

INTRODUCTION

On the Front Lines of Care

MR. JONES AND KEISHA

On a warm spring day in April, I accompanied Christina, a white public health nurse, to the home of an elderly African American man who suffers from heart disease, renal failure, diabetes, and mild dementia. Mr. Jones is a seventy-six-year-old man who lives alone in a subsidized housing complex in a low-income suburb of Central City.¹ His only regular visitor is his caregiver Keisha, a young African American woman who is paid to cook, clean, and care for him daily. As we approach his apartment building, Christina is sanguine about Mr. Jones's isolation, recalling that she'd seen much worse while on her religious missions to Zimbabwe and Mozambique years ago.

As we approach Mr. Jones's apartment, Christina motions to be quiet. After standing at Mr. Jones's door for a few minutes, Christina realizes that there is a faint sound coming from the front window of the house. We move toward the sound as Christina calls out Mr. Jones's

name loudly. From inside, a man's voice pleads for help. Christina straddles a bush and pushes her face against the closed window. She asks Mr. Jones to unlock the door if he can. Mr. Jones, fatigue in his voice, tells us that he has fallen out of bed and cannot get up. At this moment, we notice a young African American woman coming toward us. She introduces herself as Jodi, the acting "super" of the building. Christina asks Jodi whether she knows Mr. Jones, and she replies, laughing, that of course she knows Mr. Jones. Christina determines that Jodi does not have a key to the apartment but that Keisha, Mr. Jones's home care aide, does. Unfortunately, Jodi has no idea how to reach Keisha.

Christina turns away from the small crowd that has now gathered outside Mr. Jones's apartment, pulls out her cell phone, and dials 911. After about ten minutes, a fire truck pulls up in front of Mr. Jones's apartment. In what seems like seconds, the paramedics are inside the apartment; Christina and I follow close behind. The paramedics, two young men, ask us to wait in the living room while they assess Mr. Jones's condition. From the living room we can hear the paramedics speaking loudly to Mr. Jones, followed by the sound of a collective grunt as the patient is lifted into his wheelchair. Within minutes, Mr. Jones is wheeled out into the living room, where we wait seated on a couch covered with disheveled bed linens.

Seemingly unaware of the commotion surrounding him, Mr. Jones beams at Christina when he sees her. I assume at first that Christina has a well-established rapport with the man, but soon realize his smile is a vacant one, not one of recognition. Christina approaches Mr. Jones and asks him to tell her what happened. Mr. Jones does not respond but stretches out his hand toward Christina. Christina pauses, puts on her rubber gloves, and then takes Mr. Jones by the hand. She again asks what happened, but I can tell from Mr. Jones's singular interest in Christina's face that the trauma of his fall is now a distant memory. The paramedics ask Christina to sign a few papers and then head for the door. As they are leaving, they tell Christina with some condescension to try not to leave Mr. Jones alone in the future. Christina responds by thanking the two paramedics, taking little offense at the misdirected nature of their admonishment.

Once the paramedics clear out, Christina notices that Jodi, the building super, has been standing in the doorway watching events

unfold. Jodi nods in the direction of Mr. Jones and says, “Man, those feet are purple.” Christina does not respond to Jodi but bends down to examine Mr. Jones’s feet, massaging them gently. Mr. Jones laughs aloud, responding to Christina’s touch. Christina explains that Mr. Jones is severely dehydrated and is having trouble with his circulation. Jodi adds, unsolicited, that he often falls off his chair at night, which makes things worse.

At that moment Keisha, Mr. Jones’s caregiver, walks through the door with a full grocery bag. She appears to be about twenty-five years old. With a passing hello, Keisha walks through the living room into the adjacent kitchen and begins putting away the groceries. With some urgency, Christina tells Keisha what has happened, unsure whether Jodi has been in contact with her. Keisha seems unmoved by Christina’s story and confirms Jodi’s report that Mr. Jones often falls down when he is alone. Over the clamor of cupboards opening and closing, Keisha elaborates that Mr. Jones insists on trying to reach things—water, books, food—that are not easily within his grasp. When she leaves at night, Keisha puts Mr. Jones into bed and reminds him to stay there. Inevitably, he falls out of bed and cannot get up. I notice that Keisha has a bad head cold and that she looks extremely fatigued. She offers us some instant soup which we decline. What Mr. Jones needs, Keisha explains, is a “grabber,” a tool that he can use to reach things at night without endangering himself. She adds that if we really want to solve the problem, we need to get more hours of paid care for Mr. Jones, so that she can watch him at night. Keisha explains that she already works beyond her paid hours for Mr. Jones, staying sometimes until two in the morning without monetary compensation. Keisha explains that Mr. Jones is not very compliant with the social workers and doctors, so they in turn do not help him out much. He badly needs a Lifeline (an emergency call device), Keisha says, but the doctor never filed the approval paperwork to have the device covered by Medicare.

Mr. Jones, suddenly lucid, interjects and asks us to stop our “yackety-yakking.” Responding immediately, as though seeing him for the first time, Keisha changes her tone and walks toward Mr. Jones, bends down to meet his line of vision, and assures him that everything is okay. Mr. Jones appears to relax in response to Keisha’s attention. Keisha

notices that Mr. Jones has soiled himself and asks Jodi to help her out. Together the two women pull Mr. Jones from his chair and walk him into the bathroom for a quick wash and change of clothes. Christina tells me there is little else she can do today and leads the way out of the apartment toward her county car.

On the Front Lines of Care

The story of Mr. Jones and Keisha is both touching and horrifying. The less-than-favorable conditions of Mr. Jones's care, his poverty, and the disarray of his living environment seem to confirm the sociological truism that social class and economic insecurity directly impact how one experiences aging and illness (Newman 1999a). Given this reality, it is tempting to place blame—for Mr. Jones's fall, for the condition of his home—at the feet of the person directly responsible for the day-to-day care of Mr. Jones: Keisha. Considering, however, that Keisha spends many unrecorded, uncompensated hours a week providing care to a relative stranger, both because there is no one else to do it and because Mr. Jones is too poor to receive more-comprehensive care (and perhaps also because she is unable to find a "better" job), it is fairer to say that Keisha is a critical resource for Mr. Jones rather than the primary threat to his safety or well-being. Recognizing, then, that both Mr. Jones and Keisha receive and give care, respectively, in conditions of poverty, with little support from family or health care providers, we can identify a set of broader social realities that inform their experiences.

Most obviously, the tenuous bond formed between Keisha and Mr. Jones reflects the many unanswered questions about long-term care in the United States. Why, for example, is Mr. Jones left unsupervised for hours at a time? Who pays for Mr. Jones's care, and why is he ineligible for more support? Why is Keisha doing this work? Is she qualified for the job? Does Mr. Jones have other options? Does Keisha?

In the ongoing policy conversations about long-term care in the United States, these broader questions take a backseat to the more immediate issues of supply and demand. In view of the projected growth in the number of senior citizens in the United States in the next ten to twenty years—the number of adults over sixty-five is expected to

double by 2030—the question of how we will generate and sustain a “frontline” or direct-care workforce is of central concern (Institute of Medicine of the National Academies 2008). Often referred to as the “crisis in long-term care” or the “care gap” (Stone and Wiener 2001), the problem of finding sufficient numbers of quality care providers to meet the needs of the elderly is particularly acute in the United States, where family members are very often geographically dispersed and—even if they remain close by—struggle to care for a parent or loved one while also meeting the demands of career and children (Harrington Meyer 2000).

This crisis in care is expected to translate into an unprecedented growth in the personal home care industry, staffed by low-skilled paid caregivers such as certified nursing assistants (CNAs), home care aides and personal care assistants. The Bureau of Labor Statistics estimates that, between 1992 and 2005, home care aide was the second-fastest-growing occupation in the United States, with similar growth expected through 2016 (Bureau of Labor Statistics 2005; Paraprofessional Healthcare Institute 2008b; Smith and Baughman 2007b). If past conditions hold, most of the women—and a small number of men—who become home care aides will be unskilled, untrained, and underpaid (Crown, Ahlburg, and MacAdam 1995; Stone and Wiener 2001). In addition, paid caregiving is clearly a “racialized” occupation: poor women of color—often immigrants—are overrepresented in the population of home care aides and personal care assistants (Duffy 2007; Ehrenreich and Hochschild 2002; Harrington Meyer 2000; Nakano Glenn 1992).

Even with this anticipated growth in the home care industry, there remains a gap in knowledge about the challenges facing “frontline” workers (D. Stone 2000b; Wellin 2007). It is my intention in this book to enrich current debates over the long-term care crisis by describing in detail the constraints facing low-skilled caregivers on the front lines of care for the elderly and disabled, whose experiences are rendered invisible by a public that takes only passing interest in their work. Drawing on interviews with and observations of home care aides in California and Ohio, I describe the conditions under which low-skilled, low-waged caregivers provide for the needs of the elderly and chronically ill, paying particular attention to the material factors (namely, wages) and nonmaterial impulses (such as altruism, emotional attachment, and the drive for autonomy) that

propel women into the job and sustain, or undermine, their occupational commitments.

Aides in the Home

The vast majority of care provided to the elderly, disabled, and chronically ill in the home is informal, assumed by family members who do not receive monetary compensation for their labor. Women traditionally bear the responsibility for unpaid caregiving, leading to near consensus in the literature that the social organization of care is an outgrowth of the emotional and occupational sexual division of labor (Cancian and Oliker 2001; Gordon, Benner, and Noddings 1996; Harrington Meyer 2000). Nearly 75 percent of people ages eighteen through sixty-four receiving long-term care assistance in the community (i.e., not in nursing homes) rely exclusively on unpaid caregivers, most of whom are women (Stone and Wiener 2001).

While it is crucial to recognize the work of informal caregivers, of increasing significance is the growing number of paid home care aides and nursing assistants who are filling in the care gap for families or individuals who cannot provide informal care due to realities of income, geography, or indifference (Harrington Meyer 2000; R. Stone 2001; Stone and Wiener 2001). When an elderly person or a family chooses home over institution, home care aides (also referred to as personal care assistants or chore workers) are often employed to share in hands-on or “direct” care. Such care includes feeding, bathing and tending to other aspects of personal hygiene, and providing companionship, activities known among long-term care professionals as activities of daily living, or ADLs. In recent years, concerns for patient safety, agency fears of liability, as well as state-level Nurse Practice Acts have limited the extent to which aides can provide even minor medical care, such as changing a dressing, administering insulin, or helping clients manage prescriptions (Reinhard 2001). In this climate, the work of the home care aide is largely relational in nature, meaning that the job requires a sustained and often reciprocal emotional connection to a client (Parks 2003). In short, home care work is as much emotional as it is physical.

Many aides serve as formal companions to their clients (as part of their job description) and also run errands and provide light housekeeping. Indeed, the range of work tasks associated with home care broadly mirrors

the myriad tasks associated with the gendered division of labor in the home. In general, aides take on caregiving tasks that family members, specifically women in families, either cannot or will not do (Nakano Glenn 2000). Aides who do this work for pay often have many years of experience providing informal care to children and other family members without pay. Often called on in a family crisis, aides have caring trajectories that begin with unpaid care in their own home and then translate, usually in their middle years, to work as a paid caregiver. It is this history of informal caregiving that sets most aides on the path toward low-wage care work, reflecting an important link between a gendered division of labor in the home and the labor market.

Recent estimates (2006) suggest there are approximately eight hundred thousand home care aides employed in the United States, which is triple what the number was in 1989 (Kaye et al. 2006). The Bureau of Labor Statistics (2010) estimates that by 2018, there will be over 1 million home care aides in the United States. While aides in nursing homes and other institutional settings currently outnumber home care aides, the BLS projects that home care aides will outnumber their facility-based peers two to one within the next ten years (Paraprofessional Healthcare Institute 2008b). Some argue that the numbers are likely gross underestimates, as many home care workers and personal care assistants are self-employed or considered “independent providers,” paid privately for their care and not easily tracked or counted (Institute of Medicine of the National Academies 2008). The more urgent problem suggested by the demographic data, however, is that the pressure for direct care workers, such as home care aides, continues to mount, even as demand for these workers outpaces the number of females projected to enter the labor force between 2006 and 2016 (Paraprofessional Healthcare Institute 2008b). Given this projected shortfall in labor supply, it is all the more urgent for the occupation of home care aide to become a quality job that will attract and retain low-skilled workers.

To date, there are few sociological studies on aides working in home settings, perhaps because work tasks and client-worker interactions unfold in a private context, making it difficult for researchers to render visible the labor associated with home care (Stone and Wiener 2001). Existing empirical investigations of aides tend to be descriptive in nature, with an emphasis on documenting the aggregate trends in the workforce, such as burnout, turnover, and average wages (Montgomery et al. 2005; Potter, Churilla,

and Smith 2006; R. Stone 2004). Research to date shows that home care aides are, on average, poorly compensated and that the work is characterized by high rates of turnover and burnout (Brannon et al. 2002; Crown, Ahlburg, and MacAdam 1995; Stone and Wiener 2001).

The paucity of research on aides working in home settings stands in stark contrast to the sizable body of sociological research on nursing assistants and nursing aides who work in institutional settings (Chambliss 1996; Davies 1995; Diamond 1992; Foner 1994; Lopez 2006). Studies of aides in nursing homes—like Timothy Diamond’s *Making Gray Gold* (1992) or Nancy Foner’s *The Caregiving Dilemma* (1994)—identify the sources of stigma attached to low-level nursing work. They argue that the pressures to bureaucratize and “speed up” the caring process in nursing homes lead to poor living and working conditions for elderly residents and workers, respectively. While Foner disagrees somewhat with Diamond, arguing that commercialized, bureaucratic care can sometimes protect nursing home residents from aides who might act autonomously, both suggest that the general trend toward bureaucratic care and lack of worker autonomy harms residents and nursing aides alike.

Much of the social scientific literature on nursing aides focuses on this question of worker autonomy and the bureaucratization of care. However, once our focus shifts from institutional to home-based care, it is less clear how autonomy and bureaucratic control operate or whether they exist at all. Deborah Stone (2000a), in her study of home care, concludes that workers do in fact experience a conflict between bureaucratic rules and principles and their own ethic of care. Much like the health aides in Diamond’s study, Stone found that home care workers went out of their way to spend extra time with clients and to pay out of their own pocket for client expenses, thereby preserving their own ethic of care. Stone suggests the crux of the problem is that “care in the public world is often incompatible with the norms, rules and expectations of care in the private world” (91), a situation particularly acute in home care where the private meanings associated with care are ever present.

Turning attention to paid care work in the home extends the literature on long-term care beyond the institution, allowing us to see how work constraints, such as the bureaucratization of care, vary when services are provided in an informal setting. Examining the work of nursing aides in the home also allows us to consider what happens when the boundaries

between private and public space are blurred for both workers and their clients. Hochschild (2003) refers to this melding of work and family space as “marketized private life,” where it is unclear which norms—familial, workplace, or both—guide social interaction. Home care is precisely such 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. For this reason, home care is an ideal site of empirical investigation, especially when it comes to extending existing research on emotions and emotional labor at work.

Paid Care Work, Inequality, and Emotional Labor

Scholars of care work have long been interested in how women face both emotional and financial penalties for their paid care work (England, Budig, and Folbre 2002; Hochschild 1983). Women providing paid care—such as nannies, nurses, home care aides, and teachers—suffer a “wage penalty” for their work, relative to women and men in non-care work fields (England, Budig and Folbre 2002). Increasingly, paid caring labor is the work of women of color, who assume responsibility for caring work previously handled by unemployed white women in the home (Hondagneu-Sotelo 2001; Rollins 1985; Romero 1992). This racial division of paid reproductive labor (Nakano Glenn 1992) has “gone global,” as women from developing countries migrate to the United States to work as nannies, domestics, or home care workers, often leaving their own children or elderly relatives at home and without care (Ehrenreich and Hochschild 2002; Parrenas 2001). In short, women who provide paid care to others often do so at great personal expense and with little financial reward.

The penalties of care work are due, in part, to the fact that women provide care within the less-than-favorable conditions of a service economy. Beyond the obvious material hardships that a service economy generates for low-skilled workers, students of care work also consider how service economies foster an “emotional proletariat” (Macdonald and Sirianni 1996), a sector of laborers for whom self-presentation and other personal characteristics become core job requirements. These relational work demands, what sociologists refer to as “emotional labor” (Hochschild 1983),

can be detrimental to the worker because he or she experiences a “transmutation” of private feeling into a public display of emotion, resulting in alienation of self (Hochschild 1983, 19). Researchers offer examples of paid careworkers, such as nurses, who routinize care to manage their emotional labor (Chambliss 1996; Erickson and Grove 2007) or service workers who must evoke the feeling of care in a customer, so as to enhance the value of a material product, such as fast food or air travel (Hochschild 1983; Leidner 1993).

Given what we know about the demands of service work, care work in particular seems an obvious place to observe alienation that comes from emotional labor. The job requires, indeed demands, the performance of emotion to ensure the “product” of care is delivered. However, ample scholarship subsequent to Hochschild’s *The Managed Heart* (1983) suggests that emotional labor does not have a uniformly negative impact on job satisfaction (Erickson and Grove 2008; Leidner 1993; Paules 1991; Wharton 1999; Wharton and Erickson 1993). One of the key conclusions to draw from the more recent work on emotional labor is that the consequences of emotional labor are largely dependent on the *context* of emotion management. Further, we now know that people, especially women, manage their emotional labor across multiple settings and roles (work and home; mother and employee) and that context matters for the overall impact of emotional labor on one’s well-being and job satisfaction (Wharton 1993).

Care work generally, and home care specifically, provides an important point of discussion with respect to emotional labor. While the job demands “deep acting” on the part of the caregiver, I agree with Ashforth and Humphrey (1993) that the emotional labor of a home care worker is often born out of a long-term relationship with a client where genuine feelings of companionship emerge. Indeed, many caregivers emphasize the “fictive kinship” they have with clients, further complicating the nature of the emotional work (Karner 1998). Precisely because care work, including home care, involves long-term relationships between the caregiver and the recipient of care, Susan Himmelweit (1999) suggests that caring work is “incompletely commodified work,” where both alienating and empowering forms of emotional labor exist. This supports Maria Ibarra’s (2002) assertion that women caring for the elderly engage in authentic emotional labor, distinguishing them from what are characterized as emotional proletarians. Of course, the existence of authentic emotion in care work

does not preclude the alienation of the self that Hochschild predicts, but the unique context of both care and service work make home care work a rich site from which to examine new terrain in the ongoing study of emotional labor.

For aides working in the home, the boundaries of work/home and public/private space are fundamentally blurred, which in turn shapes the way in which aides provide and interpret their care. On the one hand, aides are paid employees who must follow procedures and regulations as they strive to meet client needs. On the other hand, caregiving in the space of a home cues aides and clients to a less formal set of interactional rules, akin to family relationships rather than those associated with work. In this context, the motivation for providing care also becomes confused as aides (and clients) wonder whether care is provided for the sake of love or money. Most caregivers are likely motivated by emotional connections to clients and their need for pay, but as Viviana Zelizer (2005) points out, we live in a society that believes that love and money are incompatible “hostile worlds” that should remain eternally separate (lest we sully the altruistic dimensions of love). Walking the “love or money” line is particularly cruel for home care aides, who commit themselves both physically and emotionally to clients for a paltry minimum wage. Despite the obvious inequality embedded within this exchange, most aides choose to emphasize the relational aspects of their work and downplay their own pecuniary interests, thereby reinforcing the idea that love and money are irreconcilable.

As aides cultivate companionship with clients, confusion over home/work and love/money is exacerbated. The ability to form genuine ties to clients is a source of pride for aides who view it as a form of skilled, emotional labor that gives their work lives meaning and improves quality of life for clients. At the same time, companionship can complicate formal work arrangements between aides and clients, sometimes resulting in the overwork or emotional overinvestment of caregivers who find it difficult to extract themselves from clients who feel and act more like friends or family than employers. Labor advocates are quick to point out that focusing on companionship also obscures the formal, physical labor associated with caregiving and makes it difficult for aides to mount legitimate claims to fair wages and labor protections. Aides (and some of their clients) may view companionship as work, but the law unfortunately does not recognize it as such.²

Despite compelling claims that aides are “more than companions,” I suggest that the relationship between aide and client—and the related “input” of emotional labor—is central to understanding the work of aides. This relational work of companionship (Parks 2003) influences workers’ job satisfaction and their emotional health, as well as their identities and sense of self, in ways that are not always predictable or obvious. *The Caring Self* explores both the positive and negative consequences of emotional labor for worker subjectivity, arguing that aides actively construct and narrate a sense of self, what I call the caring self, by drawing directly (and strategically) on the relational dimensions of their work.

Investigating the link between emotional labor and identity at work is crucial if we are to understand the factors that lead to high rates of worker turnover and burnout. I contend that current discussions about long-term care either ignore the emotional labor associated with low-skilled care work, or assume—with little empirical evidence—that emotional labor has only deleterious consequences for caregivers (Erickson and Grove 2008; Lopez 2006; Nakano Glenn 1992). In view of concerns about the recruitment and retention of frontline workers, it makes sense to carefully interrogate the reasons—including affective reasons—why women and some men become paid caregivers and why they stay on (or leave) the job. While by no means a treatise on workforce policy, this book aims to insert the voices and experiences of frontline workers into current discussions about the crisis in long-term care.