyfriends. (Aide 1548, Group 4)

She depends on me to take her out, to be able to go to café, to sit down. She would meet with her friends and like how we are they will be chatting. I’ll be like around these old people and they’re like talking. You would never believe what these people are discussing. You just would see the fun on her face. She’s feeling so happy that she’s out. (Aide 1100, Group 1)

She likes to go to a hairdresser, do her hair. Like, after dialysis she can have some time for herself, which she very rarely gets. So, if we get to do that, that’s a good day for me and her. (Aide 1026, Group 1)

Aides also supported patients’ choices in where they wanted to go, what they wanted to do, and even what they wanted to wear. This appeared to be particularly significant for younger patients. Two aides who worked respectively for a man in his 30s with a degenerative disease and a middle-aged woman who had been paralyzed in a car accident described how they encouraged their patients’ preferences:

Every weekend is a fun day because we go on to the community, and it’s like we go to a diner for breakfast every day – every Saturday. After that, where do you want to go? Do you want to go to a library? Do you want to go the library in Flushing Main Street? Because [the patient] likes the Asian women. So, he likes -
he say he’ll go do that. Maybe bowling too. Even though he can’t physically do it, we can make him at least try. (Aide 1732, Group 1)

She loves to go out. She loves to get dressed. Even though the most challenging thing with her is to get her clothes on, but she loves to get dressed. Sometimes she – “What am I going to wear today?” We will make some suggestions and she will say, “Okay, if you say so my boss.” She comes back and will be like, “I ain’t gone wear that.” She put what she wants. I say come, let’s roll and we go out on the street and we shop. She loves to shop. (Aide 1049, Group 4)

Filling family roles: “You have to love them”

Aides in all four groups repeatedly noted that building trusting relationships was about more than simply “performing” empathy or kindness; it required genuine fondness and even love for their patients. Some studies of nursing care refer to these bonds as “companionate love”, or a warmth, connection and affection felt between people whose lives are closely intertwined. In this group, companionate love was often experienced as kinship. Participants frequently described their patients in familial terms, referring to them as “Grams” or “Grandma”, and seeing themselves not just as caregivers or even friends, but as substitute children, grandchildren and sometimes even parents. Seeing that many patients felt lonely and abandoned, aides told us that they often felt they were standing in for family members whom they perceived to be absent or uninvolved, noting that "we treat them even better than the children that they have" (Aide 1507, Group 4). Filling the roles of absent family members helped aides to further build the “team” of care provider and recipient:

Some patients they want to rely on their family, but the family isn’t as involved like that. So what do they do – you know what?...She can’t rely on them because they won’t listen to them or whatever the case may be. So they look at upon you. It’s like, we are a team we are going to do it, or I can count on you. Just counting on us makes them happy. That, you know what, I can count on her because with my condition my family, there’s no hope. With us they see hope...If you see your patient isn't receiving that care - that love from the family - you show them that love. You show them that care, and they look up to you. It becomes a bigger relationship - a trust. (Aide 1732, Group 1)

Caring for a patient like a family member also involved a sense of personal and professional pride. One aide noted that when she took her patients to the doctor, it was important they looked well-cared for. “I like them to go well-groomed because that reflects on me...I make sure their
hair is groomed properly and they look well-dressed. I iron their clothes so they can look real good as if they were my child. My special children” (Aide 1548, Group 4).

However, as with any family relationship, not every day was a good day. Aides agreed that patients “have their grumpy days” (Aide 1324, Group 4) and “sometimes they just don’t want to be bothered” (Aide 1878, Group 4) and could be rude or irritating. In these cases, aides practiced deliberate emotional regulation by putting their “family” relationships to the side and prioritizing their patients’ emotions in a way that is not always possible in complex, lifelong family relationships:

Just like how we have different moods. Sometimes I have different moods at times. They have moods. (Aide 1324, Group 3)

You don’t get rude with them. Even if they’re rude to you, you just go away and let them cool. Sometimes they can get really annoying even though they love you and they say they love you and whatever. But the thing is you don’t make them upset. Sometimes they do get upset for other reasons and they take it out on you. But you don’t give them mouth. You just leave them and you go away somewhere – in the kitchen – and you do something else and let them calm down. (Aide 1620, Group 4)

**Setting and Negotiating Boundaries of Care**

Home care workers frequently report working extra uncompensated hours and taking on extra tasks outside their job description to care for their clients, even though agencies maintain strict policies against such off-POC or off-the-clock care.\(^5,132,133\) This was true across all four focus groups. Aides told us that for them, good care meant honoring the trusting relationships they had built with their patients by “going the extra mile” to ensure patients were happy and safe even when the aide was not at work. Being a “team” meant that the increasingly murky distinction between aides’ personal relationships and professional roles could make negotiating boundaries of care difficult, and aides all agreed that to provide good care “we do stuff we’re not supposed to do” (Aide 1304, Group 1), particularly cleaning and working extra time outside their
scheduled shifts. However, the context in which this extra care was provided was situational, and depended on the relationship with the patient, the patient’s family, and the agency.

**Negotiating Boundaries with the Patient: Going the “Extra Mile”**

*Personal and Professional Responsibility: “They Rely on You”*

Aides were conscious that many of their patients, particularly those who lived alone, often felt isolated and lonely. They also knew that these patients depended on their aides for companionship and support, which was as important to the patients as the physical tasks the aides performed. Many aides shared stories about patients feeling happy when they showed up for a shift, and sad when they left.

As soon as I knock on the door and I ring the bell, he opens the house for me. I say how are you today. How are you feeling? He said, now I’m feeling good because I see you. (Aide 1854, Group 2)

Every Tuesday when I’m ready to leave, she comes out of the shower at two o’clock. She says, I get so depressed. And she starts crying. She goes, because you’re leaving me. I said I’ll be back in three days – after three days...she has two kids that don’t have any times with her. (Aide 1620, Group 4)

Knowing that patients relied on them, aides felt a responsibility to be responsive to their patients’ needs whether they were at work or at home. These stories were often told with a tone of humor and fondness, even when the underlying situation might be more serious or frustrating. One aide noted how she always answered her patient’s calls, even on days off:

[My patient] calls the office – “Why [aide] is not coming to work today” if I’m not going to be coming in for a day. On Fridays I do not work. “Oh [name], you should be coming tomorrow. Seven o’clock Friday morning my phone rings. She’ll call me. Oh my God, I don’t want to answer, but I just have to. [Laughter from the group] (Aide 1507, Group 4)

This sense of responsibility also made aides protective of their patients. Aides were often concerned that the patient’s physical needs would not be met if they were not at work, even if they lived with family. As one aide noted, “if I don’t come on the weekend, nobody not going to take her [blood] sugar. She’s living with her daughter and husband and two sons who always
come every day. So, I’m there when like, doctor’s office. I’m the one who has to go. If that’s my
day off...she’s not going” (Aide 1854, Group 2). Aides were also very aware that they served a
low-income Medicaid population, and felt protective over their patient’s financial security. One
aide explained one of her responsibilities was to manage her blind patient’s finances,
highlighting the importance of dependability and trust by saying, “she can trust me to go with her
to cash her check, count her money, pay her bills, let her know how much the bill is” (Aide 1537,
Group 3).

Personal Gifts of Care

For legal and ethical reasons, agencies do not allow clients and aides to exchange gifts,
particularly of extra time, work or material goods. However, consistent with other home care
studies, aides told us informal exchanges often took place in the context of their personal
relationship with the patient. Reciprocal gift exchanges are an important part of building social
and personal ties, and in the home care context they “play a critical role in building good care
relationships that sustain moral personhood” by demonstrating mutual respect between giver
and recipient. Gifts of care might be given out of concern for the patient’s safety, like extra
cleaning; to make a patient happy, like cooking for a patient’s friends or children; or simply
because they made sense in the context of the household, for instance, washing a spouse’s
laundry along with the patient’s.

Many aides described giving extra care to keep clients physically safe, especially those who
lived alone:

Some of these clients’ living condition is very, very bad. I remember when I started, and when I went into
the apartment it was so filthy. I couldn’t imagine any human being would live under those circumstances. I
went and I got a broom and one of the long brushes. I just started scrubbing down all the walls and just
washing down everything with bleach. I didn’t throw anything out because we’re not allowed to do that.
But I cleaned that place as if it was mine. (Aide 1100, Group 1)
I feel bad for her because I have to leave her. I have to do overtime because I don’t want to leave her by herself. Even it’s snowing or it’s raining or whatever, I have to stay one hour late to make sure she eats something before to go to bed. She has to have a bag. I have to put everything in the bag for her, next to her so when she feels her sugar is low, she could be able to eat something. (Aide 1304, Group 1)

Often, like much of the care that aides provided, these extra “little things” supported patients’ emotional well-being as well as their physical health:

Sometimes even after work when I get home. I would always call my patient every night because she doesn’t have anyone working at night, just to ensure that she is not using the stove for her safety. Then, I would just talk and make little conversation with her on the phone just to keep her abreast. (Aide 1202, Group 1)

My patient, she depends on me to take her out because she’s bed bound – she can’t walk. I would have to put her on a wheelchair mechanically. So she depends on me. If and I don’t show up she’ll be like, “[1202] what happened?” I would give her an explanation, but hardly that would happen. Just like on Tuesday they had train issue. I’m not familiar using like the buses so I couldn’t get there. She was going to dialysis that day, so she got an aide. But I talked to her on the phone for her to be comfortable. (Aide 1202, Group 1)

It’s only her and her son which we’re not supposed to provide food for her son, only for her. But because we’re there, I know we’re only going to prepare food for her and not give it to the son that’s unable to do it for himself. So we usually put a side away for him. If she doesn’t see the food for him, she won’t eat. So, that’s something that makes her happy. Make her see a lot of stuff in there for the son, even though she doesn’t need this plate of food, but that makes her happy.” (Aide 1237, Group 1)

To build strong relationships, gift-giving requires “balanced reciprocity”, in other words, it must be mutual and ongoing. Aides not only provided gifts of care to their patients, they also understood the importance of accepting the gifts their patients could offer. These mutual exchanges often reflected the complexity of both the personal and professional relationship by separating the personal aide-patient relationship from the professional sphere, while allowing aides to support their clients’ independence and personhood:

We went to the Boardwalk. Coney Island. She enjoyed it because you know what I let her sit – she enjoyed it. She loved ice cream. She loves ice cream so we bought this chocolate she liked – double scoop ice cream. She’s small. She doesn’t eat much. But she knows she’s going to go and she just wants to be happy. She just buy the biggest scoop. Eventually she eats some. I have to eat the rest of it, but I’m not a chocolate lover. I like caramel…we just went to the aquarium. We watched all the fish. To me and to her it was a very good day. She paid for everything. I did not. She buy everything. (Aide 1548, Group 4)

“I go outside and buy lunch. Sometimes he always says, let me give you the money. Sometimes I don’t take money from him. I buy him lunch. He says, ok, next week I’m going to do it. I say no, I’m happy here. You’re so nice. He’s a very, very nice guy. I said you’re so nice - I want to buy it. Sometimes we order food. We sit at the table together. We eat and we laugh. We watch some TV. He makes me laugh and I make him laugh. I’m always telling him jokes and he tells me jokes. We have fun every Saturday. Every Saturday we have fun.” (Aide 1854, Group 2)
Both of these exchanges illustrate the emotionally astute way that aides gave and received gifts of care while still prioritizing their patients’ feelings; for instance, finishing the patient’s chocolate ice cream even though the aide would have preferred a different flavor, or allowing the patient to buy lunch just frequently enough to make him feel he was caring for his carer.

Preparing and sharing meals was another common exchange of care, particularly since cooking was a low-impact activity that even patients with limited mobility could perform with assistance. One aide shared that “I like to feed my patient more than anything else”, noting “I love when I cook her and I see her sit down and enjoy the food, and after she say, oh, that was a good one.” (Aide 1100, Group 1) On the other side, aides noted that after patients cooked, they would often “want you to sit and eat with them” (Aide 1639, Group 3) and that “you don’t have to eat much, but just sit and take a piece….just to let her know” (Aide 1537, Group 3). As one aide described this reciprocity, “she actually do one of my favorite hobby – cooking. I love cooking. So, when she always in the kitchen cooking, I love to assist… Every time we cook, we share the love together” (Aide 1324, Group 3).

Professional Boundaries: Choice and Control

When gifts of care were given freely, aides expressed a sense of pride and accomplishment in a job well done. However, when extra care was expected or demanded, aides had a different perspective. In these cases, aides often felt the need to set boundaries and assert their professional role over the personal relationship. Often, aides felt clients asked for extra services simply because they did not understand the aides’ role. One aide related a story about a client asking her to clean his plants, and telling him, “Mr X, this is not in your care plan. He was just furious. He’s like, so, you’re going to let an old man do this? He just was so upset. I just kept
telling him that it goes by the care plan that particular day. Then, after he got understanding, he was like, oh, I’m very sorry.” (Aide 1237, Group 3) While asserting her boundaries, the aide still retained some flexibility and control by noting the care plan was specifically for that day.

Aides were primarily concerned that their clients knew that any extra work, physical or emotional, off the care plan was their personal choice and not their professional obligation, something the aide would choose to do because of their “compassionate heart”. As one aide put it:

Some of the patients don’t understand if they call you maid. Because some of them is old. They think you are a maid. I said we’re the one who are supposed to explain them what we are here for. We’re not a maid, we are here to help you. We’re not the haters. We’re not here to hurt you. We are here to help you and give you help. We’ve been training, and we know what we have to do – what we’re not supposed to do. If we do it, is our compassionate heart. We’re here to help you. (Aide 1304, Group 1)

Some aides also felt that asserting boundaries was important because performing tasks outside the POC could either “create a pattern” (Aide 1732, Group 1) of unrealistic expectations for themselves and other aides, or at worst, put them or their patients at risk. In these cases, aides often had to weigh their personal concern for the patient with their professional responsibility.

For instance, one participant related a story of how her client’s other aide improperly dressed a bedsore, a task that aides are not permitted to do, and ultimately made the condition worse. She explained that “sometimes you might want to go to less trouble by wanting to be too nice to your patients. Because you feel you might have this pity….like, she’s going through difficult times, she’s depressed. There’s a lot things she can’t do on her own. She needs help. Things that are not in the Plan of Care, they want you do it. You feel you want to help, but with the agency or some other person be on your job, that might be harmful or bad” (Aide 1094, Group 3).

In cases where aides found negotiating boundaries untenable, they often felt confident in exercising control and leaving the case. This happened most frequently with new or
“replacement” cases, when aides were filling in for other workers, and there was no prior relationship with the client. One aide described her experience trying to care for a new disoriented, aggressive patient without the safety equipment necessary to transfer her in and out of her wheelchair, saying “I mean, sorry, but I didn’t go back” (Aide 1537, Group 3). Another aide described working briefly for a wheelchair-bound cat owner, which resulted not only in the extra work of cleaning up after the cats, but also brought on asthma attacks. Nonetheless, even while trying to get transferred from the case, she was determined to provide the best care she could. “I had to deal with that for six months, and it was really annoying. Really, really annoying. I complained, I complained. They still didn’t change me from the case…..but I try and I deal with it. That was the most annoying one for me until I get rid of it” (Aide 1324, Group 3).

**Negotiating Boundaries outside the Aide-Patient Relationship: “I’m here to take care of the patient”**

**Negotiating Boundaries with Family: “Family members do give hard times”**

Some participants reported that they had a good relationship with their patients’ family members and felt the family valued and acknowledged their work; that “when you give their parents good care, they appreciate it” (Aide 1125, Group 2). However, more often than not, family members were seen as a barrier to providing good care. Aides were particularly skeptical of family members because they often perceived themselves as providing the care that families could not or would not give, including tasks that were not on the care plan. One aide noted that “even though [the patient] has extended family no one comes to visit her, so I have to step in and do things that is not even on the POC” (Aide 1202, Group 1). Another explained that, “depending on their condition and if their family is involved, you feel bad. Then, because they can’t do it,
even though it’s not part of your task – well, who’s going to do it? You can’t allow your patient to live in that condition. You wouldn’t want to live in that condition, so you do little stuff like that” (Aide 1732, Group 1).

Aides’ most common complaint was that family members treated them as maids or housekeepers, rather than as health professionals. Aides were frequently asked to perform extra tasks around the house, particularly cleaning, that were outside the POC. One of the male aides noted that as a man, he was often asked to do extra physical work, and that “if you don’t stand up for yourself, they’ll have you out there on the roof sweeping leaves” (Aide 1378, Group 2). In these cases, aides generally felt confident asserting their professional role and boundaries, knowing that they were protected by the POC. One aide noted that she approached these conversations by describing her professional role:

I go and work on the care plan. If the family member have problem with that – for instance, they will want you to, okay, clean the window, do this. I said no. You stick to the care plan….if you need cleaning service, the agency do have it. You could call and request a cleaning service. Make them know I’m a certified home health aide and I do what’s my duty. (Aide 1854, Group 2)

Unlike negotiations with the clients, aides often felt that family members knew and understood their professional role but were trying to “test” them. Some aides shared stories about family members hiding the POC, or claiming it was lost. As one aide put it, “they know what you’re supposed to do, what you’re not supposed to do” (Aide 1100, Group 1). Aides especially resented this perceived sense of entitlement because they did not view the family as employers or supervisors, but outsiders who were not part of the core care “team” of aide and patient. As one aide said, her client’s son “feels like he’s the one who’s paying us out of his pocket, like he’s the one paying towards the aide…where I get to get them clear that that money is not coming out of their pocket. It’s coming out of the city – the government pays for us to work for them” (Aide 1807, Group 1).
However, while they did not directly employ aides, family members still wielded considerable power over aides’ work environment and schedules. As one aide put it, “they look down on you. They look down on you and tell their self that, you know what, you have to do what they say…that is what happens or else you got to go” (Aide 1100, Group 1). Aides were very aware of these power dynamics and the need to be “diplomatic” and not “create an argument” (Aide 1100, Group 1) when negotiating work boundaries, fearing that if they asserted themselves too strongly, they might lose shifts or be dismissed from a case entirely, which would both compromise care for the patient, and affect the aide’s schedule and income. One aide described an incident with her disabled client’s mother, when she tried to tactfully explain that she could not do extra cleaning. She told the group that the mother responded that “this isn’t working out. I don’t think the Tuesday nights are going to work….she is basically in a way kind of threatening me saying, okay, you’re not going to do it. I didn’t say I wasn’t going to do it. I just said if I can get around to it then – just letting you know if I forget, I can’t do it. Because I have other important things to do” (Aide 1732, Group 1). While attempting to assert her caring role by prioritizing the “other important things” she needed to do for her patient, the aide nonetheless was careful to avoid directly declining the extra tasks.

Even when family members did not try to negotiate extra services, aides still often saw them as disruptive to patient care and their patients’ moods. One aide described, with strong agreement from the group, how much more easily the day ran when she and her patient were alone:

A good day for me is when the husband is not at home [laughter from the group]. Oh my gosh, he is so annoying, aggravating… If he's not at home, we get along. There's no shouting. I would just do what I have to do…if he is not there, whatever meal I give her, she will say this is good. She loves to watch Price is Right and we would be laughing and cheering on as people win. We're having a good time in the house. That's a good day for me. (Aide 1100, Group 1)
In fact, there was strong agreement across all the groups, and in the report back sessions, that if the family were not there at all, “it would be perfect. No drama. Stress-free.” (Aide 1732, Group 1) One group, when asked what would make dealing with family members easier, had the following exchange:

1382: Get them out the house
1324: Yeah, exactly [Laughter]
1382: That’s it, Nothing else. Just got to get rid of them.
1324: Get them out of the house. Yeah.
1878: You got to. That’s it. The ones that got them family members – no.
1094: Yeah. Whenever the aide’s there, they should get them out the aide’s way. (Group 3)

In the worst cases, aides feared that family members could be a danger to the patient and to them. Aides reported family members who abused or neglected patients, took money from the patient or the aide, or put the patients’ safety at risk. In these situations, aides often felt responsible for stepping in to protect their patients, fearing that no one else would help them. One aide shared a particularly harrowing story of finding her patient alone and in danger after her home was flooded in an accident that she assumed was caused by the patient’s son:

The house was full of water, she spent the night sitting in the wheelchair. Then, the lady who was there before me left, and she say it wasn’t her time she has to leave. That’s what the patient told me. Then, the son was there too…I don’t know what [the son was] doing in the bathroom, popping something. I find so many messes on the floor and then when I come in the morning I find my patient sitting in the wheelchair...she was freezing to death and everything. I said did you call 911? She said, “Yes, I called 911. I called the housing people, they never showed up. So, after that I take the mop and the bucket. I dried it, and I put her inside. I wash her and everything. After that, I cleaned everything before they come there. When they came it was too late I had already finished. They say what did you do? I said, “I already finished after I dried my patient. I don’t want to leave her in the cold and dirt”…I rescued her. (Aide 1304, Group 1)

Negotiating Agency Boundaries: “They’re not concerned about the patient”

While home health aides technically work under the supervision of a nurse, in practice, aides’ first and often only point of contact with their agency is the administrative coordinator who manages their schedules and cases. As one aide noted, “the supervisor is basically it. The nurses, you deal with them if something is wrong with the patient. Still, you have to go to your
supervisor before you go to them” (Aide 1639, Group 1). This chain of command was extremely frustrating to aides, since they were formally instructed to “call [the supervisor] if you have any problem”, but in practice, “when you call, you can never reach your supervisor” (Aide 1094, Group 3) and calling was often “wasting your time” (Aide 1094, Group 3) since “the phone is always ringing out….they never answer” (Aide 1639, Group 3).

When aides could reach a coordinator to report concerns about their patient, they often felt dismissed or even reprimanded. Aides felt that coordinators were not interested in patient care and only wanted to know about liability issues that might affect the agency’s bottom line, such as “who do this, who do that. When you call to report [the coordinator gets] mad, they said you’re not supposed to call…to report stuff. Only if [the aide is] the one who do it. So, if you’re not the one who do it, you’re not [supposed to call]. They said you have to call anything – if the family abused the patient, if they eat their food, if they take the money. But once you [call], they say you’re not supposed to do it” (Aide 1065, Group 2). One aide related a story of calling the agency when her patient’s husband cut the patient while trying to trim her nails. “Oh my God. He made a big mess. Blood coming never stopped…so, what I do - I have to call the agency to say what's going on. The coordinators told me, oh, you called to report on her husband? That's her husband...they said, Oh, you're not supposed to call on family” (Aide 1065, Group 2). The other aides in the group agreed that in this case, the best course of action was to call 911.

For aides who were deeply committed to their patients’ well-being, this lack of communication and respect from the agency was frustrating on two levels; not only did aides feel legitimate concerns about their patients’ health were disregarded, they also felt the agency did not care about their patients and saw them only as a source of revenue. As one aide put it, to strong
agreement from the group, “[the agency is] not concerned about the patient. They’re concerned about they get the check” (Aide 1854, Group 2).

In a few cases, aides were able to circumvent the chain of command during a nurse supervision visit. These aides reported that this contact made them feel that their role was valued; nurses gave them feedback on their work and in some cases provided “a direct line” for the aide to phone them if needed. Receiving positive feedback also made aides feel that they were providing good care; as one noted with pride:

I had the nurse visited my client. He had to do an assessment…I had to administer care for her feet. So I did that, and then he made the assessment. That’s when they know whether you are really good at what you do. Then, after I did that and then he made the assessment and it was good. It was great. (Aide 1202, Group 1)

However, while all of the aides who had interacted with a nurse reported positive experiences, the majority said they “don’t remember the last time I saw her” (Aide 1700, Group 3) or had never seen a nurse at all. One group observed that this may be due to budget cuts and service limits in New York State’s new managed care program; as one aide reminded the group, “nurse cut back, you know” (Aide 1125, Group 3).

Aides also reported that they were frequently sent to new cases with little or no information about the patient’s health or home environment, which interfered with their ability to provide good care. Across the groups, aides told stories about arriving at patients’ homes to find they did not have lifts or other needed equipment, or were in a wheelchair, suffering from dementia, or physically or sexually aggressive. This was particularly troubling since the coordinator is “supposed to tell you when and what you have to do for the person” (Aide 1324, Group 3) but in practice “you don’t know what kind of case you’re going to until you get there (Aide 1537, Group 3). Some aides even suspected that coordinators might deliberately withhold information about patients who required more care so the aide would take the case. One participant shared a
story of a bad experience with a difficult new patient, commenting that “I knew [the client was aggressive] when [the coordinator] didn’t tell me. I knew when she didn’t tell – I was like, how’s this case? Can you tell me a little bit more? She says, ‘No, I can’t tell you. All I can tell you is that the lady’s nervous.’ That’s a red flag right there. If you’re telling anybody else that, they’d be like, mm-mm, I’m not taking that case.” (Aide 1537, Group 3).

However, there was also some disagreement among the groups about whether prior information about cases was necessary. Some aides saw managing challenging patients as a professional responsibility, noting with pride that a good home health aide should be able to care for patients who may not otherwise receive good care. As one participant noted:

The reason why they don’t tell us what kind of patients we’re going to deal with is because it doesn’t matter what kind of patient you’re going to deal with. That’s the thing. Let's say they give you a patient that is bed-bound or you know, you’re going to have a patient who’s bed-bound. And you can decide you know what I don’t want a patient who’s bed-bound. …But this is your job. That is your job. Your job is to take care of people with disability, mental issues, you don’t choose your patients, and you can't do that because you're a home health aide. That is your job, you are supposed to do that. (Aide 1732, Group 1)

This sentiment came up in the other groups as well; as one aide put it, “as a home health aide, you should be ready to work with any kind of patient….Any kind. Whatever the patient’s problem might be, you should be able to work with that” (Aide 1094, Group 3).

As opposed to family members, who aides would prefer were absent, many aides expressed a desire for the coordinators to leave the office and actually come observe what was happening in the home:

We’re telling them that we’re having problems on the case, and then coming out doing something about it before something happened. Because you can tell them. You call up, you can tell them, but they don’t come out. Then, when something happens, they’ll be like, oh, okay. They really don’t care. Like I said, their job is to get you on that case. That’s it, that’s all they care about. (Aide 1537, Group 3)

But, as with family members, aides expressed concern that if they did notify the agency about patient care issues, their hours would be cut or they would be dropped from the case entirely. In
this case, aides’ feelings of responsibility to the patient presented a difficult choice: protect the client by making sure problems were reported and recorded; or protect the client by staying on the case. One participant who had repeatedly tried, unsuccessfully, to report her patient’s other aide to the agency for neglect expressed her frustration to the group:

> I had that job there for ten year. It’s like I cooked for the patient. I give her a bath. I’m the one that goes out there and make the grocery. I called [the coordinator] several times and keep on telling her. The first thing – oh, I’m going to move you off of the case. Oh my goodness. It’s a lot… Sometimes you know I have to hold back tears. You know? The patient is so sweet. Sweet patient. She don’t deserve this.” (Aide 1854, Group 2)

**Discussion**

Overall, aides’ understanding and practice of high quality home care was much more expansive than the tasks listed on their agencies’ Plan of Care, and included a significant amount of relational work. Aides did not see the relational aspects of the job as optional, but as a necessary pre-condition to meeting both their patients’ physical and emotional needs. However, since this care was outside the work they were formally hired to perform, they received little support in their efforts to go “above and beyond” to fill care gaps for their patients. In addition, since this “invisible” care was not formally recognized by agencies or patients’ families, tensions often arose around the scope of aides’ roles and responsibilities, and without specific guidelines outlining these “invisible” responsibilities, aides were left to negotiate these boundaries on their own.

**Gaps in Aides’ and Agencies’ Understanding of Care**

While aides felt their agencies’ definition of good care was limited to the POC, they took a more holistic, and personal, view of the care they performed. To aides, good care meant meeting all of a patient’s needs, including both the physical and relational. As shown in Figure 5.1, aides felt that while the POC was central to their work, their patients required additional levels of care
beyond the care plan to stay safe, comfortable and happy. The clearest and most visible of these care gaps were the additional physical tasks aides performed, such as cleaning homes that were dangerous or in disrepair, or seeing patients safely home from the doctors’ office even though their shift had ended. The equally important, but less visible care gap was in the relational care that ensured patients were not lonely or sad. Aides saw their role here as both clinical and companionate; at times helping to keep their patients’ minds sharp with word games or other cognitive exercises, and at others entertaining them with outings, cooking meals, or conversations.
Importantly, aides provided these three levels of care within the context of a deliberately constructed, mutual aide-patient relationship. These relationships did not happen accidentally; aides employed their emotional intelligence and skill to carefully build “special bonds” with patients over time by practicing open communication, empathy, respect and even love. Each of these elements further supported patient well-being by demonstrating that the aide valued and respected her patient’s individuality and personhood – a sharp contrast to the way aides felt agencies viewed both workers and patients.

Table 5.2. Why Do Aides Perform Extra Care?

<table>
<thead>
<tr>
<th>Rationale</th>
<th>Physical Tasks</th>
<th>Relational Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Necessary for physical health or safety</td>
<td>• Extra clinical care (e.g., blood pressure readings)</td>
<td>• Calling/visiting to check on patient’s physical safety after work hours (e.g., making sure patient hasn’t fallen, or isn’t using the stove)</td>
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<tr>
<td></td>
<td>• Heavy cleaning</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Staying past work hours if doctor/transportation runs over time</td>
<td></td>
</tr>
<tr>
<td>Necessary for emotional health/comfort</td>
<td>• Accompanying patient on outings on days off</td>
<td>• Calling/visiting to check on patient’s emotional state after work hours (e.g., making sure patient isn’t lonely)</td>
</tr>
<tr>
<td></td>
<td>• Staying past work hours if doctor/transportation runs over time</td>
<td></td>
</tr>
<tr>
<td>Practicality (makes sense in context of patient’s life)</td>
<td>• Washing spouse’s laundry</td>
<td>• Reading to patient and spouse</td>
</tr>
<tr>
<td>Makes the patient happy</td>
<td>• Cooking for patient’s family</td>
<td></td>
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<td></td>
<td>• Preparing holiday meals for patient outside work hours</td>
<td></td>
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<tr>
<td>Supports patient’s mental and cognitive independence</td>
<td>• Assigning “homework” or playing word games with patients</td>
<td></td>
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Why Do Aides Fill Gaps in Care?

In our aides’ view, the physical and relational tasks they performed outside the care plan were not extra or optional, but filled important gaps in care that could otherwise compromise their patients’ physical and mental well-being. These ranged from physical tasks that expanded on the
care plan, such as heavy cleaning, to the emotional support and companionship that kept their patients happy, comfortable and emotionally stable. The most common reason aides gave for performing this care was also the simplest – there was nobody else to do the work (in fact, “who else is going to do it?” was a recurring theme). Aides were keenly aware of the vulnerability, isolation and precarious economic status of many of their patients, and felt both a personal and professional responsibility to fill the gaps that family and health or social services could not. This commitment was strengthened by the recognition that many patients, like many home care workers, were low-income women of color who often felt marginalized and disrespected. (In 2008, 80% of New York City Medicaid personal care patients were women, and 70% were non-white.\textsuperscript{137})

When aides built a “special bond” with patients, their own “compassionate hearts” often won out, and they performed extra tasks for patients both on and off the job out of a sense of both personal and professional responsibility. But when these same tasks were demanded by family members, who understood aides’ work only at the level of their physical tasks, the response was different. In these cases, aides set boundaries and claimed recognition for their professional roles as healthcare providers to distinguish themselves from housekeepers or maids. Aides felt that agencies had a similarly narrow sense of their professional role, and saw them only as bodies to cover cases, generate revenue, and avoid lawsuits. But unlike their interactions with family members, aides often felt they had no control over demanding more open communication or respect from their employers.

\textit{What Prevents Aides from Providing Good Care?}
On the job, aides often found that their comprehensive definition of good care was at odds with families’ and agencies’ understanding of the work, which understandably frustrated many workers. While participants saw their job as providing respectful, compassionate care, families and agencies associated their work with specific physical tasks, which meant their work was often viewed as housekeeping or supporting more “skilled” members of the care team, such as the visiting nurse. While aides felt that families asked them to do too much, agencies allowed them to do too little. But in both cases, whether they were negotiating their way out of washing windows or trying to get an agency coordinator on the phone, aides felt that this disregard for relational care prevented them from meeting their patients’ needs.

In fact, one of the strongest and most troubling findings in this study was the overwhelming lack of support that aides felt from their agency. Studies of care workers, and home care workers in particular, have shown that both supervisors’ behavior and organizational support positively affect job satisfaction and make workers feel respected, trusted and confident in their ability to perform their jobs. On a personal and professional level, workers cared deeply about their patients’ welfare, and were frustrated that they had nowhere to turn with concerns about their client. Since aides both desire more expanded roles in patient care, and are the members of the care team who spend the most time with their client, limiting their role is clearly a missed opportunity to improve patient care.

Aides also recognized that while family members and agency coordinators did not respect their caring role, they still benefited from the extra gifts of care that the aides provided, which kept patients happy and relieved family members of many caring obligations. However, because the family and agency coordinators did not consider this additional care to be part of the job, aides were largely on their own to determine what kind of relational care to provide, and how to
deliver it. As Maria Ibarra noted in her study of California workers, while aides may be trained to feed and transfer patients, they are not given specific “feeling scripts” to navigate the relational aspects of their work. While aides’ emotional intelligence may help them to create and manage these “scripts”, aides in all groups nonetheless told us that they needed additional support from their agencies to navigate relational care. (These challenges are explored further in Chapter 6.)

Supporting Aides in Performing Caring Work

The relational care that home care workers provide is often referred to as “extra” or “surplus” care. Neither term is correct. Aides are not providing “extra” care, they are providing necessary care. Supporting patients’ emotional health is a critical step in fulfilling the HCBS goal of allowing elderly, frail and disabled individuals to live healthy, independent lives and be integrated fully into their communities. Because of their sense of personal and professional responsibility to their patients, home care workers are currently filling this care gap at no cost to states, families or their agencies – but at significant cost to their own financial and, as I demonstrate in the following chapter, emotional well-being. The fact that aides genuinely care for their patients does not mean that they should not be fairly compensated for their work, and supported in performing all aspects of the job that good care requires.

Perhaps most concerning is the wide gap between formal agency policies and the care that is practiced in the field, for two reasons. First, while aides with high levels of emotional intelligence may be able to navigate this work, they nonetheless need formal acknowledgement and support for their emotional labor. In particular, aides told us that they needed help negotiating boundaries with patients and family members, and reaching a member of the clinical
care team to report patient concerns. Second, it is ethically troubling that while agencies formally restrict aides from working additional hours or performing work off the care plan, they are clearly willing to look the other way when this uncompensated work benefits patients and the agencies’ bottom line. In fact, agencies actively market these services, offering consumers “quality, loving, in-home care” and “trustworthy, kindhearted, senior home care” that “enhances the quality of [your loved ones’] lives.”138,139

States’ ongoing efforts to rein in the costs of long-term care may exacerbate these tensions. In my follow up conversation with the focus group participants, many expressed concern that in the year since New York State implemented a Medicaid managed care program, they and their clients had seen a decline in hours. This perception is supported by a recent report from Medicaid Matters NY, which found that that New York City’s managed care providers had been systematically cutting patient’s hours, often without proper notice or legal justification.140 In the last six months of 2015, the number of hearings per month challenging service reductions for managed long-term care home care beneficiaries increased by 600%.140 Aides told us that these reductions were putting further pressure on them to go the “the extra mile” to make sure their clients’ emotional as well as physical needs were met. One aide shared that to compensate, "you take your personal time and stay longer…sometimes they’ll offer to pay you. They don't want to see you not get paid for your time.” But, at the same time, she noted protectively that “the patient has insurance - they shouldn't have to pay” (Aide 1732, Group 1). And, although new minimum pay and overtime rules for home care workers are now in effect, many states report that agencies are restricting work hours to control potential cost increases, which could lead to even larger gaps in the already insufficient provision of care.141 While controlling skyrocketing healthcare
costs is an important issue, these efforts should not be made at the continued expense of the quality of patient care.

Improving the quality of patient care will require expanding our definition of home care services to include the critical physical and relational care gaps that aides are currently filling. Reframing these tasks as visible, necessary care is an important first step to both ensuring that patients receive the full scope of services they need to live independently, and that workers are prepared to provide them. On the policy and agency side, this will mean explicitly building relational care into care plans and quality assessments. On the workforce side, it will mean building relational care competencies into home care job descriptions, training, and worker support.

It will also mean leveraging home care workers’ expertise by integrating them more fully into the home care team. Home health aides and personal care attendants provide the vast majority of home care services, and are highly attuned to their patients’ health, yet their extensive patient knowledge and caring skills are often dismissed. Rather than reporting care concerns to an administrative coordinator, aides should have a reliable direct line of communication to a nurse or supervisor to report on patient care, or receive immediate support for any problems at the worksite. With so many channels of communication available, from email to texting, agencies could implement a range of solutions that could connect aides directly to clinical staff. Some efforts are currently underway to do this; New York State’s 2017 budget allocates funding to an Advanced Aide program, which will allow aides to take on more clinical responsibilities, and a small number of pilot programs that provide aides with tools to alert nurses and care managers to early changes in their patients’ health and behavior have shown promising initial results.
Overall, these findings demonstrate that re-aligning our understanding of quality care to reflect the work that aides are already performing, and their central role in the care team, is the best way to ensure we can provide our aging population with high-quality care that fully supports their physical, cognitive and emotional well-being.
Chapter 6: The Effect of Caring Work on Aides’ Well-Being

While Chapter 5 examined aides’ perceptions of the nature and delivery of quality care, this chapter focuses on the other side of the caring relationship; namely, how providing “good” care affects the well-being of workers, including their physical, emotional, and economic health. While the intrinsic rewards of caring labor, such as close, affectionate relationships with patients, feelings of pride and accomplishment in one’s work, and a sense of meaning and value can support aides’ well-being on the job, external factors like a lack of respect and appreciation, lack of control over the work environment and work/family conflicts can harm it.

In discussing quality care, aides identified two important concepts; the “special bond” they cultivated with patients that allowed them to provide holistic, comprehensive care, and the conflict between personal and professional roles in navigating what type of care to provide, and how. Both of these concepts are key to understanding the emotional impact of caring work. Annemarie Mol writes in The Logic of Care that caregiving often requires those who provide services to “inhabit multiple roles” both as healthcare professionals and caring individuals. Good care is not just a set of technical tasks, or “a matter of good sentiments and warm relations between people” but a carefully calibrated combination of both. Sociologist Clare Stacey proposes that home care workers in particular face this duality, since home care is a site of “marketized private life” where “the ‘feeling rules’ associated with aides’ emotional labor dictate that care is both a familial obligation provided altruistically as well as a job that requires professionalism, objectivity, and distance.” In other words, providing good care requires aides to continually make decisions about whether to draw on their emotional skills, technical skills, or both.
Inhabiting these dual identities can be both emotionally rewarding and challenging for workers, either supporting or undermining their ability to “feel good and function effectively.” On one hand, aides often genuinely enjoy and find fulfillment in their relationships with their patients. On the other, the emotional work of caring for elderly, ill, aggressive, or dying patients can cause tremendous strain. In their work on family caregivers, gerontology scholars Rhonda Montgomery and Karl Kosloski proposed a “caregiver identity theory” to help understand these conflicts. The theory posits that as one’s parents or spouse grow older and more dependent, existing family relationships give way to a new caregiving identity as family members shoulder an increasing number of caregiving tasks. This shift causes strain when the activities family members find themselves performing are incongruent with their previous role identity as a wife or daughter. But with paid caregivers, the opposite is true - aides start as professional caregivers, and then take on more familial roles as they build trusting and ongoing relationships with their patients. It makes sense that aides would also experience similar stresses in trying to reconcile these two roles, one in which care is given freely, and one in which it is paid for.

In these four focus groups, home health aides clearly described the stress that could come from balancing their professional roles with their personal relationships to their patients. But on top of this duality, they described an additional strain, which came from feeling undervalued both as individuals and as skilled professionals by the agencies that employed them, and at times their own patients and the patients’ family members. This emotional strain, like the practical challenges aides faced in providing care, stemmed from the invisibility of their relational work. While on the professional side, aides felt they had little support in providing or negotiating relational care with patients, on the personal side, they felt they had little support in navigating the effects of that relational work on their own lives.
Caring Relationships and Emotional Health: “Just making the patient happy makes you happy”

Chapter 5 illustrated that for aides, good care meant making patients happy, a consistent theme in studies of home care workers.47,132,146 But providing this good care also generated personal and professional rewards.

Personally, aides found the close relationships that they worked to build with their patients emotionally satisfying. Participants described these relationships as more personal and companionate than professional, sharing how they and their patients would “[have] fun together” or “joke around…talk to each other, listen to music, we play bingo, cards, everything” (Aide 1100, Group 1). When asked to describe a good day on the job, one aide shared that “a good day for me is after we have a doctor’s visit and then she would say, ‘Let’s go for a coffee.’ Then we’ll just sit down and laugh and talk and it’s good” (Aide 1202, Group 1). One of the male aides noted that as a man, he was placed solely with male patients, which helped foster mutually companionate relationships. “Most of the male – they’re going to be like, oh, you know what? I want you to stay with me. Because you’re just cool. It’s like a friendship. They don’t see me as really the aide” (Aide 1237, Group 3).

Professionally, on days that they could make their patients happy, aides described a sense of pride and accomplishment in their work; it “makes you feel good, like you’re doing something that’s good” (Aide 1700, Group 2) or “like you accomplished something” (Aide 1620, Group 4). As one aide put it, “by the time I get home, I say, oh, you know what, I did a great job (Aide 1206, Group 1). The rest of the group agreed emphatically, with other participants adding, “yeah, you pat yourself on the back” (Aide 1732, Group 1) and “you feel accomplished, like you’ve done something good. You’ve done a good deed for the day. Just to leave them with a smile on
their faces, that’s just enough.” (Aide 1100, Group 1) The genuine connection that aides experienced with their patients on these “good” days also reduced the strain of “performing” emotional labor, since these feelings aligned with their authentic emotions. Aides described feeling “light” or “free” at the end of these days, or as one participant put it, “you don’t feel overwhelmed. You don’t feel bombarded. You feel confident enough to where you feel like you’re home. You can be yourself” (Aide 1732, Group 1).

However, aides acknowledged that it wasn’t always possible to make a patient happy, and this could be stressful. Many agreed that patients “are not always nice” (Aide 1732, Group 1), and could be demanding and unpredictable. As one aide shared, her patient was “good at times. She can be very nice. Very, very nice woman. Then, the next time she just blows up and goes crazy” (Aide 1049, Group 4). In these cases, aides did have to “perform” caring emotions, practicing emotional regulation in order to remain calm, supportive and caring. But, with long-term patients, the close relationships and open communication aides had established often gave them the confidence and sense of control to address or resolve this “grumpy” behavior head on:

- I think if my patient, when she has her bad days, the next day she would come and apologize. She said, “you know what I did yesterday? I’m very sorry. Will you accept my apology?” (Aide 1094, Group 3)
- I said to her you need to calm down. You need to know how to talk to people, and do not disrespect me. Because never ever one day I walk in this house and disrespect you. So the respect that I gave to you, I am demanding it. (Aide 1507, Group 4)

Caring for patients with declining mental health could also prove emotionally challenging. One aide described the mental and physical strain caused by working with a long-term patient who was beginning to experience dementia:

- Some of these patients – they take a toll on your health. It take a toll on my health. Stress. One [patient], she was totally Alzheimer’s. I have to be running every minute. She’s get up – have to be behind them. If she tried to open the door – have to be behind, almost 12 hours a day…from 8:00 to 8:00…she’d get up – I’d have to walk behind her because I don’t know what she was going to do. You understand? Sometimes she want to go to the bathroom…I say, Grams, let me help you - before she reaches the bathroom – I tried
to put her on the toilet – she done messed the whole place. She kept saying, “I want to go to the bathroom.”…I was so depressed and tired that I tell my agency – I said I don’t want this job…The [patient’s] daughter cut off the fire because [the patient] boiled water on the stove. She disconnected the gas. Because she would go and turn the stove on. Sometimes she would go in the bathroom and turn on water. Sometimes she wants to go out in the park. She wants to open the door and go…I say let me lead her because she can’t walk…That takes a toll on you. It did with my health. Until I reach a point I say, I have to leave this patient because, like, you’re going crazy. (Aide 1620, Group 4)

With physically and emotionally difficult cases such as these, aides would often have to make a judgment about whether staying on the case was “worth it.” When a patient’s mental decline occurred in the context of a long-term relationship, aides seemed more inclined to stay. However, with newer cases, the challenges often outweighed the benefits. One aide described how caring for a new “nervous” patient was affecting her health, and making her consider leaving the case: “The family is there to assist, but I’ve been there for a week and my back is already out of socket. Already. Already. And I have to feed her and I have to bathe her. Anytime she has to go to the bathroom, I got to pick her up. In the wheelchair. She’s a very nervous person, so if I just do this, she’s screaming and hollering….It’s not an easy case” (Aide 1639, Group 3).

Valuing the Care: Appreciation and Respect

Aides’ well-being was often mediated by the level to which they felt they and their work were valued, meaning that their personal contributions were appreciated, and that their professional work was respected. Acknowledgement of the value of their work by others reinforced aides’ own sense of the importance of their work, and confidence in their skill in providing it. Aides generally felt that their patients were the most consistent and frequent source of appreciation and respect, an important recognition since so much of aides’ work went unacknowledged outside the caring relationship. Simply “hearing them say thank you and they appreciate what you do” (Aide 1854, Group 2) made aides feel valued. As one aide put it, “A lot of my clients appreciate what I
did for her, it made me feel wonderful. I go home smiling. Happy” (Aide 1507, Group 4). Aides also remembered when clients acknowledged their professional expertise, and shared these stories with pride:

Sometimes patients can say they’re happy for you. Because I remember I had one patient – that man was blind and they had to close my case. They closed it because they had to change the agency. Then he called my supervisor, told her, “Thank you very much to [name]. She was the best.” It was so happy for me. (Aide 1485, Group 4)

She loves her when I groom her … she will pat it and say, “Good job, thank you.” Anything I do for her, she always says thank you. She will tell me I’m the best, I’m number one. (Aide 1854, Group 1)

However, not all patients were appreciative, and many aides shared stories of feeling personally and professionally disrespected. As one aide noted, “one of the things I do not like, we provide care for the clients and yet they look down on us” (Aide 1507, Group 4). Others agreed that some patients could be “very mean” and make aides feel unwelcome and untrusted in their homes. Participants recounted stories of patients saying “you can’t touch your phone” (Aide 1094, Group 3), “you can’t put your food in the fridge, you can’t warm your food in the microwave” (Aide 1202, Group 1) or even that “you can’t touch the paper towels” (Aide 1620, Group 3). One aide recalled feeling hurt when a patient reprimanded her about electricity use, saying “‘don’t waste my energy. You don’t pay my light bill here.’ That was very challenging to me that I used to cry in bed and everything a couple of times… ‘Don’t sit on my couch because you’ll break my couch. You don’t pay for my couch. I had a chair for you to sit down there next to the door like, you sit’” (Aide 1202, Group 1).

Aides found the perception that they were untrustworthy to be particularly insulting, since they were on the job to help, and put significant effort into building trusting bonds with patients. As one aide asked, frustrated, “why do they think we are thieves? I’m saying every client that I work with, from the moment you stepped in the house, they show you a seat. See that chair over there?
Put your stuff over there. That’s where you are to stay” (Aide 1049, Group 4). With ongoing patients, aides generally made the choice to laugh these incidents off, although often with underlying feelings of hurt and frustration. One aide shared a story about how her long-time patient had grown suspicious of her after learning about a friend’s bad experience with her own aide:

The time her friend tell her that, that woman started hiding stuff. One thing I know, she has the Alzheimer’s. She’s forgetting when she moves stuff. She likes to blame me. Say I moved it. I said I didn’t move it. I say Grams, I did not move your stuff. You’re going to find it. Sometimes I see where it is, but I wouldn’t bring and give it to her because the first thing she’s going to say is I put it there. Then eventually she finds it. Like she was looking for some panties – some new panties….she keeps saying I took them. I said Grams I did not take your underwear. It’s where you put it. She’s looking there, she’s looking … she started smiling. I said where did you find it. She put it in her drawer all – [Laughter]…Once someone come and tell her something, she go with it. She runs with it. She changed. She didn’t used to be doing that before. (Aide 1507, Group 4)

However, while this aide presented the problem as a side effect of her patient’s dementia, others disagreed over whether a lack of respect could, or should, be explained away by a patient’s confusion, mental faculties or moods. One group debated over how much leeway patients deserved, capturing the mixed emotions that aides often experienced when reconciling their own feelings with their professional roles. Again, while the group joked about these difficult patients, there was nonetheless an undercurrent of hurt feeling:

1125: Some of them, they don’t care [about showing the aide respect]
1854: Yeah, some of them don’t care. [Laughter] My patient – she’s like moody.
1125: They say, “That’s your job.”
1854: One day she’s really nice. Because of her disease – the Alzheimer’s – she’ll be like cursing me and saying stuff. Then, the next minute she’s really, really nice…
1378: That’s a disability that she has. It’s not really directed at you. That’s how Alzheimer’s -
1065: Because sometimes if they – if this is what they have. Like dementia. So they say those things….
1700: Sometimes some of them – they don’t have dementia. [Laughter] (Group 2)

Grief and Bereavement: “This affects us, too”

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This was a source of some disagreement, particularly in Group 3, where the majority of the aides did not feel distrusted by their patients.
While the close, caring relationships aides built with their patients could provide happiness and satisfaction, they could also lead to tremendous grief and loss when patients passed away – a common occurrence when caring for a frail elderly and ill population. One aide poignantly described her last few days with a terminally ill patient, which included an off-hours (and unsanctioned) trip to Atlantic City:

I went to Atlantic City with my patient. She knows she’s going to die soon, so she tells me, “It’s in my bucket. I’ve never been to Atlantic City. Don’t go to work Saturday. Come with me. I’ll pay your ticket.” So, I go with her. We have a great and fabulous day that I never had before. We went to the hotel casino. We drank mojitos. “I’m going to die of happiness,” she say. We went to the beach. We take a little shower. That’s when she say, “[name], thank you for this. Tomorrow will die happiness.” Couple days later she died…. But she made me happy and I made her happy. (Aide 1507, Group 4)

The complex feelings conveyed in this story resonated with the other participants, one of whom commented, to agreement from the group, that this was a “happy sad ending” (Aide 1620, Group 4) – a term that could describe many of the conflicting emotions aides experience in long-term caring relationships.

Compounding workers’ own experience of loss was a lack of support from the agency after the death of a patient. The few studies that have examined home care workers’ experiences of patient death have found that with close patients, aides experience emotions similar to losing a family member. In these cases, support from agency supervisors and ongoing contact with the patient’s family can be important factors in processing grief. But participants in these focus groups reported that when a patient died, the loss was rarely acknowledged by the agency. Instead, aides felt that the agency only viewed the death as a scheduling issue to be resolved, and that they were often quickly reassigned to a new case. For aides who had formed close bonds with their patients, this lack of recognition of their personal bond could be devastating. As one aide told the group, “three months ago my patient who I had actually for seven years passed away and I had her for a long time and she’s like family. But no one – don’t know nobody come to ask me how
I’m doing, I feel there’s a poor system with the family, because they don’t come to find out how I’m doing. The supervisors don’t ask you how you’re doing, all they tell you go to another case. You get a new patient” (Aide 1029, Group 1). But several aides said that they simply couldn’t face taking on another patient so quickly. As one shared, “I was working for a little guy and he died. And I had a bond with that boy. And after he died, I was so depressed it’s like a part of me just left. You know like when you’re working with children, it’s like you develop that special bond with them and then he died and it’s like I felt like something left me, and I was in a stage of just depressed. I had to stay away from work for at least two, three weeks. Before I could start it again” (Aide 1202, Group 1).

These experiences could become even more stressful when aides were unprepared for a patient’s death. One aide captured this emotional “perfect storm” when describing a particularly harrowing experience of comforting a dying patient she hadn’t been informed was terminally ill, without training or preparation around patient death, while caught in the middle of a conflict between the patient’s family members:

They prepare us to be a good home healthcare. They don’t prepare you in the classes to be prepared when the patient is going to be dying. I had a situation. My patient is a hospice so she’s probably dying in the house. I didn’t know that. I didn’t know. I’m just starting to the job. At 50 years, she didn’t feel good. She started breathing little bit, her pulse going down. I call her daughter – she’s coming right away. Her granddaughter called the paramedics. The paramedics came, and I see the big fight I’ve never seen before. Because the daughter said I got the paper that she didn’t want to be [resuscitated]. Okay, so [the granddaughter] denied it. Okay, so they starting fighting in front of me. The patient starts dying. I hold her hands and dying in the throw of my hands. I feel nervous because this is the first time I see that somebody’s going to die. Nobody did tell me what are the next steps to do….I have to clean up the body until the police came, put her into back of the thing. But it really impacted me. After six months I could fall asleep. I went to the doctor, say I’m really anxious because every time I close my eyes I see me in my grave.

(Aide 1548, Group 4)

Across these cases, aides emphasized that it was not simply the death of the patient that caused them emotional pain and distress, but the lack of outside recognition or support for their loss.
This emphasized that patients are often aides’ most consistent source of support on the job, and when patients die, aides often lose both a companion and a support system.

**Emotional Rewards and Challenges outside the Aide-Patient Relationship**

When aides felt valued by those outside the aide-patient relationship, they were able to view themselves as skilled and caring professionals, which increased their sense of confidence and self-worth. However, when aides felt their work was taken for granted, or that they were simply considered “bodies” providing a service for pay rather than individuals with personalities and feelings, these factors could cause stress or compound the strain they were already feeling, often negatively affecting their confidence or satisfaction with their job and even themselves.

**Recognition from Patients’ Families**

Aides mentioned that appreciation and positive feedback from patients’ families gave them a sense of pride and accomplishment. As with patients, aides remembered and acknowledged these gestures, recalling how pleased they were when patients’ children said things like, “whatever you’ve done for mom, you know, I appreciate it. Thank you very much. You’ve worked hard” (Aide 1878, Group 3). This recognition also often made them want to continue to go the extra mile in their work. As one aide noted, it “makes you feel good. Feel like you want to do more work as well. Because if the family’s telling you that you’re doing good, you know, you want to do more and more.” (Aide 1382, Group 3) Aides agreed that when family members treated them respectfully, they were often more willing to make exceptions to the POC since “it’s not asking you to do something, but the way [the family] does it”, and that “you would go willingly and do something, although you know that this is not way it works” (Aide 1100, Group 1).
In some cases, appreciation and respect from family members could mediate the emotional strain of working with a difficult patient. For instance, one aide who had worked with a volatile patient for several years noted how the family’s recognition of her work kept her on the case:

My client’s daughter – she always go, “Ms. [name], thank you. Thank you for taking care of my mother”…[the patient’s son] doesn’t talk much, but he’ll come and say thank you – “Thank you for taking care of my mother.” I feel good because I know that I’m doing a good job and they’ve seen that things have been changed as I’m doing them. You know how much I want to leave that job. Sometimes I feel like – like I felt yesterday when [the patient] cussed me out. Yeah, she cussed me out real bad. (Aide 1049, Group 4)

However, like patients, family members could also be “mean” (Aide 1537, Group 3) or “ugly to you” (Aide 1639, Group 3), and often disrupted aides’ work or their relationships with their patients. One aide felt that the disabled son living with her patient provoked her for his own entertainment. “He will come up with any little thing just to make an argument,” she said. “You know just when he gets bored to be nosy, and just watch everything that we do. Which is very kind of annoying. Makes it kind of hard for me” (Aide 1807, Group 1). As described in Chapter 5, many aides also felt disrespected by family members who perceived them as “housekeepers” or “maids” rather than healthcare professionals, and asked them to take on more household tasks. Even though aides had the power to refuse work outside the POC, in practice, these negotiations could be emotionally and diplomatically complex, since aides feared that refusing extra work could result in losing hours, being removed from their case or causing tension in the household. One participant likened these negotiations to walking a tightrope, noting that it “takes a lot of work. You got to make that family member happy and you got to make that client happy…sometimes I get like, wow, I don’t know how long I’m going to be on this job. It takes a lot of toll” (Aide 1378, Group 2).

Balancing patients’ and families’ needs could be especially difficult when aides found themselves in the middle of family disagreements. One participant described her conflicting
emotions during an argument between her patient’s mother and brother over whether the aide could be asked to perform extra cleaning. As her patient grew more and more upset, the aide simultaneously felt guilty for being the source of the argument and angry about the family’s lack of respect for her role:

They’re really fighting, and that’s affecting my patient….he is kicking and yelling…he’s getting angry….so that’s upsetting him. Then it’s like, my concern is him. In my head, I’m thinking what did I do that was wrong that started everything. … Then again it’s like, you know what, it’s not even what you did. It’s the fact that the family member doesn’t know how – [the patient’s mother] doesn’t know how to talk to the workers … Then that’s the challenge where you have to deal with family issues – problems in the house and then having your patient being emotional towards everything. (Aide 1732, Group 1)

At the same time, the aide felt a responsibility to keep the peace in the household and stay on the case for her patient’s emotional health as well as her own. “You know that the only person that loves you and you love them back is your patient,” she explained. “More reason for you to stay in a way where it’s like, you know what, if I leave, his health, his condition is going to get worse. It’s gonna break my heart, and it’s gonna break their heart.”

Support from Agency Coordinators

Studies of job satisfaction among agency-based home care workers show that because of the decentralized nature of the work, aides often feel disconnected from their supervisors and receive little feedback on their work. This was true across all four groups; one of the strongest and most consistent themes that emerged in both the focus groups and the report-back sessions was the lack of respect and appreciation that aides felt from their agency coordinators and supervisors, around both patient care and administrative issues like scheduling and payroll. The general consensus was that “they don’t care about us” (Aide 1202, Group 1) and “they don’t appreciate what you do” (Aides 1065 and 1378, Group 3). Aides often felt the agency viewed them as interchangeable, and that “it’s all about the money. Make sure you have a body there to take care of that client. That’s the main thing. Have a body and they can get their money” (Aide
1378, Group 2). Since aides were often deeply and personally invested in their patients’ well-being, this lack of appreciation for their specific role in patient care was both frustrating and insulting.

When agencies did treat aides respectfully, workers noticed and appreciated it. A few aides noted that their agency was “nice” and coordinators supported them in issues like negotiating boundaries with family members. One of the male aides described how meaningful he found the personal touch and acknowledgement he experienced working with a smaller, non-union agency, noting that:

[The small agency] always call and say, “Oh [name], thank you very much” before I leave. I appreciate that compared to a bigger company… they’re going to write you up if you’re not able to work with that client….bigger companies.. don’t appreciate you. Just sometimes [it’s important to hear], you know what, thank you. You’re doing a good job. (Aide 1237, Group 3)

In addition to not respecting the work they performed, aides also felt that agency coordinators did not respect their time. Almost every participant had shown up to a patient’s home to find another aide already there, which often resulted in a standoff to see who would stay and who would only be compensated for travel time. One aide recalled the frustration of juggling her own schedule to be available for her patient, only to find another aide had also been sent to the case:

“Sometime I cancel my doctor’s appointment to go and help a patient. When I get there, they send somebody else there. You know and I have to go back home. That person doesn’t want to leave. Even I was there first, they want me to leave …it’s stressful” (Aide 1304, Group 1).

Several participants also mentioned how the office culture of non-response made resolving payroll or scheduling issues difficult. One aide recalled calling her supervisor about a payroll issue, and “you know what she told me? ‘I don’t have nothing to do with that. Don’t call me.’ …

And then she had the nerve to call me and says, ‘Can you come in on Wednesday to do some
extra time?’ I said, no, no. I didn’t get paid. I’m not” (Aide 1878, Group 3). Often, because reaching a supervisor by phone was so difficult, aides were forced to resolve issues in person, which meant finding time during business hours to travel to an office far from home or work. Many aides felt that they were “wasting time…going in there…you have other things to do…you got to go in the office every minute just to run down for your own money. That’s so annoying, so annoying” (Aide 1324, Group 3).

Aides experienced similar frustrations when trying to negotiate work hours, often feeling that they were at the whim of the coordinator. Some participants in Group 3 suspected that the agencies had “favorites” who were assigned more hours and better cases. In Group 4, several participants felt coordinators deliberately denied them time off for classes to keep them from moving on to better jobs:

I tell my coordinator the days that I have to go to the school – [then] I speak with the supervisor over the coordinator. She didn’t care. So, I go to the head – to the director – said, “Listen to me. I’ve been working with this company for 15 years, and I’m just asking for my schedule.” I need only 40 hours [of work] so I’m just asking for two days that I make sure that I complete my 40 hours. Why did they do this to me? Because they don’t want you to continue to study. (Aide 1485, Group 4)

There was general agreement from the group on this issue, with one aide describing how she felt she needed to “fight” for her schedule, or remain in a job where she was undervalued and undercompensated. “I fight for my Saturday to go to class on a Saturday. Do my class,” she told the group. “I said no I’m not working weekend. I said I need that Saturday off. I need it…..I said listen to me. I want something better. If I want to be in this company 20, 25 years and then…when I retire, they have nothing to give me. I have no retirement plan. No retirement plan. They don’t got 401k. You want to stay in a job where you have a 401k – why are you working for this little bit money they’re giving you” (Aide 1049, Group 4).

*Negotiating Boundaries: Physical Safety*
The complex emotional struggles and lack of support that aides experienced in trying to provide the best patient care while navigating relationships with patients, agencies and families were most clearly illustrated in their stories about personal safety. Many aides shared experiences of managing aggressive patients, unsafe living conditions, or untrustworthy family members with little outside support, which often left them feeling isolated and vulnerable on the job.

Chapter 5 described how aides often walked into new cases cold, without prior information about the patient’s health status or home environment. This lack of preparation, along with many aides’ prior experience with aggressive or unpredictable patients, caused workers to approach new cases with caution. Aides framed many of these stories as humorous incidents, but there was an underlying current of fear and anxiety:

I have been attacked three years ago by a patient that they were supposed to tell me or other home aides that this patient was mental. If you do not have the experience you do not know how to deal with the patient. If I did not have the experience, I would have been in trouble. Because this lady she enraged because I told her, I said, “Ma’am, we have a doctor’s appointment, can you please let’s go a little faster because the ambulance is waiting for us.” She raged, took off the bathroom, coming after me, I ran from the kitchen, run to the living room, take my stuff, like all of it, whenever I go to any patient home, even to my patient now I always leave my stuff at a door. [Laughter] Because if I have to run – (Aide 1026, Group 1)

Aides’ self-reliance was a recurring theme across these stories, along with the conviction that in the absence of agency training or support, only aides’ own experience and skills could keep them safe.

Although the moderators did not ask about patients who were sexually aggressive, these issues came up organically in two of the groups. Agencies make an effort to link male patients with male aides, but this is not always possible because of the gender imbalance in the workforce. Many of the aides in these two groups said they were wary of working with men because they were “fresh” and often “kind of want to touch you or they want to – err – do the nastiness” (Aides 1324, Group 3). In some cases, where aides did not feel physically threatened, these
advances might be laughed off. For instance, when one aide shared the story of a friend whose patient exposed his genitals to her and asked her to touch them, the group laughed and agreed “that’s normal” after hearing the patient was in his nineties. However, in cases where aides felt unsafe or isolated, these situations could be frightening and degrading. One aide had experienced sexually aggressive behavior from several male clients, including one who offered her money for sex. She noted that when she reported the incident to her supervisor, she was simply asked why she hadn’t walked away (Aide 1807, Group 1). Another group member agreed that in these cases, “you walk away humiliated” (Aide 1202, Group 1).

Since they did not feel they could rely on the agency for protection, aides often felt it was their responsibility to be hyper-aware of their surroundings and “smart” about their safety:

I try to be smart, always close the door in case I have to run anything like that because [the patient] was very heavy. He always took about two or three minutes to get up you know from the bed, from the chair….Then you know [a patient] got something – have maybe a mental issue – they could get up any minute when you’re not expecting it. I was always afraid kind of… It was all dark besides his room – only one light. It’s like he wanted to turn off the lights – I said, oh, no, no, hold on, at least turn on the two lights. Because I will have to sit there in his room next to him in his chair, kind of next to him. Like this is his bed here right here and I’m right there, and that’s it right there. I was sitting right there next to door just in case I had to leave, you know run. It was very, very funny. The supervisor expects you to call them when things like that happen. But sometimes, like I said, I figured out you have to use your brain. Be as smart you know how to entertain for this not to happen, you know. (Aide 1807, Group 1)

Yeah. I think something was wrong and [the patient] couldn’t walk that much – that properly. [Laughter] Yeah. He threw himself down so I can hold him. [Laughter] But it was just a weekend case. I was like, Lord, please let my two days finish so I can just leave this man’s house. Since them, I tell them never send me back to no males please. Please….at least he cannot walk properly. Because he might hold me down in there. (Aide 1324, Group 3)

These situations appeared to occur primarily with new patients, or when aides were filling in for other workers. In these cases, aides would general report the incident and not return to the case; the consensus among all four groups was that the dangers weren’t “worth it”, and that after a bad experience or two, “I ain’t taking chances no more” (Aide 1878, Group 3). But, in some cases
the need outweighed the dangers; some chose to remain on dangerous cases because “I need the hours and money for me to pay my bills” (Aide 1807, Group 1).

Several aides also expressed concern that they never heard how their reported incidents were resolved. As one aide put it, “you report it. Then, they let you know, okay, well, we not assign [you] back to the case. We’ll just report. But I don’t know what they’ll do with [the patient]. I don’t know” (Aide 1324, Group 3). This lack of feedback, along with the lack of advance information about new cases, understandably made workers apprehensive about taking on new patients. As a result, aides felt the need to be constantly on their guard and to “just carry yourself with you” (Aide 1732, Group 1) in case a “quick exit” was needed.

Aides in all four groups also expressed safety concerns around their patients’ families, sharing stories about family members who would borrow or steal money from them, or rifle through their personal belongings. One aide described the anxiety she felt leaving her possessions unguarded after she found her patient’s son looking through her purse:

> When I have to leave like I know that he’s going to check my purse or I don’t know what he’ll do to my purse….It is very uncomfortable. Like, now, ever since that happened, I always have it in my head, what is he doing in my purse when I’m not there? What is he doing when I’m bathing my patient…I have that in my head…once, I had like my gym backpack, I could put a lock on it so. But I cannot always carry it out because then I have to go to both my jobs. I’m not always going to the gym. So, whenever I’m at their place I could put a lock on it, I feel like oh my God. (Aide 1807, Group 1)

Outside patients’ homes, aides were also often anxious about their personal safety in the neighborhood. Participants noted that working with a primarily low-income, Medicaid population meant going to neighborhoods that could be dangerous. As one aide noted, to strong agreement from the group, “you could just feel that it’s not safe…you know the kind of people that you see coming out in the building – I mean I don’t want to judge anybody, but you could just look at somebody and just be so afraid” (Aide 1202, Group 1). In one extreme case, an aide
described caring for a patient who was harassed by neighbors because of her religious beliefs, and how she feared she would also become a target:

I used to go with uniform. She would tell me when I come in do not come with uniform. I would put my uniform in my bag because a previous aide before got beaten up very badly and hurt. One Sunday we heard like someone throw something at the door. When I looked through the peep hole I said I think they threw like a bag and a bottle. When I opened the door, oh my god, I wanted to die. [Laughter] I called the super and I told him what happened. He said, “Okay don’t worry about it. I’m going to send someone to come and clean it up.”...It was feces, urine, garbage, all kind of stuff, dirt, everything. They throw at her door. (Aide 1026, Group 1)

Aides acknowledged that in situations where their physical safety was threatened, the formal policy was to call the agency coordinator and then leave. However, in practice this could be more difficult. As one aide recalled, “They send me to a location, and you walk into a location and you don’t feel safe – it looks like drugs, or - call [the agency] immediately and go home. But a problem, you have to call them first” (Aide 1507, Group 3). Since aides could rarely reach their coordinators to report these incidents, both the agency’s own rules and aides’ sense of personal and professional responsibility prevented them from leaving vulnerable patients alone. While aides said coordinators claimed “they’re not going to put our life at risk” (Aide 1485, Group 4), in practice, “you cannot leave your patient alone...in case something happened. You are responsible for your patient” (Aide 1202, Group 1). In these cases, aides’ concern for their patients generally won out over fears for their own safety.

**Competing Caretaking Roles: “We have to please our parents, our friends, and our patients too.”**

Many aides were not only caregivers at work, but also at home. This was another source of tension as aides juggled their physical and emotional responsibilities to their patient “family” and their actual family. In negotiating these competing roles, aides’ own needs often came last.
The clearest conflicts were around time and scheduling. Aides were acutely aware that “most of your time is not with your family”, and even when they were at home, their schedule was often at the mercy of the agency. “You can get a call – I could be sitting right here, and the phone ring, and they call you,” noted one aide. “You on call. You can refuse it, but you don’t know when they’re going to call you” (Aide 1324, Group 3). Other participants agreed that when the agency calls, “you got to take it” (Aide 1878, Group 3). Family time could also be cut short by a patient’s transportation running late, or a doctor’s visit lasting past a scheduled shift. While agency policy instructs aides to call for a replacement in these cases, many aides found this impractical and disruptive, and chose to see the patient home even if they were not compensated for the extra time.

On top of physical scheduling, aides also experienced the stress of competing emotional scheduling, often feeling that they were disappointing one “family” member by prioritizing another. One aide shared that she often cooked her patient a Thanksgiving dinner to make sure she wouldn’t be alone on the holiday. But, this caring gesture ended up creating tension when it was interpreted as a job responsibility rather than a gift by both the patient and the agency:

Sometimes that patient don’t have no family. We do our best. Then, I bake turkey buffet and make it for her. She invites her friend over and her [friend’s] family. Some other years you don’t have time. You need to spend it with your family too. Sometimes the stressful way she doesn’t like it. She wants you to stay there with her. If you ask for a day off she doesn’t like it. Sometimes you don’t have no choice. We have to please our parents, our friends, and our patients too. Certain people in the agency they don’t understand that if you are asking for a day off. You see what I mean? It’s because you are stressed – they say, “No, you can’t have it.”…I said this year I have to spend it with my family because I have a sick mother who needs me too. But I try to treat the patient the way I treat my mother. But some of the people in the agency, they don’t like it. They think even then and all – they don’t treat you right. They say, “Well you can have that day off. You’re fired.” That hurts me. (Aide 1304, Group 1)

One aide noted ruefully that after her shift ended, “I go home and I do mostly the same thing…. Because I have children” (Aide 1537, Group 3). Other aides described feelings of guilt when their families “pick up on stuff” after a bad day:
It affects you emotionally and your feelings. Because after that you find yourself expressing yourself, expressing those emotions to people who really don’t deserve them. It’s like you don’t catch yourself until they point it out to you – listen, something’s going on, you don’t look right, you don’t sound right, do you want to talk about it, do you want to vent. Sometimes it’s like you want to but you don’t because you don’t want to bring – you don’t want your problems to be their concerns. So that’s an issue. (Aide 1732, Group 1)

I try not to go home and be angry, but I talk with my husband…and once I talk about it, I’m all right. I try not to take it out on my kids either. But they know – they know me. They know when I’m happy, they know when I’m sad. They know something happened. They can see the expression on my face, but I try not to take it home. But you got to let it out. (Aide 1537, Group 3)

Managing the expectations and needs of patients and families often left little room for aides to ask for or receive support for themselves. As one participant asked with some frustration, “who’s taking care of us?” (Aide 1049, Group 1)

**Coping Mechanisms and Support: “We’re on our own”**

When patients, their family members, or supervisors were disrespectful, unappreciative, and unsupportive, aides felt angry, anxious, exhausted and overwhelmed. Aides described these challenging experiences as stressful and “a hard burden” (Aide 1125, Group 1), and noted that sometimes after a bad day, “you don’t want to go back” (Aide 1639, Group 3). Disrespectful behavior was particularly hurtful when aides felt they had put so much of themselves into their work, and given up time with their own families. As one aide described these hurt feelings, “someone is just not appreciating what you do. Leaving your family to come and care for them. I mean that’s a lot” (Aide 1202, Group 1). Others were frustrated with themselves for being limited to a low-quality job; as one aide noted, “like, at this point in my life why didn’t I do what I had to do when I was going to school? It’s like I just started beating on myself” (Aide 1100, Group 1), a sentiment was shared throughout the group:

1620: Yeah. Makes me like why am I even doing this.

1202: Yes. I cry. These are not really tears, but straight down in here [pointing to chest] I cry. Say Lord why do I have to go through all of this just to survive.

1049: Sometimes I say, Lord, it has something better than this, but then I just don’t – some days that’s how I think. (Group 1)
When asked how they coped with these challenges, aides said they largely managed them on their own – an unsurprising finding, given the lack of support participants felt from their agencies and, to a lesser extent, patients’ families. Many aides took a fatalistic approach, noting that the bad days were simply part of the job. As one aide explained, “that’s what you take the job for, right? To be a home health aide. Some days good, some days bad” (Aide 1854, Group 2).

Many aides said that they tried to “let it go” or “just cope”, or, as one of the male aides commented, “you got to discipline yourself. Just like a soldier. You got to suck it up” (Aide 1378, Group 2). Aides also said it helped to remember that stressful days were temporary; as one participant said, “my favorite little saying is that this too shall pass” (Aide 1202, Group 1). But others felt that “letting it go” wasn’t always easy and took deliberate work – in this case, practicing emotional regulation for their own benefit, rather than a patient’s. Several participants mentioned that prayer helped get them through the hard days; as one noted, “I do pray to God so that he may give me strength, I get patience” (Aide 1807, Group 1). Another aide explained how she made a conscious decision to let the work stresses go in order to be fully present for her own family. “I’m not going to get mad and get stressed with nobody,” she shared. “I let it go. I’m not going to stay for the whole day with this…and home or whatever. So, I mean it’s not easy. I know just that you have to deal with the agency. You have to deal with something at the home. Like I have three children. You know. So, I’m not going to get somebody else in to make me stressed and get in my way and make me have a bad day...I never keep something inside for two days. One second and that’s it” (Aide 1065, Group 2).

Some aides did receive emotional support through other outlets. Despite not wanting to burden their families, several participants said their partners helped to “calm [their] nerves” and “take [their] mind off it.” One aide shared that, “I talk with my husband. He says, ‘Did you have a bad
day? I talk about it, and once I talk about it, I’m all right. (Aide 1537, Group 3) Another said that “my boyfriend makes me laugh a lot. So, my mind comes off of it totally….if I’m having a hard day and I just go in and he say something funny, it’s – I laugh. Go, oh my God. It can never be that bad” (Aide 1324, Group 3). Aides also felt that their Education Fund classes were an important support, both to “[do] something for yourself” and to connect with other workers facing similar challenges. As one aide said, “coming to school has helped me a lot to cope. Because when you come you associate with people and then the teacher, if she’s a good teacher” (Aide 1202, Group 1). Another agreed that, “it gives you hope and it kind of strengthens you in a way where it’s like, I’m bettering myself” (Aide 1732, Group 1).

Overwhelmingly, aides felt that their agencies did not help them to manage either the emotional or logistical challenges of the job. However, there was some disagreement within the groups about the role that agencies should take to support workers. On one hand, some aides felt the job was the job, and it was unrealistic to expect support from the agency coordinators. “You’re there to do a job, and I say don’t look for that,” noted one of the participants. “If you’re looking for support, then that’s the wrong job. They ain’t going to give you that….They’re feeling that you get that check. That’s enough” (Aide 1378, Group 4). Others agreed that “you can tell your supervisor about this, but their job is to get us on the case. That’s their job” (Aide 1639, Group 3). On the other hand, many participants expressed a desire for more help managing job challenges from the agency, acknowledging that “sometimes it’s stressful on us. And then we need to find support” (Aide 1026, Group 1).

Aides were also asked about specific types of support they would like to have on the job. The answer, overwhelmingly, was more communication and connection with the agency and with each other. As they had mentioned in Chapter 5, at the most basic level, aides wanted to be able
to reach a coordinator easily, and ideally, know that their concerns and questions were heard and addressed. While practical on the surface, this request also revealed a deeper desire for the coordinators to better appreciate and respect the challenges aides faced on the job. This was a theme that came up across groups; as one aide described it, it was the agency’s responsibility to protect the aide. “[The agency] need to look. They are the ones – we need the job. We go to them. They employ we, and then they send us out to the patient. They should look out first to see if we are going to X, Y place what the place is like and all of that. Sometimes you go into someplace, oh my God” (Aide 1049, Group 4). Aides in other groups expressed similar sentiments, even while acknowledging that home assessments were not the coordinators’ responsibility: “some of the coordinators need to leave the office, come to the patient’s home, see what’s going on there….The visiting nurse comes and she will see if everything is going on straight. But the coordinator need to get up there in the office. Don’t sit in the office. They need to come up [to the patient’s home] and see what’s taking place” (Aide 1065, Group 1).

Discussion

The relational nature of home care work was central to home health aides’ well-being, and their understanding of themselves both as caring individuals and skilled, confident professionals. Overall, aides found their work, and the emotional bonds that they formed with their patients, rewarding and meaningful, and felt their work was valuable. They enjoyed much of the time they spent with the patients and were proud of the work that they did, and confident in their skills and ability to build the strong, mutually caring relationships with patients that allowed them to provide good care. But, there were also challenges and frustrations that “took their toll” on aides’ well-being. Aides’ ability to navigate these challenges was often connected to whether they felt
respected, valued and appreciated. While many aides felt their clients appreciated the care they provided, this was not always the case with their agency or the patients’ family.

The complexity of the relational care that aides provide, and the conditions under which it is provided, demonstrate the limits of standard frameworks for job satisfaction such as the Job Demand-Control-Support model. While the JDCS model measures the demands of a job against the control and support a worker received (suggesting, for instance, that jobs with high demands and low support create stress and dissatisfaction), these measures are largely objective and reflect specific tasks and organizational structure. However, in home care, a significant amount of job demand is outside the assigned care plan; in fact, many relational tasks are self-imposed, even if workers feel they are necessary for patient care. In addition, the decentralized nature of the work and lack of direct supervision or participation in a care team means that support and control are also often nebulous and subjective. Although agencies had formal policies about chain of command reporting or worker complaints, in practice they were rarely followed. Finally, while job satisfaction may be a useful measure for human resources specialists and organizational theorists to understand turnover, it does not answer the larger question of how aides navigate their caring work and the skills they must employ on the job. While job demands, control and support were certainly central to aides’ well-being, a more complete understanding of how these issues affect workers and in turn, patient care, requires a broader framework that moves beyond job satisfaction to encompass worker well-being.

What Does “Well-Being” Mean for Home Health Aides?

Schulte and colleagues, in arguing for a more meaningful definition of worker well-being, note that well-being is most frequently understood in two ways: objective definitions, which include
agreed-upon, standard measures of work and living conditions, such as income, employment and job opportunities; and *subjective* definitions that reflect workers’ experience, such as sense of purpose value. More recently, policymakers have introduced composite measures that attempt to reflect the importance and interplay of emotional health and the work environment, particularly as they affect workers’ ability to perform their jobs (such as the Finnish “workability” index, while assesses work demands, worker health and mental resources).

Schulte and colleagues also raise the question of the scope of the definition; should an understanding of worker well-being be job-specific, or should it also include workers’ general feelings outside their job, and ability to function in life?

Both of these points are critical in conceptualizing the well-being of home care workers. First, the idea of a composite definition is particularly important in home care; while much of the work that aides perform is intimate, relational labor, which has been shown to be connected to subjective feelings of accomplishment and happiness as well as stress and exhaustion, it also takes place within a low-quality job structure that fails to protect workers’ economic security, physical safety or work-life balance. Second, home care workers’ personal and professional lives are deeply connected and often overlap, meaning that a comprehensive model must include aides’ well-being both on and off the job. Because of this, a comprehensive understanding of home care workers’ well-being must include the structural components of the job, as well as the relationships they form on the job, their engagement in their jobs, and the meaning and value they attach to their work.

*What Factors Contribute to Home Health Aides’ Well-Being?*
Chapter 3 described the structural, objective measures affecting aides well-being; namely, wages and benefits. These focus groups confirmed that these factors are important. Despite specifically asking aides to leave issues like wages, paid time off and health coverage out of the discussion, these issues nonetheless arose in every group, reflecting how much they affected workers’ daily lives. But interestingly, they also arose in a number of different contexts that speak to the overlap of objective and subjective well-being, and the need for a “composite” understanding; for instance, in addition to being unable to pay bills, low wages also made aides feel undervalued and disrespected; and while unpredictable scheduling led to lower income, it also affected aides’ sense of control over their work and their ability to juggle work and family responsibilities.

Perhaps most strongly, we heard that it was important to aides’ well-being that their work was valued, meaning they wanted to be appreciated as individuals, but also respected as skilled professionals. As Figure 6.1 shows, this sense of value and meaning was greatly influenced by the context of their relationships (or lack of relationships) with their patients, patients’ families, and employer agencies.

*Relationships with Patients*

In general, workers’ well-being improves when they feel their work is respected and valued, and that they have control over their job. In this project, as studies applying the JDCS framework in home care have found, patients were aides’ main source of support, respect and appreciation.

When patients expressed gratitude for their work, aides felt a sense of pride and accomplishment. But when aides did not receive this support - either because of the patient’s mental health or simply their personality - they experienced higher levels of stress and frustration, as well as less confidence in their ability to do their job. This is consistent with the literature on emotional
labor, which suggests that while “surface acting” that is incongruent with true emotions can be stressful, “deep” acting where workers genuinely feel the emotions they express to clients can be both personally and professionally rewarding. This “deep acting” not only allowed aides to feel authentic affection and pleasure; it also increased their confidence in their ability to make their patients happy and fulfill their needs.56,151

Often, aides received appreciation and respect in the context of strong, ongoing relationships with patients. Not only could aides express authentic fondness for their patients, but their bond better allowed them to regulate their emotions by switching from “deep” to “surface” acting during those times when patients were difficult or “grumpy”. Some research suggests that in cases when emotional labor is too challenging, workers withdraw and are less engaged in their
However, while some aides in this study left cases that required high emotional regulation, others took pride and satisfaction in their ability to manage difficult patients. This effect has been found in the nursing literature, which suggests that high emotional job demands can actually be a motivating factor and improve psychological well-being, since emotional demands are often interpreted as “challenges that provide an opportunity to grow and to develop personal and professional abilities.” Making patients happy, particularly in demanding situations, allows nurses to view themselves as the “ideal of nurse”, or as moral and caring individuals, which generates satisfaction and a sense of control over their work. But importantly, nurses only experienced the psychological benefits of these “challenges” when they had institutional support and resources from an employer to manage them.

*Relationships with Families and Agencies*

Perhaps the most significant issue affecting aides’ objective and subjective well-being was the lack of support they felt on the job. It is problematic, to say the least, to rely on patients as the primary support for aides. While aides found their mutual relationships with patients rewarding and empowering, they also remained keenly aware of their roles as professional caregivers, and the need to prioritize their patients’ emotional well-being over their own. In addition, patients’ own health or characteristics often prevented them from providing the support aides needed. Patients’ families rarely filled this gap. Aides did remember and appreciate when family members acknowledged their work, and these interactions made them more confident and engaged in their work, and wanting to do more. However, more often, family members were absent or interacted with aides in ways that made them feel disrespected and unappreciated as individuals and professionals.
Feeling they had nowhere to turn for support, aides often felt isolated, frustrated, exhausted and stressed. Participants in these groups felt strongly that their agencies did not want to hear about their job challenges, whether these were addressing concerns about patients’ well-being to scheduling, payroll and other administrative issues, or the emotional strain of the patient care. These support gaps were most dramatically evident in aides’ experience of patient death. In addition to managing their own personal emotional loss, aides were frustrated that their caring labor, and as a result, the depth of their loss, was not acknowledged. Rather than expressing concern for the aide, aides felt that agencies primarily viewed patient death as an administrative challenge, or another “body” to be moved to a new case. Several recent studies about aides’ experience with patient death reveal that although aides are “profoundly” affected by the death of a patient, very few feel they can turn to their supervisors or peers for support. However, those who can are better able to process their grief and even stay in jobs they might have otherwise left. 49,147,148

**How Does Aide Well-Being Affect Workers and Patients?**

Why should the well-being of aides matter to policymakers, funders or employers? The impact can be understood in two ways; as an outcome in itself, and in its effect on patient care. First, both objective and subjective well-being have been connected to a variety of physical and mental health outcomes; while worse well-being leads to depression, burnout, stress and exhaustion, higher well-being allows workers to “flourish” and feel better about themselves, and function more productively. 105

The emotional labor and emotional intelligence that are essential to caring work may also be essential to well-being. Karimi and colleagues suggest that effective emotional regulation can
produce a “boosting” effect for workers, where the ability to control emotion provides a sense of confidence and control.\textsuperscript{56} While emotional regulation, in the context of emotional labor, is generally understood in the context of emotions performed for others, in many cases aides in this study described regulating their emotions for their own benefit, and making a deliberate choice to let bad days go to keep themselves healthy. Research also suggests that workers with high degrees of emotional intelligence, as many aides displayed, are less affected by emotional job demands and experience less job stress, and as a result, better well-being.\textsuperscript{55} This may help to explain why many aides in this group of experienced, long-term workers said they were able to navigate job stresses on their own; those with lower emotional intelligence may simply not be able to manage these challenges and leave the industry quickly. In addition, having a strong support system at home seemed to be a mediating factor; several of the aides who most convincingly said they were able to let go of work challenges also noted that their partners were important in helping them to cope.

While aides were unwilling to admit that their own well-being could affect patient care, they did discuss how the stress of dealing with difficult patients with little to no outside support could force them to leave a case.\textsuperscript{131} And, when their contributions are not supported or respected, aides may withdraw and become less engaged, reverting to performing “surface” emotions instead of forming deeper bonds with patients. This is commonly referred to as “stress-related presenteeism”, where employees are physically present but their full attention is not on their job, reducing the quality and quantity of their work.\textsuperscript{55} Not only could this affect patient care, it also affects aides’ own perception of themselves as caring individuals performing valuable work.

But, with the right support and encouragement, evidence suggests that emotionally challenging work can actually improve aides’ engagement and commitment to their job. While no studies
have yet tied together aides’ and patients’ outcomes, several studies of nurses in residential
facilities found that a “culture of companionate love”, or mutual affection, between staff and
patients resulted in better emotional health for workers, as well as better moods, quality of life,
satisfaction, and fewer trips to the emergency room for patients.\textsuperscript{131}

\textit{Supporting Aides’ Well-Being and Patient Care}

Schulte and colleagues suggest that for too long in occupational health, worker well-being has
been presented as an afterthought (“…and well-being”) rather than a guiding principle.\textsuperscript{144} This is
certainly true in home health care, where workers are often viewed as interchangeable or
disposable. Too often, policymakers focus on “the workforce” as a whole, which often limits
discussions of stabilizing the industry to improving wages and benefits. While these are
tremendously important, this reductive approach fails to understand what workers’ emotional
labor adds to the system, and what is lost when poor well-being limits their ability to perform
this work, or to stay in the industry at all. Many aides enter these jobs because of the intrinsic
motivation to perform this work, but these motivations cannot replace extrinsic rewards.\textsuperscript{153} As it
stands, home health aides have all of the challenges, but few of the personal and professional

To perform their work well, home health aides must manage a host of emotional, cognitive and
physical demands on the job; workers must make decisions quickly, employing both empathy
and their technical skills and medical knowledge to keep their patients safe and happy. Yet,
while evidence suggests that supporting workers in meeting these challenges produces better care
and a stronger workforce, in practice home care workers must manage these challenges on their
own. By supporting workers on the job, we can not only improve aides’ own well-being, but retain and build an engaged, committed and skilled workforce.
**Limitations**

There were several limitations to the qualitative section of this project. Most importantly, this research only reflects the experiences and particular set of concerns of aides working for one type of agency, in one type of program.

First, this group of Home Health Aides primarily worked with Medicaid beneficiaries in New York City, a patient group that is very demographically similar to aides themselves in terms of economic status and race. As a result, many aides identified closely with their patients and formed protective relationships that may not reflect the dynamics of aides working for higher-income private-pay (or as the aides called them, “high-class”) patients, or primarily white patients. These aides also worked for state-certified licensed home care services agencies, which are primarily dependent on public dollars to pay for services, and experience different administrative challenges than those in a private, for-profit agency or franchise. For instance, LHCSAs must meet state and federal regulations around care provision and reimbursement for services that private agencies do not, and this could affect aides’ experience and perceptions of their job structure, agency policies, and the care they provide.

It is also important to note that these focus groups reflect the perceptions of only one side of the care team. While some agency policies could be independently verified, aides may have misunderstood or not known some of their agencies’ rules or structures. However, the intent of this project was to reflect the lived experience and expertise of workers, which is often left out of debates over quality care. The way in which aides perceive and experience agency structures are certainly as important to understand as agencies’ formal policies and goals of care.
Finally, perhaps because of their union status and benefits, this group of aides was highly experienced, and had a longer tenure in the field than many aides, so it does not capture the experience or characteristics of those who leave the home care industry – a particularly important factor to explore when considering workforce development.

However, even with these limitations, many of the themes that emerged in these focus groups were remarkably consistent with findings across the home care literature, particularly around the “surplus” care that workers provide, workers’ sense of isolation on the job, and the need for more on the job support. The findings in this paper add to the growing body of evidence on the importance of acknowledging the full scope of home care workers’ roles and the emotional impact of providing and receiving care.
Section IV:

Conclusion and Recommendations
Chapter 7: Conclusion and Recommendations

Ensuring a healthy stable, healthy workforce, and high quality care will require re-aligning the goals of the home care industry. That begins by acknowledging that the “invisible” caring work that home care workers perform is both necessary and important. As it stands, underpaid and marginalized paraprofessional workers are filling in critical gaps in care to compensate for a fractured and underfunded system. If aides were to stop performing this “surplus” labor, it would have a tremendous negative impact on clients, clients’ families, clinical care teams and the administrative agencies that organize this work. Depending on aides’ “gifts” of care to fill the gaps that policymakers, payers and employers will not is not only unethical, it is unsustainable. By performing this unrecognized emotional labor, with little to no support, acknowledgment or compensation from their employers or the health care system, aides jeopardize their own well-being as well as their ability to continue providing a high level of patient care.

As importantly, by dismissing the relational work that home care workers perform, the system is missing out on a wealth of expertise that could inform quality care. Home care workers are uniquely positioned to be an integral part of the care team. They spend more time with their clients than a nurse or doctor, and in many cases, than family members. They are often trusted confidantes, and are attuned to their patients’ overall well-being. Recognizing this knowledge and integrating it into care would benefit both workers and the patients for whom they care.

Recommendations for Future Research

In attempting to link the well-being of home care workers to that of their patients, this project revealed many gaps in the ways we currently measure and analyze both home care jobs and home care quality. First, the delivery of home care services through tens of thousands of agencies, hundreds of thousands of individual providers, a murky informal grey market, and a
myriad of funding and reimbursement structures has made measuring both workforce characteristics and care quality in a meaningful way nearly impossible. Available data on both workers and clients is both limited and siloed, making it difficult to connect the care that workers provide, and the characteristics of their jobs, to client’s outcomes. As I found in this project, workforce data are limited to large national data sources like Census surveys, which almost certainly undercount the workforce, or from smaller studies of individual groups of workers, which may not accurately reflect the status of all workers. National administrative data, like the Medicare cost reports I used, collect only aggregate data on the costs of salaries and benefits, which makes it difficult to understand the amount and types of compensation that individual agencies provide.18,78 On the other end of care, the home care quality measures that do exist are inconsistent across the industry, and focus entirely on the custodial care that aides perform. Even this project, which used the most comprehensive publicly available data capable of linking wages and benefits to quality outcomes, found little connection between the two because the data failed to capture so many potential unmeasured variables, from worker-level compensation data to the emotional and cognitive health of patients. To gain a more complete and comprehensive view of home care quality, researchers should look toward building better reporting structures and instruments that reflect the industry as a whole, rather than its individual parts. Data sets that capture both worker and patient data at the individual level, link agency characteristics to the individual workers that they employ, and allow for linkages of aide care to patient outcomes will allow a much more comprehensive picture of the complex interactions between employers, patients and workers and how these structures and relationships support or hinder quality care. The CDC made efforts toward this with the National Home Health Aide survey in 2007, which collected nationally representative data on both agencies and their employees; however, this
survey was conducted only once and the measures were adapted from the CDC’s nursing home survey, and may not capture many of the unique aspects of home care. In addition, aides were contacted through to participate through their employers, which may have affected participation. In future surveys, aides may need more assurance that their responses will be kept confidential form their employers.

This project also raised important questions about the value of relational care in home care services, particularly the need to look more closely at the role of companionship. Aides in this study clearly felt that companionship was one of the most important criteria of quality care. However, the concept of “companionship” has a fraught history in the field. For decades, advocates have sought to overcome this designation that excluded workers from labor protections, and re-position home care as skilled and critical labor. However, this study demonstrates that discounting the companionate aspect of the job, particularly in a climate of fiscal austerity, creates vulnerabilities for both workers and patients alike, and leads to critical gaps in care.

Going forward, health services researchers will need to develop more systematic ways to look at the role of relational care, specifically around companionship. What specific skills do workers need to provide companionship, and what outcomes can we expect? As importantly, how can we recognize and professionalize this work without reducing it to a Taylorized set of tasks, as we have done with the physical aspects of care? Giving workers the support and skills they need to perform this work well while still allowing aides control and flexibility is a daunting task, and it will require examining expectations of care and core competencies of caregivers from the perspective of all of the members of the care team, including family members, patients (to the extent to which they are able), and employers.
The other major issue that arose repeatedly related to relational care was the challenge of negotiating boundaries. This study found that when relational care is invisible, the burden of deciding if and how to provide it falls solely on the worker. While aides in this study were technically protected by their POC, in reality, their daily work consisted of constant negotiations around the type and level of “extra” care they would provide, often leading to a slippery slope of negotiations with patients and family members. While agencies formally prohibited off-POC work, in practice, these policies were rarely followed.

Clearly, pretending relational care does not exist is not a solution. Aides will continue to perform this work, and patients and agencies will continue to expect it (either explicitly or implicitly). The question is how best to establish boundaries in a way that protects workers, patients and agencies alike without losing what is unique and special about this type of care. Future research will need to take into account the perspectives of other members of the care team, as well as the aide. For instance, interviews with agency supervisors and front-line managers might explore the differences in formal policies and real-world practice. What boundary issues come up in daily practice, how are they resolved, and who resolves them? Do frontline managers have the power to use discretion in these situations, and if so, how do they use it? What systems are in place to protect workers and patients, and what systems would they like to see? What skills do they think that aides need, and what types of training would be useful? The experiences of front-line managers would also be useful to explore in terms of communication and integrating aides into the care team; for instance, what are the challenges that front-line managers face in managing both up and downstream, from meeting agency and administrative requirements to covering cases?
Another important issue to consider that was beyond the scope of this research are the role of changing trends in the industry, including the emergence of large, for-profit franchises and new payment models such as managed care. Results from the Medicare analysis suggest that large agencies and chains may have the resources to put more formal systems in place that either promote quality care, or at least enable stronger reporting and recordkeeping. What formal employment and care policies do these agencies put in place, and are they followed? How are workers and cases managed? Interviews with franchise owners about their priorities, employment practices, and clients’ expectations would be a helpful way to understand how this shift toward for-profit care is influencing workers, patients and the industry. Workers’ own stories, as well as recent reports suggest that states’ managed care programs are reducing service hours to a level that makes performing even the medically necessary physical tasks on the care plan impossible, much less providing additional relational work. Documenting the health impact of these troubling trends may help policymakers better understand the importance of this care.

Of course, in any job that involves working intimately with others and performing emotional and relational work, there will always be tension. Care work involves many personalities and personal characteristics, and the very real stakes of caring for a vulnerable individual lend intensity and urgency to the work. However, addressing these gaps in organizational structures and policies can limit the conflicts that inevitably arise, leading to better care for patients, and a more stable, supported workforce.

**Policy Recommendations**

While researchers can help to start filling these knowledge gaps between aides’, agencies’ and patients’ experiences, policymakers can also take steps to better recognize and support this work.

1. **Make “Invisible” Care Visible**
**Align Our Definition of Home Care with the Care Clients Need**

The first, and most crucial change we must make is to expand our definition of home care to acknowledge that home care services are about more than protecting physical health; they are about supporting overall physical, mental and emotional well-being. If our goal is truly to ensure that elderly, ill and disabled individuals can lead productive and independent lives, we must acknowledge that independence means much more than ensuring one can still bathe and eat; it also includes the right to retain cognitive and emotional independence, to the best of an individual’s ability. This means that care plans for clients should not just include meal preparation and bringing clients to the doctor’s office, but helping them remain mentally and emotionally active and engaged to the extent which they are able. The shift toward person-centered care in the nursing home industry may be one model to follow; in addition to monitoring patients’ physical care, many nursing facilities now consider quality of life, community or social engagement, and self-advocacy as important components of and outcomes of care. A more holistic definition of home care services also means acknowledging that emotional support is part of the job, and that it should be explicitly built into job descriptions, staff competencies, compensation structures and perhaps most importantly, training for both front-line staff and their managers.

**Make Home Care Count**

To better inform our measurement and understanding of home care jobs and home care services, we could better leverage the significant public monies that pay for these services to require more robust and meaningful reporting from agencies. While CMS requires Medicaid-certified agencies to adhere to some baseline federal contracting requirements, such as competitive bidding and fraud and abuse prevention measures, they are not required to comply with any labor standards...
or report on workforce data.\textsuperscript{14} However, as NELP proposes, CMS could require contracting agencies to report data on workers’ wages, benefits and work hours as a condition of reimbursement.\textsuperscript{14} Beginning to collect these data would allow us to better understand this workforce at a national level and begin to get a national perspective on labor and working conditions across the industry, as well as providing greater oversight to ensure that a disproportionate share of public funds are not being directed toward overhead and profits rather than workers’ wages and benefits.

CMS, which provides half of the funding for state Medicaid programs, could also require consistent reporting of home care quality that include measures of relational care. However, it is important to note that the introduction of “value-based” care has resulted in an explosion of quality measures, which some researchers fear serves only to introduce noise into the system rather than further our understanding of what processes and outcomes are truly important. The labor-intensive OASIS is one such instrument that requires a significant investment of staff time without producing much meaningful quality data. In fact, this project suggests that onerous reporting requirements may unfairly burden agencies with fewer resources and make it appear that their quality measures are lower, even as larger agencies “game the system” to artificially inflate their quality scores. Measuring home care quality effectively will require us to thoughtfully align indicators with the goals of care, rather than simply adding more measures into an already crowded system.

\textbf{2. Invest in Long Term Care and the LTC Workforce}

Labor advocate Steve Dawson warns that the United States is headed toward a “triple threat” in long-term care due to an increased demand for services as the population ages; a constricted
labor supply as demand for positions exceeds the supply of women entering the workforce; and falling unemployment, which has led to wage increases across multiple low-wage sectors that are providing higher-paying opportunities for individuals who might otherwise take direct care jobs. As he notes, “publicly funded employer and managed care entities must acknowledge that they have a choice; either continue to fight increased compensation and risk vacancies across the public long term care system, or agree to seek higher reimbursements that are exclusively dedicated to higher wages.”

By undervaluing and underfunding home care services, we risk widening the existing care gap even further. The policy and funding debates around home care services have created a false narrative that pits the needs of home care workers against the needs of their clients. Making jobs better, opponents argue, will mean fewer service hours for clients, and price private-pay clients out of the service market altogether. But if we truly value this care, we must be willing to pay for it.

The first, and most critical change that must occur is that aides should be fairly compensated for the work that they do with a living wage, overtime pay, paid time off, and quality health and retirement benefits. Aides should also be compensated for the full scope of their work, including travel time, and extra hours when, for instance, a doctor’s appointment runs long or the patient’s transportation is late. As with measuring job and care quality, public funding can be leveraged to improve compensation; for instance, NELP also proposes attaching job quality standards to Medicaid and Medicare home care funding, requiring that contracts and subcontractors for Federal contract observe minimum wage, safety and health standards and maintain detailed employment records. Some states also require a percentage of public LTC dollars go to direct care costs, which can include wages, benefits, insurance and training costs.
In jurisdictions around the country, the Fight for $15 movement has raised wages for many workers, including home care workers. In New York City and in California, minimum wages will increase to $15 per hour over the next several years, benefiting home care workers as well as other low-wage workers.¹⁵⁶ In one analysis, Laura Dresser found that the cost of raising the home care wage floor to $15 an hour with health and retirement benefits would cost $110 billion per year, or an annual investment of $350 for every American – a significant but reasonable cost, when considering that at some point in their lives almost all Americans will need direct care.¹²

Of course, while significant, these victories do not go far enough to make home care a viable and stable career; $15 per hour will still leave workers in New York City almost $10 an hour below the living wage required to support a single adult with a child.²⁰ As labor economist Stephanie Luce notes, increased wages alone will not resolve the structural challenges workers face on the job, and these initiatives must be part of a broader strategy to empower workers and give them a collective voice. While unionization for home care workers has not been a panacea, it has provided a set of protections and support for 600,000 workers, including higher wages, health coverage, modest pension benefits and training and educational opportunities that improve workers’ economic stability. Going forward, Luce recommends organizing workers, strengthening existing labor organizations and linking with other progressive movements to push for supports like a stronger social security system, pensions, unemployment benefits and child care and transportation subsidies – much more costly and comprehensive proposals. As she wryly notes, a recent Onion article succinctly summed up the challenges ahead by declaring the $15 minimum wage “a bargain” compared to the cost of an “actual social safety net.”¹⁵⁶

In addition to wage victories, states are also beginning to recognize the importance of improving working conditions and labor protections for low-wage workers. In New York State, Gov.
Andrew Cuomo recently made permanent a task force aimed at protecting workers who are particularly vulnerable to exploitation, including those in home care. In addition to protecting workers from wage theft and safety violations, the permanent task force also intends to target worker misclassification.  

3. Leverage Home Care Workers’ Expertise

Agencies, clients and the healthcare system are missing out on a tremendous opportunity to draw on home care workers’ close relationships with their clients and their skilled relational and technical expertise to improve care quality. As the people who spend hours each day with their patients, home care workers are uniquely positioned to observe and report on changes in their patients’ health status, potentially averting health problems before they become a crisis.

_Integrate Aides into the Care Team_

Studies of the home care workforces suggest that feeling valued by their agency and being consistently involved in challenging work improves aides’ job satisfaction and commitment.  

While home health aides are technically supervised by the case nurses or social workers, in practice aides reported that they had little or no contact with members of the care team. Some efforts are currently underway to change this. In its 2017 budget, New York State allocated funding to an Advanced Aide program intended to create career paths for aides. The program will allow aides to receive additional training to take on more clinical responsibilities, like administering medications with existing patients. However, this new role still focuses primarily on teaching aides to take over specific clinical tasks from nurses, rather than working collaboratively as part of a team. Other “advanced aide” programs also include additional support and peer mentoring for workers. For example, in New York, Jewish Home Lifecare
currently employs 100 workers in “Senior Aide” positions. These aides, who earn an extra $1 per hour, act as peer mentors or counselors to new aides, receive training in communication skills, and also work in the field with “difficult to serve” populations. One recent pilot program at three New York City agencies hired and trained senior aides as salaried office workers to serve as educators and liaisons for aides in the field. These aides taught workers in the field to help clients adhere to their medication, use mobile devices and tablets to report changes in their patients’ conditions directly to the care team, and schedule doctors’ appointments, as well as educating them on emergency room use. Aides also had direct access to an agency nurse, who provided feedback on the medical issues they reported and consulted with the patient’s physician if necessary. In the first year of the program, agencies saw a 24% decrease in ER visits.

**Improve communication**

The strongest and most consistent finding from the focus groups in this study was the lack of responsive, timely communication from agency coordinators. While aides were providing frontline care to their patients every day, they had no reliable channel to report concerns about their patients’ health, and when they attempted to report these issues to supervisors, their concerns were often dismissed. While the New York State home care curriculum instructs aides to “observe, record and report” any changes in their patient’s health, in practice aides reported that they were seldom able to do so. In addition, aides often felt that they were prevented from providing high-level care because they did not have information about patients’ health status or home environment before starting a new case.

Agency supervisors are admittedly under tremendous pressure to juggle a high volume of worker and client schedules to ensure cases are adequately staffed and agencies are generating income. However, to ensure the highest level of care, aides must have a reliable direct line of
communication to a nurse or member of the clinical team to report on patient care, or receive immediate support for problems at the worksite. With so many channels of communication, from email to texting, agencies could implement a range of solutions that would not require aides to wait for a phone call back from a busy supervisor or call 911.

4. Support Workers’ Emotional Well-Being

Aides’ desire to leave home care industry jobs is frequently misunderstood as a signal that caring work itself leads to burnout and stress. However, while caring work is physically and emotionally demanding, it is not the work itself that is driving instability in the workforce, but the structural gaps that provide little formal support to help workers manage the demands of the job. In other words, it is the structure of care, not care itself, that often makes these jobs unsustainable. In fact, aides frequently report in this study and others that relational care, and their relationships with patients, are the most rewarding part of the job.8,47

To support workers in providing holistic, comprehensive care, we need to introduce supports that draw on the rewards of caring work while minimizing the challenges. This means shifting away from limited measures of job satisfaction or worker turnover toward a broader understanding of worker well-being that encompasses and addresses the structural, physical and emotional challenges workers face on the job.144 In these focus groups, aides related that their main sources of support were often their own patients – a difficult dynamic to navigate when aides also often had to put their own needs aside to care for their patients, and when aides often needed outside support to address concerns about their patient’s well-being. Aides consistently expressed the desire and the need for more formal channels of support to help manage the emotional and organizational challenges of their jobs, whether this came from their agency, their union or their peers.
Support from Agencies

Aides’ relationships with their agencies are often strained; aides in this study and others report limited contact with their agency and little feedback or encouragement on their work. When aides in this study did receive feedback, it was often disciplinary in nature.

Implementing or scaling up training programs that focus specifically on workers’ needs would be an important first step to supporting aides in their work. Currently, the New York State home care curriculum focuses primarily on accomplishing specific tasks – bathing, toileting, and infection control focused specifically on the patient. As one of the focus group participants put it, training tends to be “all about the patient and its nothing about us…we need something for us” (Aide 1049, Group 1). One example of a worker-focused approach is PHI’s Homecare Aide Workforce Initiative (HAWI), which includes task-based training as well as peer mentoring, supportive services and case management both before and after placement, and perhaps most importantly, coaching of HHA supervisors to help them support workers and problem-solve with them, rather than being overly directive and punitive. This program has shown significantly higher retention for aides at 30 and 90 days after placement, although the long-term effects remain to be seen.

Aides also told us that they would like to see trainings that specifically focused on managing the emotional challenges of the job, especially around negotiating boundaries of care, managing patient death, and protecting their personal safety. To design these programs, agencies could look to initiatives such as the ACA-funded Personal and Home Care Aide State Training Demonstration Program (PHCAST), which recently provided six states with funding to train personal care workers on ten core competencies, one of which was self-care. It is worth noting that the grantees with the lowest attrition rates addressed both structural and psychosocial
barriers for workers in their trainings by providing child care, transportation, stipends and scholarships, and offering mentoring and peer support services. While the final evaluation provides only a few high-level outcomes, attrition in these training programs was much lower than national averages, and workers rated the training highly. This is just a first, small step in acknowledging the need to support workers’ well-being on and off the job, but it is an important one.

Finally, agencies can support aides by structuring jobs to reflect the specific challenges of caring labor, including paid sick days, bereavement leave, low-cost or free counseling services and robust mental health benefits to allow aides respite from caring work or time to process patients’ death without jeopardizing their economic stability or their jobs.

Support from Peers

For aides who are often isolated on the job, opportunities to connect with other workers were an important support. In addition to contact with their agencies, aides expressed a strong desire for more contact with their peers to share experiences and expertise, or even “just vent” or have “a place where we could go and just talk.” In fact, many participants mentioned both in the groups and in post-discussion class papers that they found the focus group discussions to be a helpful and supportive experience, and rarely had these opportunities to interact with their peers. One aide wrote that the group “was the first time I really had a chance to speak about what I was feeling” (Aide 1202, Group 1), and another noted that “it was...a relief to be able to communicate to each other openly” (Aide 1304, Group 1). Several participants asked specifically for support groups, noting that “maybe we could have a group like this every three months” (Aide 1304, Group 1). This peer-to-peer contact may be particularly important for aides dealing with difficult emotional issues; one participant wrote about the “heart-wrenching” experience of watching a
patient die, and that “after this happened, I wish I had a support group to vent all my stress and anxiety to. The only thing I could have done was to pray to God that the pain I felt inside would go away” (Aide 1202, Group 1).

In fact, once prompted, aides had many suggestions for supports that would be most helpful to them, from bereavement groups and grief counseling to regular support groups, trainings that focused on issues aides faced on the job like negotiating boundaries with family members or managing aggressive patients and even a regular magazine with coping strategies and tips. This suggests that aides do have specific ideas about what they need to manage the challenges of their work, and their input should be sought when designing training and supports; those closest to the work understand best what they need.

It should be noted that with family caregivers, who face similar emotional and scheduling challenges as aides, supports like peer counseling are often underutilized. In designing supports to connect aides to their peers, we must take into account the competing priorities and complex schedules that many aides juggle, for example, by offering virtual counseling or online or telephonic support groups. Again, the input of aides themselves is critical to the success of these programs.

Support from Unions and Worker Organizations

Around the country, unions and other worker organizations, such as the Domestic Workers Alliance and Caring Across Generations, are providing important support including training, peer support and advocacy for home care workers. In addition to bargaining for higher wages, regular schedules and paid time off, unions in particular can provide aides with comprehensive physical and mental health benefits to manage the physical and emotional challenges of their
work. For instance, the 1199SEIU Benefit Funds recently conducted polls with members to determine why their behavioral health benefits were underutilized, and is designing programs and outreach to help members get the care they need. In addition, based on the findings from this project, the Funds intend to start support groups and bereavement counseling for home care members.

Strengthening home care quality will require us to acknowledge, value and support the skilled care that home care workers perform every day. Investing in and leveraging the expertise and experience of these workers is the only way to ensure high quality care in the future for our families and eventually, ourselves.
Section V:

Appendix and Bibliography
Appendix A: Terms Used in this Dissertation

1199SEIU UHWE (1199SEIU): The union representing approximately 66,000 home health aides, home attendants and housekeepers in New York City, as well as 300,000 healthcare workers across all sectors.

Activities of Daily Living (ADLs): Routine activities that people tend to do every day without needing assistance, such as eating, bathing, dressing, toileting, transferring (walking) and continence.

Bureau of Labor Statistics (BLS): The unit of the Department of Labor that serves as the principal fact-findings agency for labor economics and statistics.

Centers for Medicare and Medicaid Services (CMS): The federal agency within the Department of Health and Human Services that oversees both Medicaid and Medicare.

Custodial Care: The physical, non-clinical tasks that home care workers perform for their clients, including ADL assistance, light cleaning and housekeeping.

Department of Labor (DOL): As used in this project, this refers to the federal US Department of Labor, the department of the US federal government responsible for occupational safety, wage and hour standards, unemployment insurance benefits and other worker regulations and protections.

Home Care: Services that allow elderly, disabled, ill or frail individuals to remain safely and independently in their homes. Home care may be provided for a short time for patients recovering from an operation or illness, or long-term for clients who are permanently disabled or frail.

Home Health Aide: Home care workers who perform some clinical tasks for their clients, such as range-of-motion exercises and blood pressure readings. They also help with activities of daily living (ADLs) including eating, bathing, dressing and toileting and occasionally perform light housekeeping tasks like changing sheets or preparing food.


Relational Care: The cognitive, mental and emotional support that home care workers provide to their patients.

Licensed Home Care Services Agencies (LHCSAs): Medicare-licensed agencies which are contracted by states to provide home health services.

Long-Term Care (LTC) – Non-acute services performed in nursing homes or client’s homes.

Medicare Certified Home Health Agencies (MCHHAs): Home health providers that are licensed by Medicare and receive payment for services from the Medicare program

Medicare Payment Advisory Committee (MedPAC) an independent body that advises Congress on Medicare benefits and payments
National Employment Law Project (NELP): A national advocacy organization for employment rights of lower-wage workers.

Outcome and Assessment Information Set (OASIS): The assessment tool that measures the quality of services for Medicare and Medicaid patients receiving skilled care.

Paraprofessional Health Institute (PHI): A national advocacy and training organization dedicated to supporting direct-care workers.

Personal Care Assistant: Home care workers who provide ADL assistance, housekeeping and meal preparation, and ensure their clients remain engaged in their communities by helping them prepare for work or accompanying them to the grocery store. PCAs are sometimes referred to as housekeepers or homemakers; they do not provide any clinical care.
Appendix B: Focus Group Reportback Summary

THE CITY UNIVERSITY OF NEW YORK
Lehman College/The Graduate Center
The Effects of Job Characteristics on Home Care Aides’ Well-being

Early Findings: What We Heard From You

The Big Picture:

- Overall, you told us you are happy with your jobs, proud of your work, and enjoy the time you spend with your patients.
- But, as in any job, there are also frustrations. These “take their toll” on your mental and emotional health, and even your relationship with your family.
- Your happiness or frustration with your job is often connected to whether you feel you and your work are trusted, respected, valued and appreciated.
- Many of you said your patients trust, respect, value and appreciate you, and you generally feel confident and in control of the care you provide. But this is not always the case with your agency or the patient’s family.

What is “Good Care”?

You said: “Emotionally, it’s not always about, you are doing your job and you are following everything that’s there. Sometimes patients just want companionship. They want someone to talk to. Maybe they just want a best friend. Maybe they feel lonely – their own family doesn’t pay attention to them. You’re the only person there for them, so they want a connection with you, and that helps them emotionally, physically, and mentally.”

When we asked about providing good care, you told us your agencies think good care is about covering the case, and making sure you follow the plan of care; bathing the patient, preparing meals, shopping, and keeping the home “safe, clean and clutter-free”.

But you see good care as more. While you feel the POC is important, you also told us that keeping your patient happy is the most important part of the job. Many of you talked about the importance of building mutual trust, appreciation, respect, and communication with your patient. You said the two of you are “a team” and that “you become their family”. You “try to treat the patient the way I treat my mother” or “the way you would want someone to take care of you.” As you would for a family member, you often “go that extra mile” beyond the POC if it means providing good care; you might do heavy cleaning if the patient’s house is unsafe, “go beyond your work time”, or call a patient after your shift to make sure she is safe or not lonely.

But as with any family relationship, there are hard days, too. Many of you told us patients “have their grumpy days” but you also agreed it is “just their moods”, and that they often apologize afterward. For the most part, you said you feel trusted, appreciated, respected and valued by your patient. And when
you aren’t, you generally have enough confidence and control in the situation to assert yourselves and set boundaries, or leave the case if necessary.

**What Makes Your Job Hard?**

Many of the challenges you told us about came back to a lack of trust, respect, value, or appreciation, mostly from your coordinator and your patient’s family. Often, you feel the coordinator or family see you as generic “bodies”, and not as people.

**Your Agency/Coordinator**

*You said:*

“They really don’t care...their job is to get you on that case.”

“Sometimes, just say “you know what, thank you. You’re doing a good job.”

Many of you are frustrated by the lack of communication and respect from your agency coordinator. You often feel agencies have the power to keep you on call or schedule you at their convenience, but do not respect your time or treat you as a person with other responsibilities, like family and school. Their job is to “get that body over there.” This is especially difficult in dealing with scheduling, or emotional situations, such as a close patient passing away; “Nobody come to ask me how I’m doing. The supervisors don’t ask you how you’re doing, all they tell you go to another case.”

You also receive mixed messages from your coordinator. “You have to call” the agency to report any issues, but “they take their time” getting back to you, even if the problem is urgent. And, when you call about an issue not directly related to your tasks (like possible abuse, or another aide not following the POC), “they say you’re not supposed to do it.” Some of you feel calling the agency is “wasting your time” since “they never answer”. In some cases, when you can’t reach the coordinator you can share concerns about a patient’s health or home with the nurse (“she gives me a direct line”). But others told us they have never seen the nurse at all.

Lack of communication can be an inconvenience at best (for instance, when two aides are scheduled for the same shift) and at worst, put your safety and your client’s safety at risk. You are often sent to new cases where “you don’t know until you get there” that the patient needs special equipment, if there are pets, mold or other hazards, or if the patient is physically or sexually aggressive (which can be both frightening and “humiliating”). But at the same time, many of you feel the agency is in control, and you can’t say no or “they’ll never call you back again.”

**Your Patient’s Family**

*You said:*

“One thing that does get to you is the family”; “The only challenge I have is her husband”

“I’m not here to clean windows, I’m here to take care of the patient.”

Some of you told us you have a good relationship with your patient’s family, and that they make you feel appreciated, respected and valued. But others do not, and see family members as an obstacle to providing good care. The family “can be ugly to you”, and may treat aides “like we’re a housekeeper”, asking for cleaning or other tasks outside the POC “that [family members] don’t want to do”. Many of you are frustrated by this because you feel “the family is not there for them.” Control over limits and
boundaries with family members can often be a challenge. While you explain that you need to stay on the POC, you are concerned that family members try to “test you” or “intimidate you”, and may retaliate by threatening to cut shifts or have you moved off the case. But, you also said attitude makes a difference; “it’s the way they ask you”, and if a family is respectful, “you feel like you want to do more work”.

Many of you said there is a lack of trust on both sides; some family members think every aide is a “thief” and keep an eye on your bags, but you often felt it was more likely that family members would steal from you. Many of you agreed that if the family wasn’t there, “life would be perfect….it would be stress-free. No drama.”

**How Does Your Work Make You Feel?**

*You said: “A lot of my patients appreciate what I done for her, it made me feel wonderful. I go home smiling.”*

*“You have a life, that affects you because you have somewhere else you have to be. You have responsibilities of your own.”*

Many of you told us that “just making the patient happy makes you happy.” A good day with a patient is often “having fun together”. After a good day, you feel “excited”, “accomplished” and proud of your work. You “pat yourself on the back”, and “feel good because I know that I’m doing a good job.”

But on the challenging days, you feel overwhelmed, angry, sad, stressed out, and disrespected. Some of you see physical effects, like exhaustion and hair loss. Bad days can be frustrating “especially when you know you put so much effort into what you’re doing.” Difficult patients, like those with dementia, can get you “all sad and depressed…that takes a toll on you.” Feeling disrespected by the patient’s family also affects you emotionally: “when they come on and treat us like that, it hurts.”

And, many of you are not just caregivers at work, but also at home. You told us it can be hard when “most of your time is not with your family”. Days when you feel unappreciated are made harder by knowing “you’re leaving your family to come and care for them.” But on the other hand, you don’t want to take your bad days out on your partner and children; even if you want to “vent”, “you don’t want your problems to be their concerns.”

**How Do You Cope?**

*You said: “You’re there to do a job...if you’re looking for support, then that’s the wrong job.”*

Many of you said that the challenges are just part of the job; on bad days you tell yourself that “this too shall pass” or that “you’ve got to suck it up.” Some said they pray, or just “let it go….distract from the negativity and draw in all the positivity.”

Others said your families are an important support, and can “calm [your] nerves”, “make [you] laugh a lot” and “take your mind off it.” You also said coming to school helps, as a way to “do something for yourself”, “associate with people” and get support from the teacher; “it gives you hope and it kind of strengthens you in a way where it’s like I’m bettering myself.”
What Other Support Do You Need?

You said: “Who’s taking care of us?”

Beyond your family and your classes, most of you felt you don’t get support on the job and that “we’re on our own.” While in-service trainings can be helpful, they are often “all about the patient, and nothing about us.”

You told us you need:

- “Advice on how to cope” and how to “deal with patients with mental issues”
- “How to deal with people who want us to go beyond our limits”
- “A place to go and just talk” “or vent”
- Advice/training on personal safety (with physically or sexually aggressive patients)
- More flexible scheduling around life issues and school

Some sources of that help could be:

- A formal support system
  - Support groups and/or one-on-one support to manage emotional aspects of the job, especially “for aides that have to deal with patients who die”
  - In-service trainings that focus on the aide’s needs
  - Classes on dementia care or dealing with difficult patients (from the aides’ perspective)
  - A magazine with information and advice on coping strategies and skills
  - Support in setting boundaries and navigating the POC with patients’ families
  - “Coordinators need to leave the office, come to the patient’s home, see what’s going on there”
- An open line of communication
  - “Someone you can call or go to” who will “listen to you”, either a designated and responsive agency coordinator, or an outside advocate to “represent us in the agency”
  - Quick responses to questions about scheduling, pay, and client issues
  - Communication across the care team (nurse, coordinator, family and aide)
  - Complete information about the patient and their home before arriving on-site (patient mental and physical health; lifts, wheelchairs or other equipment; pets and household conditions)

Tell Us: What Did We Miss?

If there is anything missing, or something you want to clarify or make sure we include, we want to hear from you! You can reach me at [email], or [phone] anytime.
Appendix C: Informed Consent for Screening

THE CITY UNIVERSITY OF NEW YORK
Lehman College/The Graduate Center

INFORMED CONSENT FOR ELIGIBILITY SCREENING

Title of Research Study: The Effects of Job Characteristics on Home Care Workers’ Well-being and Job Performance

Principal Investigator: Emily Franzosa, MA, DPH candidate, The Graduate Center

Thank you for your interest in this study. We are researchers from the City University of New York who are affiliated with Lehman College and the Graduate Center. We are interested in talking to home care workers about the work that you do. This eligibility survey will take approximately 5 minutes to complete, and you must be at least 18 years old to complete it.

You are being asked to participate in this study because you are an experienced home care worker. The purpose of this research study is to learn more about how your job affects your health, and other parts of your life. If you agree to participate, we will ask you to complete a brief survey to determine your eligibility and learn more about your personal background. If you are eligible, you will be asked for your contact information so that we may follow up with you, and if you agree to participate, we will ask you to join a group discussion with other workers in your class that will last approximately 90 minutes.

It is possible that you may feel uncomfortable answering personal questions about yourself or your relationship or personal experiences with your clients. If, while you are taking the survey, you begin to feel uncomfortable for any reason, you may stop your participation at any time. The data you provide will be kept securely on a password protected computer, and will only be shared with the members of the research team. Your participation in this research is voluntary. If you have any questions, you may contact the Principal Investigator, Emily Franzosa, at [email] or [phone]. If you have any questions about your rights as a research participant or if you would like to talk to someone other than the researchers, you can contact a CUNY Research Compliance Administrator at (646) 664-8918.

Do you consent to participate in this eligibility screening?

_________________________  ___________________________  ___________________________
Printed Name of Participant  Signature of Participant  Date Signed

_________________________  ___________________________  ___________________________
Printed Name of Person Explaining Consent Form  Signature of Person Explaining Consent Form  Date Signed

_________________________  ___________________________  ___________________________
Printed Name of Investigator  Signature of Investigator  Date Signed
Appendix D: Participant Eligibility Questionnaire

THE CITY UNIVERSITY OF NEW YORK
Lehman College/The Graduate Center

The Effects of Job Characteristics on Home Care Workers’ Well-being

PARTICIPANT ELIGIBILITY QUESTIONNAIRE

Researchers at the CUNY Graduate Center and Lehman College are inviting home care workers to participate in a study about the ways your job affects your health and other parts of your life. We will be inviting workers to join us for a 90-minute group discussion on [April 6 or 7]. If you qualify for the study and participate, you will receive $25 and a $5.50 Metrocard to thank you for your time.

If you are interested in participating in this study, please answer the questions below, sign the form, and include your contact information.

1. About how long have you worked as a home health aide or home attendant?
   - 0-6 months
   - 1-3 years
   - 6 months – 1 year
   - More than 3 years

2. About how many clients have you worked with over the course of your home health career?
   - 1
   - 2
   - 3-5
   - More than 5

3. Do you generally work with long-term clients, clients recovering from an illness or surgery, or both?
   - Long-term clients
   - Clients recovering from illness/surgery
   - Both

4. Is the client you currently work with most a member of your family?
   - Yes
   - No

5. What is the longest length of time you have worked for the same client?
   - Less than 6 months
   - 6 months to 1 year
   - 1 to 3 years
   - More than 3 years
6. What is your age?

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<td>Under 18</td>
<td>18 to 24</td>
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<tr>
<td>25 to 39</td>
<td>40 to 59</td>
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<tr>
<td>60 or older</td>
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Name:____________________________________________________

Phone:___________________________________________________

Email:___________________________________________________
Appendix E: Informed Consent for Focus Groups

THE CITY UNIVERSITY OF NEW YORK
Lehman College/The Graduate Center
CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

Project Title: The Effects of Job Characteristics on Home Care Workers’ Well-being and Job Performance

Principal Investigator (PI): Emily Franzosa, MA
CUNY Graduate Center
365 5th Ave, New York, NY 10016
[phone]

Site where study is to be conducted: 1199SEIU Training and Employment Funds

Introduction/Purpose: You are being asked to participate in this research study because you are an experienced home care worker. The purpose of this research study is to learn more about how the work that you do affects your emotional health and well-being, and what you consider to be “quality” care. The results of this study may inform the types of support that home care workers receive on the job, and the way that the quality of home care work is measured. Results will also be used in a dissertation by Emily Franzosa, MA. In order for us to capture important information discussed today for later review, we will be audio recording the focus group conversation.

Procedures: Approximately 32 individuals are expected to participate in this study. Each participant will complete a short demographic survey and participate in a focus group with other participants. The time commitment of each participant is expected to be 2 hours (including the consent process, the demographic questionnaire and the focus group). Each session will take place at the 1199SEIU Training and Employment Funds.

Possible Discomforts and Risks: Your participation in this study may involve some discomfort answering questions about your work experience and your personal relationships with your clients. You may also feel some anxiety or stress when discussing personal characteristics that may influence the decisions or choices you make on the job. As with any study, there is always a risk of breach of confidentiality with regard to data/information collected. However, the PI and the research team have designed the study using methods to enhance the security of data and this risk is very minimal.

Benefits: There are no direct benefits. However, participating in the study may increase general knowledge of the challenges that home care workers face in balancing their work and home lives. You may also feel a sense of accomplishment by contributing your knowledge and expertise in order to help improve the ways that home care jobs are structured and how the quality of the work you do is measured.
Voluntary Participation: Your participation in this study is voluntary, and you may decide not to participate without prejudice, penalty, or loss of benefits to which you are otherwise entitled. Moreover, you have the right to not answer any questions or participate in any part of focus group should you choose to do so. You may also leave the focus group at any time. If you decide to leave the study, please contact the principal investigator, Emily Franzosa, to inform her of your decision.

Financial Considerations: For your participation, in appreciation of your time and to cover your travel costs to and from the focus group site, you will receive $25 and a $5.50 MetroCard (round-trip) upon completion of the focus group.

Confidentiality: The data obtained from you will be collected via written questionnaires, digital audio recordings and handwritten notes. The collected data will be accessible to the PI, the study team and CUNY IRB members and staff. The researcher will protect your confidentiality by coding and securely storing the data in either locked filing cabinets or on a password protected and encrypted computer. The research team will include the PI, her faculty advisor, and CITI certified assistant moderators. While the confidentiality of the data collected will be upheld to the fullest extent possible by the PI and research team, individual participants (peers) in the focus group may not maintain confidentiality.

Contact Questions/Persons: If you have any questions about the research now or in the future, you should contact the Principal Investigator, Emily Franzosa at [email]. If you have any questions concerning your rights as a participant in this study, you may contact CUNY HRPP Coordinator, Ms. Arita Winter, at arita.winter@cuny.edu.

Statement of Consent:
“I have read the above description of this research and I understand it. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions that I may have will also be answered by the principal investigator of the research study. I voluntary agree to participate in this study. By signing this form I have not waived any of my legal rights to which I would otherwise be entitled. I will be given a copy of this statement.”

_________________________                  ___________________________                  ___________________________
Printed Name of Participant                  Signature of Participant                  Date Signed

_________________________                  ___________________________                  ___________________________
Printed Name of Person Explaining Consent Form                  Signature of Person Explaining Consent Form                  Date Signed

_________________________                  ___________________________                  ___________________________
Printed Name of Investigator                  Signature of Investigator                  Date Signed

CUNY IRB PROTOCOL #2015-1032
Appendix F: Participant Demographic Survey

THE CITY UNIVERSITY OF NEW YORK
Lehman College/The Graduate Center
The Effects of Job Characteristics on Home Care Workers’ Well-being
PARTICIPANT DEMOGRAPHIC SURVEY

PARTICIPANT NAME: ______________________________________

1. About how many years have you worked as a home health aide or home attendant?

☐ 0-6 months       ☐ 1-3 years
☐ 6 months – 1 year ☐ More than 3 years

2. What is your job title? (circle one)

☐ Home Attendant       ☐ Home Health Aide
☐ Both Home Attendant and Home Health Aide
☐ Other: ________________

3. Generally, about how many hours do you work in one month? ________________

4. Generally, about how many clients do you visit in one month? ________________

5. About how many clients have you worked with over the course of your home care career?

☐ 1       ☐ 2       ☐ 3-5      ☐ 6-9      ☐ 10 or more

6. What is your age?

☐ Under 18       ☐ 18 to 24
☐ 25 to 39       ☐ 40 to 59
☐ 60 or older
7. In what country were you born? _____________________________

8. Is English the primary language you use at home?
   - Yes
   - No

9. If ‘no’, what is the primary language you use at home?

10. What is the highest level of education you completed? (check one)
    - No formal education
    - Less than high school graduate
    - High school graduate/GED
    - Vocational training
    - Some college/Associate’s degree
    - College degree (BA/BS)
    - Advanced degree (MA/MS, PhD)

11. Who else lives in your household? (check all that apply)
    - Spouse or partner
    - Children under age 18
    - Children over age 18
    - Parent or grandparent
    - Other ________________

12. Are you the only person working for pay in your household?
    - Yes
    - No
13. Are you currently working in another paid job that is not a home care job?

☐ Yes  ☐ No

14. If yes, what is that job? _________________________________________

15. Which category best describes your household’s yearly income?

☐ Less than $5,000 per year  ☐ $5,000 to less than $20,000 per year

☐ $20,000 to less than $35,000 per year  ☐ $35,000 to less than $50,000 per year

☐ $50,000 or more per year  ☐ Do not know for certain

☐ Do not want to answer
Appendix G: Focus Group Discussion Guide

THE CITY UNIVERSITY OF NEW YORK
Lehman College/The Graduate Center
The Effects of Job Characteristics on Home Care Workers’ Well-being
FOCUS GROUP DISCUSSION GUIDE

Make yourselves comfortable, please help yourselves to food….

Welcome

Thank you so much for being here today. I know you all have demanding jobs and that your time is valuable, and I appreciate your help with this project. Your thoughts and expertise are very important.

Introduction/Purpose

My name is Emily [or alternate moderator’s name], and I am a doctoral student at the CUNY School of Public Health. [introduce Assistant Moderator] This focus group is a project for my doctoral degree. The information you share today will be used in this project, and possibly in published articles. We’ll also share a summary of the findings with you, and with the Funds.

The goal tonight is to get to know more about your work, and how it affects your health and other parts of your lives. When people talk about home care, they tend to put the client first. But, we know that you are really the experts - your health and happiness and your client’s health and happiness are connected, and it’s important that we talk about you, too.

We’ll be here for about an hour and half. If you need to step out or use the restroom, just do so quickly and the [coordinator] outside can show you the way. I’ll be asking questions and ____________ will take notes. At the end of the session, you will each receive $25 and a Metrocard to thank you for your time.

Ground Rules

A few ground rules. First, we are recording our discussion because we don’t want to miss anything you say. So, please turn off your cell phones. We ask that everyone speak up, so the recorder can catch you, try to speak one at a time and speak to the group and avoid side conversations, so we make sure to capture everything.

My coworkers and I will keep everything you say tonight confidential. What you share in this room will stay here. We won’t use any names or identifying information when writing about this project, and we ask that you protect everyone’s privacy by not speaking to others about what is said in the group today. Is everyone ok with that?

Finally, this project is about you, for your benefit - so it’s important that we get your honest opinions. Don’t tell us what you think we want to hear, or hold back because someone else might disagree. There are no right or wrong answers. This is about your own thoughts and experiences, which are all important. It is also important for us to hear all sides of an issue – both good and bad.
Any questions/is everyone ready to get started?

**Introductory Questions [10 minutes]**

We know your work can be rewarding, and it can also be stressful. Tonight I want to talk about what you do for your clients, what you enjoy about it, and what makes it harder. Things like how much money you earn and health coverage are obviously big issues. But for tonight, we want to put these issues to the side, and focus on your day-to-day work and how it makes you feel. If you do have any questions about your benefits or the Union, [outreach coordinator] is here and she can answer them after we’re finished.

*Participants may still want to focus on structural issues like pay, benefits, or physical demands of the job. Try to redirect back to client care and emotional/mental impact of that work, and how it affects their own work*

Let’s start by going around the table and getting to know each other. Tell us how long you have been working in home care, and say a few words about the client you work with now and what you do for them.

**Quality of Care [20 minutes]**

Ok. I’d like to hear more about the care you provide. I’m sure that your agency, the visiting nurse and case managers all have an idea of what good care looks like.

- How do you think your agency or the nurse/case manager would define good care? What are they looking for when they come to evaluate/assess your client?

You spend more time with your clients than they do, and you know your client best. So, tell me what good care means to you. Does it look different than the agency/nurse’s definition?

- In thinking about the work that you do, what does providing “good care” look like?
  - Probes: What do you do that makes your client feel safe, happy or comfortable?

- What do you think is the most important thing you do for your client?
  - What is the most important thing you do outside of your assigned tasks?
  - Probe: If you were training another worker to do your job, what would you tell her is the most important part of the job?

- You know your clients well. What signs do you look for from them that show you’re providing good care?
  - Probe: Do you get comments or feedback from other people about your work – like your client’s family, or the nurse or case manager? How do they let you know if you’re providing good care? How does that feedback make you feel?

I have a good sense of your work, so now I’d like hear more about you…
Rewards [20 minutes]

- We know that in any job, there are good days, and there are days that are harder. Can anyone share a story about a really “good” day with a client? What does a good day look like?
  - Probes: Can you tell me more about what makes a day “good?”
  - Most of you have worked with a lot of different clients – are the “good” days different depending on the client?
- How do you feel after one of those “good days” with a client? Physically? Mentally?
  - Probe: value, pride, accomplishment, respect

Challenges [20 minutes]

Let’s talk about some of those “not so good” days….

- Can anyone share a story about a harder day with a client?
  - Probe: What makes a day harder or more challenging? What does that day look like?
- How do you feel after a hard day? Physically? Mentally?
  - How do the issues we’ve talked about affect you at work?
    - Possible probes: stress, putting client needs first, managing time
  - How do the issues we’ve talked about affect your home life?
    - Probe: feeling “used up” at the end of the day, trouble balancing work and home life, time pressures; what’s one word that describes how you feel after a good day?
- Is there anything you do to manage the way you feel after a hard day?
- Say you didn’t have to worry about [x issue].
  - What would you be able to do for your client that you don’t feel you can do now?
  - What would you be able to do for yourself/family that you don’t feel you can do now?

Support [10 minutes – cut if time runs short]

- We’ve talked about what you do to manage the hard days. Is there a support or resource you don’t have now that might help you manage them better? [Record answers on whiteboard]
  - Probe: managing challenges in your work life; managing challenges outside of work; managing challenges to keep yourself and your client happy
  - Probes: What might help you deal with [name some challenges mentioned]? Is there something you wish had been covered in your training that would help? Is there something you wish you’d known or been prepared for before starting your job?
• Now that we have a list of ideas, I’d like you to choose the 3 solutions you think are most important, and place a post-it note next to those. [Summarize answers and probe if some participants’ choices are significantly different]

Wrap-Up [5-10 minutes]

- Is there anything I missed that you would like to talk about?

Thank you so much for your time, and for everything you’ve shared tonight. Your experience and expertise has been so helpful. If you think of anything else you would like to add, you all have our contact information and you should feel free to contact us. We’ll also share our findings from these groups once we’ve reviewed all the information.

*Moderator or AM: Make sure to take a picture of the whiteboard and send to PI.*

*Check recording to make sure it’s audible, and return recorder to PI*
Appendix H: Institutional Review Board Approval

![CUNY Logo]

Approval Notice
Initial Application

09/30/2015

Emily Franzosa,
The Graduate School & University Center

RE: IRB File #2015-1032
The Effects of Job Characteristics on Home Care Workers' Well-being and Job Performance

Dear Emily Franzosa,

Your Initial Application was reviewed and approved on 09/30/2015. You may begin this research.

Please note the following information about your approved research protocol:

- Protocol Approval Period: 09/30/2015 - 09/27/2016
- Protocol Risk Determination: Minimal
- Expedited Categories: 5, 6, 7

Documents / Materials:

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Please remember to:

- Use the IRB file number 2015-1032 on all documents or correspondence with the IRB concerning your research protocol.

- Review and comply with CUNY Human Research Protection Program policies and procedures.

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

If you have any questions, please contact:
Zoltan Boka
718-960-4108
ZOLTAN.BOKA@lehman.cuny.edu
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