Critical Gerontology Comes of Age

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CHAPTER 8

Paid Caregiving for Older Adults with Serious or Chronic Illness: Ethnographic Perspectives, Evidence, and Implications for Training

Chris Wellin

Care involves a constant tension between attachment and loss, pleasing and caring, seeking to preserve an older person's dignity and exerting unaccustomed authority, overcoming resistance to care and fulfilling extravagant demands, reviving a relationship and transforming it.

(Abel, 1990, pp. 204–205)

The preceding statement contains the crux of what I wish to convey in this chapter regarding the challenge and skill required to care for disabled older adults. As it happens, the quote concerns *family care*: adult children caring for parents. However, it captures equally and vividly the subtle and poignant relational subtext that underlies *paid care* for delicate selves and bodies. In principle, one might expect the public to recognize and value care for relative strangers as virtuous, even heroic, as compared to that which we provide in the context of lifelong familial ties. Such is not the case. Moreover, in shifting attention to care from the private to the public sphere, many people—policy analysts no less than lay people—contract a form of blindness to the skill, empathy, and moral commitment such work demands.

The costs of this blindness are steep—for paid caregivers, those for whom they care, and for family members and friends who have a stake in the availability of humane, consistent, and skilled care for those who are chronically ill or disabled. The premise of this chapter is that, while we have an abundance of academic and policy research on the severity and financial pressures of the growing need for paid caregiving, too little attention has been paid to the processes and relations of care, and to the occupational skills and demands of caregivers. But, in recent years, we have seen a flowering of research on this topic, which I undertake below to summarize, synthesize, and connect to emerging policy issues bearing on occupational skills and rewards in this large and fast-growing segment of the service sector of the economy.

What is the larger context for this effort? Given demographic changes in the United States, which portend higher rates of chronic illness and disability in the years to come, and growing pressure to contain health care costs (which are

highest in medically oriented settings such as nursing homes, and met by public sources via Medicare and Medicaid), the need to address the caregiving dilemma has become acute. Moreover, labor projections reveal that over the next decade, service-sector occupations—especially in paraprofessional or "direct care" jobs such as nurses' and home health aides—will be among the fastest growing in the United States (Dawson, 2007; Hecker, 2005; Paraprofessional Healthcare Institute, 2003a, 2003b; Sommers, 2007). There are wide-ranging economic, political, and moral implications of consigning such a large and growing segment of the labor force to poor wages and unstable career conditions. As Stone (2000b) argues, the quality of life enjoyed by the aged and disabled, over-burdened family care providers, and direct care workers are inextricably intertwined.

My agenda in this chapter: After describing the research background and approach I bring to this topic, I summarize demographic and labor market trends that have propelled issues of low-wage care workers (LWCWs) to the forefront of policy concern in the United States. Then, we discuss distinctive conceptual and empirical issues that have informed ethnographic research on care work. Of particular importance in this review is how one defines and documents *skill* as a key referent in the study of work. Next, I identify and discuss recurring themes in ethnographic research on care work, with special attention to the (often subtle or neglected) skills that characterize competent and exemplary practice. Then, after addressing how skill demands vary, within particular work settings and in response to the needs of particular kinds of care recipients, I summarize contemporary perspectives and strategies, within groups that represent and/or advocate for LWCWs, aimed at enhancing the recruitment, retention, performance, and public recognition of care workers. Finally, I offer suggestive implications of the argument for education and training initiatives designed to enhance recruitment, practice, and retention of LWCWs.

A Focus on Low-Wage Care Workers

Our focus is on the lowest-paid and ostensibly least skilled personnel within this sector of the health care workforce—those "frontline" workers who provide direct care in nursing homes, rehabilitation centers, residential care facilities, and in the community through "home health" agencies. Whether termed nurses' aides, CNAs, or personal care assistants, these LWCWs share many common challenges, as well as rewards, in their efforts to enhance the independence, dignity, and morale of the large and growing numbers of people who live with chronic illness or disability (Atchley, 1996; Dawson, 2007; Paraprofessional Healthcare Institute, 2003b). Indeed, Whitebrook (1999) showed similar dynamics of the labor market for and experiences of *childcare* workers.

Who are these workers? What is their socio-demographic and economic profile? A report by the Institute of Medicine (2001, p. 181), citing data from the Bureau of Labor Statistics, indicates that, "in 1998, nursing homes, personal care facilities, residential care and home health and home care agencies accounted for nearly 3.2 million jobs. Of these jobs, 1.18 million, or 37 percent, were paraprofessional

(including nursing assistants, personal care aides, and home health aides) ... Approximately 57 percent were employed by nursing facilities, 28 percent by home care agencies, and 15 percent by residential care facilities or programs in 1998." Potter, Churilla, and Smith (2006) enhanced the portrait by drawing on two waves of national survey data, comparing full-time direct care workers and female workers generally. They concluded that over one-third are African-American (who comprise about 12% of the larger group); fewer are married than is true of women workers in general (42 vs. 56%); 67% have a high school degree or less (vs. 38% in the larger group); and 25% (vs. 18%) have at least one child aged 5 or younger. Roughly one-third of direct care workers are also poorer than female workers generally (one-third have family incomes below 150% of the poverty level), and only 40% receive employment-based health insurance.

Demographic and Labor Market Trends Propelling Interest in Care Work

Research and policy interest in LWCW has been propelled by well-known and well-documented demographic and labor market trends: the conjunction of falling birth and death rates in recent decades has produced dramatic growth in the aging population in the United States. In little more than a single life span—that is, between the mid-twentieth century and the year 2025—the proportion of those older than 60 years will roughly quadruple, from about 5% to more than 20% (Quadagno, 2014). The fastest-growing group of elders is the "old-old," those aged 85 and above, who by 2040 are predicted to number nearly 14 million (Quadagno, 2014, p. 79). Improvements in diagnostic, pharmaceutical, and therapeutic medicine—especially in the treatment of cancers, heart disease, diabetes, and other chronic conditions that continue to be leading causes of mortality—have extended life substantially. However, even though the current "baby boomer" cohorts are, in the aggregate, healthier than those of the past, we can still expect a "compression of morbidity" at the end of life (Quadagno, 2014, p. 251), which will place enormous economic and logistical demands on the long-term care (LTC) system.

That system, broadly defined, encompasses a continuum of care, which spans (1) family/kin support in the community, (2) the growing world of assisted living/residential care, and (3) medically intensive institutional care. Movement through this continuum is neither linear nor unidirectional, and arrangements and relationships within these "points" on the continuum are not mutually exclusive (Kane, 1995). In fact, a combination of funding pressures and patient preferences is driving a compositional shift, in which a substantial percentage of nursing home residents return to community settings after rehabilitative care. Still, in our fragmented or "disaggregated" LTC system, there are "disparate programs, each with its own segregated funding 'silo.' In this vertical design, nursing home services are funded separately from home care services, which in turn are funded separately from assisted living and residential care settings" (Paraprofessional Healthcare Institute, 2001, p. 15). This has important implications for recruiting

and training care workers, inasmuch as core aspects of work—including the nature of supervision, staffing ratios, and the primacy of residents' preferences—differ across care settings, and the fragmented nature of the system undermines continuity of care that is central to achieving quality.

Historically, family care for the aged has been both a cultural ideal and an historical norm, a pattern that persists. Barker (2001, pp. 6–7) claimed, in this connection, that most studies of non-kin care have assumed family care to be the ideal, and assessed alternatives in terms of a "deficit model." Kaye, Chapman, Newcomer, and Harrington (2006, p. 1113) estimated that, currently, only 16% of "personal assistance care" is provided by paid caregivers. However, lower fertility rates have curtailed the availability of family caregivers, to say nothing of the higher proportion of those in current cohorts who are single or childless. In this connection, Potter et al. (2006, p. 358) reported that "the supply of women aged 18–45 (the direct care worker pool) is decreasing relative to the exponential growth in the number of elderly Americans." Nonetheless, family members continue to provide the vast majority of care to the extent (and beyond) that they are capable. At the same time, intensifying work demands have placed ever greater stress on family/kin caregivers—typically women—many of whom jeopardize their own present and future economic security in order to provide care in the final years of their parents' lives.

Ironically, a prime legacy of the success of our acute-care medical system is an increase in the prevalence of chronic conditions of late life, which often leave elders with multiple health problems.[1] This profile of age and disability is driving the expansion of demand for long-term, non-medical care. Too often discussed in terms of instrumental "activities of daily living," such care (assisting with bathing, dressing, transportation, shopping, and housekeeping) is essential to the maintenance of independent, fulfilling adult life in the community. Projections of future demand are that "The number of people needing these services will more than double, from thirteen million in 2000 to some twenty-seven million in 2050" (Potter at al., p. 1113). Compounding the challenge will be increasing rates of dementias, which require not only medical and practical supports but also "identity support"—complex socio-emotional care to maximize quality of life (Wellin & Jaffe, 2004).

Thus, the serious nature of the current shortage of frontline LWCWs (Atchley, 1996; Paraprofessional Healthcare Institute, 2003a, 2003b, 2001) pales in comparison with that we will face in the years to come. Gatta, Boushey, and Applebaum (2007, p. 35) cited data from the *Monthly Labor Review* predicting that between 2005 and 2014, home health aides and nursing aides/orderlies/attendants would be among the top ten occupations with the greatest job growth (approaching 50%) during the period. Within this labor force, there is also a compositional shift in terms of work settings—increasingly toward home and community-based options which are both less costly, and more responsive to the preferences of care recipients (e.g., Kitchener, Ng, Miller, & Harrington, 2005).

The ethnographic evidence (e.g., Karner, 1998; Piercy, 2000; Rivas, 2003) reveals that there are important social/interactional and skill-related implications of this

shift in the work locales in which care workers are likely to be found: it is truer in-home care and small residential settings, than in nursing homes, that LWCWs must adapt care tasks to individual circumstances, preferences, and schedules of care-recipients. The character of this contrast, and related assumptions about power and autonomy, are suggested by comparing the terms "patient" or "resident" with "client." Though home-health workers may have a significant number of clients, they work with them one at a time and in clients' territory, so to speak. We will find below that there are trade-offs in this arrangement for care workers. But the salient point here is that inter-personal skills and rapport, that may be marginal or even penalized in more medically oriented and bureaucratic nursing home settings, are expected and even required in home and community-based care.

Key Assumptions and Empirical Themes in Ethnographies of Care Work

Stated broadly, ethnographic research methods seek to provide richly detailed descriptions of work processes and interactions, and according to Friedman and McDaniel (1998, pp. 113–114), "a sensitivity to perceptions, and an opportunity to discover important new issues, (discoveries) that cannot be achieved through *a priori* theorizing." They note further that "Naturalism also allows the researcher to see the cumulative effect of multiple forces on people's actions." Although the ethnographic perspective has long been central to the field of cultural anthropology, it is now applied across a wide range of disciplinary and policy fields. In ethnography, the prime research instrument is the field researcher, who draws upon interviews, observation, and documents in order create a rich portrait that, ideally, is both informed by and generative of theory.

Though ethnography stresses internal validity and attention to conjunctions of factors in particular settings, there is growing interest in combining and interpreting findings across studies of a particular topic, which Noblit and Hare (1988) discussed as *meta-ethnography*. In this approach, which I take here, one seeks to confirm, integrate, and refine themes and findings from multiple studies, often to shed light on a theoretical or policy question that may have been tangential to the original research.

In reviewing ethnographies of care work, there are three critical issues that, in my view, cut across and inform the literature and thus warrant brief mention here: 1) defining and studying skill; 2) the gendered nature of care work, and its effect on the social appreciation and rewards of such labor; and 3) the legacy of the biomedical model in shaping the culture and distribution of professional authority in LTC institutions and policies.

Defining and Studying Skill

Theoretical and empirical approaches to studying workplace skills vary considerably (see Gatta et al., 2007 and Vallas, 1990, for a review of approaches in sociological research). Ethnographic research on care work asserts and reveals

the value of assessing "skill" (and related issues bearing on worker recruitment, selection, and training) in the context of situational and interactional *contexts* in which work occurs. Kusterer (1978) developed an argument, based on industrial workers, which has clear relevance in the present case: many of the skills employees possess are "tacit," that is, exercised without conscious or public acknowledgement, and in contradiction to formal, managerial accounts of the work process. This insight underscores the importance of excavating workers' own perceptions and practices, via ethnography, and of skepticism regarding more abstract "top-down" conceptions of workers and work-skills (see Shortell, 1998).

Following Attewell (1990), there are especially sharp contrasts between *objectivist* and *positivist* approaches to skill, and others which are *constructivist* or *ethnomethodological*. While terminology varies across time and disciplines, Attewell argued that the former approach is taken by "those who treat skill as an attribute that is amenable to quantitative measurement and believe that this attribute or quality has an objective character independent of the observer." This conception of work skills, central to "human capital" models, is found in research on industrial and clerical work, and has provided powerful leverage in addressing such questions as the role of technological change in accounting for wage inequality (Fernandez, 2001). Attewell explained that "Human capital is typically measured as the sum of years of vocational or formal education plus years of on-the-job experience" (p. 425). However, as Gatta et al. (2007, pp. 9–10) point out, many of the fastest-growing service occupations require skills such as active listening, instructing others, speaking effectively, promoting a service orientation, and social perceptiveness. These skills—contextual and relational in nature—are difficult to assess outside of the practical sphere of work, and are seldom the focus of formal training. Moreover, when these skills are expressed in care work, linked to gendered assumptions about women's instinctual capacities for nurturance (Cancian & Oliker, 2000; Gatta et al., 2007, pp. 24–29), they tend to be all the more obscure or devalued.

Ethnographic research elaborates conceptions of skill that combine or contrast two other schools which Attewell reviews: ethnomethodological and neo-Marxist approaches (1990, pp. 429–443). The first, as noted, emphasizes "the fine texture, the many steps and contingencies, of activities that are normally thought of as simple" (p. 430). Despite its distinctive insights, ethnomethodological research is vulnerable to the critique that it reduces social processes to micro-level dynamics and fails to engage constraints of social structure, power differentials, and formal organizations. In turn, neo-Marxist perspectives have been fruitfully integrated with fine-grained ethnography, in order to analyze how and why particular labor processes are fragmented, coerced, and intensified in the name of efficiency and profit (e.g., Burawoy, 1979). Integrating these analytic stances also allows for inclusion of cultural/ideological rankings in assessing the work status and rewards. For Attewell (1990), "What is striking about this literature is the frequency and centrality of the social constructionist aspect of skill within Marxism, the idea that the social standing and perceived skill of an occupation stems in large part from the power of those workers rather than from intrinsic complexity of the work itself" (p. 440).

Care work certainly involves tasks that appear at first glance to be mundane or *un-skilled*, such as dressing, bathing, feeding, and comforting people. However, these tasks require complex, empathic, and embodied practices, which must be adapted both to the normative expectations of social relationships in which they are carried out (e.g., parenting or teaching children vs. caring for an older person following a stroke) as well as to the immediate practical and temporal division of labor.

Gendered and Racialized Assumptions and Inequalities Regarding Care Work

Integrating ethnographic insights into the practice of care work with critical attention to managerial strategy and coercion (aimed at "de-skilling" work) sharpened qualitative analyses of care work. What was missing, to achieve the explanatory power of the strongest contemporary research, was an explicit analysis of gender as a fundamental status system in which work is defined and remunerated (see Cancian & Oliker, 2000; England, 2005; Glenn, 2000; Steinberg, 1990) and of how tasks and qualities usually associated with women are perceived and rewarded more generally in occupations. These considerations become central in any analysis of care work because of the gendered, familial meanings that are—whether explicitly or subtly—attached to caring labor. As England, Budig, and Folbre (2002, p. 456) argued, caring work should be distinguished from the larger domain of interactive service work (e.g., in retail, food service, or customer service). They pointed out that, while there are structural similarities between the two (such as low wages and flat career lines), they involve different, if not opposing, skills and demands. Whereas interactive service work typically requires *routinization* of tasks, to promote efficiency and inter-changeability of labor in the provision of a service (see Leidner, 1993), care work ideally involves *personalization* of tasks in order to help maintain or enhance recipients' independence and quality of life. This commitment is clearly salient for workers and recipients, if not always for employers, a tension that is central to recurring dilemmas in care work.

The "helping/nurturing" dimension of care work has repeatedly been found to be a powerful lure in drawing people to such jobs (e.g., Aronson & Neysmith, 1996; England, 2005; Foner, 1994; Kopiec, 2000; Stacey, 2005; Wellin & Jaffe, 2004). Kopiec (2000), who conducted individual interviews and focus groups with LWCWs in New Hampshire, writes,

> The most common overarching reason for becoming a Certified Nursing Assistant (CNA) is the desire to help others. As one participant explains, 'It just started as a helping thing . . . I think because I like to chit chat and the fact that I can involve myself in somebody else's life.' Several women have personal experience caring for an ill family member, which they found rewarding and led them to this type of work . . . Joanne explains: 'I have a big heart and don't like to see people be by themselves, to suffer. I took care of my first husband; when we were 24 he got cancer and later died . . . It's a talent I have inside of me'.
>
> (p. 4)

In a similar spirit, an online CNA forum hosted by *Nursing Assistant Central* features personal, consciousness/pride raising statements such as: "I am the one, in many people's lives, who provides them with their basic human needs. What others take for granted—dressing, bathing, eating—some people are unable to perform for themselves anymore, and they depend on me. I am the one who goes to great lengths to maintain their privacy and dignity . . . Yet I am also the one they rage at, venting their frustration, anger, confusion and fear. I am the one who performs care, even though doing so will often put me at risk of physical or verbal abuse at the hands of those I care for."

The Legacy of the Biomedical Model

Public perceptions and professional problems of LWCWs cannot be understood without awareness of their historical role in the dominant, acute-care biomedical system (Henderson, 1995; Freidson, 1970/1988). Until recent decades, most of these workers were employed by hospitals, nursing homes, or rehabilitation centers, where they were regarded as menial and transient underlings in a hierarchical division of labor. Clearly, there are strong rationales for this organization of medical care, in the context of curative techno-medicine: in that case, there need to be clear lines of authority and responsibility, along with smooth intermeshing of administrative, laboratory, and clinical work. In this context, the patient is expected to comply with medical advice and to accept impersonal detachment on the part of members of the medical team, in exchange for timely and expert treatment (Parsons, 1951, pp. 428–479). As Morgan and Kunkel (2007) explained (pp. 270–273), the "medical model" carries cultural meanings that extend beyond discrete care settings. It also enshrines a dichotomy between mind and body, and a narrow reduction of illness to somatic causes and manifestations (the "doctrine of specific etiology"), to the exclusion of broader socio-cultural factors. To the extent that care for the person *qua* person is addressed in the acute-care setting, it typically is provided by nurses or by social workers or clergy for whom this mission is central and bolstered by professional training and status.[2]

Themes and Findings Regarding LWCWs in the Ethnographic Literature

In ethnographic studies of nursing home and elder care, only rarely have the roles (still less the perspectives) of LWCWs taken center stage. More often we have had mere glimpses of these workers and their impact on the quality of care and life. Rather than begin with descriptive vignettes and build up to broader themes and findings, I have chosen to develop the themes up front, in order to frame the

meaning and implications of the sources I review now in greater detail. It will be instructive throughout to bear in mind a set of recurring, work-a-day dilemmas that plague LWCWs, laid out in a discerning essay by Stone (2000a); these serve to link the broad conceptual themes discussed earlier, and the ethnographic stories and perspectives: *talk versus tasks, love versus detachment, specialness versus fairness, patience versus schedules, family relations versus work relations,* and *relationships versus rules.*

Nursing Home Ethnography

I begin with the tradition of *Nursing Home Ethnography,* which has a longer and more extensive history than does research on LWCW in other settings. Several sketches from a couple of important studies will help show the nature and development of knowledge of LWCW.

The contemporary nursing home sector is poised between ever greater consolidation and intensification of labor, on the one hand, and innovative programs to humanize care, on the other (see www.pioneernetwork.net/; Thomas, 1996). Eaton (1999) reported that "Today, 75% of nursing homes are owned by private, for-profit firms, 20% by private nonprofit institutions, and 5% are public. Public funds pay for the majority of nursing home care; 15% of all revenues go to the top six nursing home corporations . . . whose operating profits increased by 122 percent on a revenue increase of 19% between 1996–1997 . . . More than 1.7 million people live in nursing homes, a number that will double in the next twenty five years. Between 50–70% of residents suffer from some kind of dementia; more than 80% of residents are women, as are more than 90% of nursing home workers" (pp. 75–76). Eaton observed that as nursing homes seek to maintain profits in a more competitive managed-care atmosphere and with more seriously ill residents, they turn with increasing ardor to cutting labor costs, which account for roughly 60% of costs: "This increases the pressure on front-line workers, many of whom complain of understaffing, lack of training and support, inadequate supplies, and unresponsive management" (p. 77). The current political economy of long-term care shapes the issues that are central to critical ethnographies, and sets limits on the range of plausible remedies to recurring problems of staff recruitment and turnover, which varies widely, from roughly 30% for nurses, to more than 100% for aides (Castle & Engberg, 2006).

Gubrium's (1975) *Living and Dying at Murray Manor* is a widely cited ethnographic study (based on months of fieldwork and varied field roles) which revealed the deep *segmentation* between various "worlds" within the nursing home. He elaborated the rather self-contained domains of the "top staff," the "floor staff," and the world of residents—including their experience of time passing, friendships, and the nearness and reality of death. A crucial insight of *Murray Manor,* with implications for LWCWs, is that their labors are little known or appreciated by administrators, and thus are not integrated into larger goals. Principal among these is creating a "home-like" atmosphere conducive to "total patient care" (1975, p. 48). This fragile ideal took shape largely through an invidious

comparison with hospital care, which most of the top staff had fled for Murray Manor. Nurses, too, found nursing homes to be "more personally satisfying" than hospitals as work locales, though they conceded that they had had little training for addressing residents' personal and emotional problems. Gubrium suggested that the floor staff members are potentially critical in enacting "total care." However, his portrait shows how rushed and physically grueling is their daily routine (pp. 124–157). Also, in *Murray Manor,* aides are presented as heedless of privacy, resistant to innovation or to any interactional digression as annoying barriers to getting through their round of "bed and body work." "Aides believe that the fact they're working for the patients, and working hard at that, is good enough reason to 'get 'em goin.' Thus, aides may enter rooms and urge patients along to their scheduled destinations with obvious exasperation or patronizing indulgence. Typical statements on these occasions express their sentiments: 'What *are* we going to do with you, Cora?' . . . Let's get moving now" (p. 129). Ultimately, the book shows how aides can be viewed, by residents, as intrusive and instrumental; there are few vignettes that reveal a warm or intimate quality to caring encounters. However, in concluding the section describing their work, Gubrium observed that:

> Floor staff, more than top staff or clientele, experience the social complexities that arise when [sense of] place is not well-insulated. As members of the floor staff enter and depart certain places as part of their work, they tacitly raise doubt about whether these places are private or public . . . Floor staff conciliates both top staff and clientele in order to guard what it considers normal work routine. This is a highly precarious working policy.
>
> (p. 157)

So, in the fragmented world of the nursing home, aides play a critical—albeit "precarious"—role in mediating the mission of total care. Still, to their arduous physical and emotional tasks is added the burden of simultaneously enforcing and buffering the most intrusive aspects of institutional life. Ideally, this role-conflict could be acknowledged and explored in the orientation and training of such workers, as a constructive step in retaining and supporting LWCWs in such settings. (See Gubrium [1993] for an important narrative study of residents' perspectives on nursing home life.)

Shield's (1988) *Uneasy Endings* is another rich ethnographic study of nursing home life, in which there are only glimpses of the circumstances and roles of LWCWs. An anthropologist, Shield is comparative in assessing distinctions between nursing home life and that in other "total institutions" as defined by Goffman (1961). She is also attentive to the significance—by their absence—of ritual and reciprocity in the lives of people who, after all, are collectively facing the existential crisis of death. For Shield, the puzzle is that a group facing the ultimate *rite of passage* should be denied the sense of togetherness (*communitas*) which would afford greater meaning and sustenance to the ordeal (pp. 205–209). The author also develops the themes of exchange and reciprocity, as generic qualities of

relationships that promote interdependence and a sense of control. The bane of nursing home life, from this vantage point, is not illness or institutional residency, per se; rather it is the asymmetrical nature of relationships—in particular between care workers and residents—that cast the latter always in the role of supplicant and dependent. Shield (1988) explained,

> Because residents have little power and must receive, they must be grateful. The responsibility that staff members exhibit toward residents is also reduced by the constraints on reciprocity. When one can repay nice staff members or visitors, one is able to rely on the other person's mutual sense of responsibility. A person who is unable to tap the other's sense of responsibility attempts to induce guilt, and with time guilt is resented. There is little reason for staff members to feel responsible toward the resident because staff members' obligations are to their bureaucratic duties.
>
> (pp. 158–159)

Shield (1988) lamented that residents are "de-cultured . . . misunderstood as children, as people with no pasts, as recipients with no legitimate input into the factors that determine their lives. Treated alike by staff, they recognize no bonds with each other—instead they splinter into their heterogeneous identities because there are no rituals to bind them together as separate individuals undergoing the passage from life in the community to death" (p. 216). Apart from barriers to *communitas* posed by cognitive illness, which is increasingly prevalent in nursing homes, Shield's account also contains seeds of insight about, and implications for staff development among LWCWs. If rituals are to be constructed and observed in the nursing home setting, it would seem to require the support and involvement of direct care workers. Given sufficient tenure in the particular setting, it is they who are uniquely possessed of the ongoing, personal knowledge about residents that would be required; also, it is they who are chronically starved for casual time with residents and, often, search out opportunities to step out of the formal routine and celebrate that which can be celebrated. An important caveat concerns the need for administrators and organizational routines to be oriented toward residents' quality of life.

Wellin and Jaffe (2004), in their study of residential care for older people with dementia, found that staff members often had detailed biographical knowledge about residents. However, they typically invoked and shared this knowledge in punitive ways—to criticize or pathologize residents' behavior—rather than with empathy or a desire to lend comfort. This process, which we term *appropriation of biography*, was rooted in the combination of a functionally diffuse division of labor (involving domestic labor, cooking, and field trips, as well as instrumental care), and the taxing nature of some behaviors associated with dementia (Jaffe & Wellin, 2008; Wellin & Jaffe, 2004, p. 286).

There is abundant evidence throughout nursing home ethnographies that staff members are kept in the dark about such issues as resident transfers and discharges,

changes in health status, and, especially, death and dying. This reflects the more general concealment and "management" of death that prevails in the larger society (Shield, 1988, pp. 69–71).

A relevant study (Castle & Engberg, 2006) of staff turnover in nursing homes found the highest rates among Certified Aides (56.4%), with between 35 and 40% for licensed practical nurses (LPNs) and registered nurses (RNs), respectively. Organizational variables that were clearly associated with higher turnover include lower staffing ratios, for-profit ownership, and higher number of beds (and see Seavey, 2004). The authors also confirm the importance of mediating factors shaping job satisfaction, including pay and benefits, autonomy/lack of intensive supervision, loyalty to the setting, and the quality of relationships with residents and fellow staff members. Variables of facility structure and scale would appear to be necessary, but not sufficient, explanations for this core problem. Beyond this, initiatives such as the *Eden Alternative* and *Greenhouse Model* (nationally prominent models of nursing home reform), which promote more flexible, team-oriented work arrangements, appear to further enhance worker morale and reduce turnover (Kemper et al., 2008). A further incentive for moving toward these employment conditions, noted by an advocate for *Eden*, is the roughly $2000 savings (in recruitment and training costs) for every nurses' aid retained on staff (Thomas, 1996, pp. 73–75).

Before concluding the discussion of LWCW in nursing homes, it is important to highlight findings and implications from two other, critical and innovative ethnographies of nursing home life, Diamond's (1992) *Making Gray Gold* and Nancy Foner's (1994) book *The Caregiving Dilemma.* The analytic and stylistic qualities of *Making Gray Gold* convey, perhaps more fully than had any prior source, the perspectives and challenges of LWCWs, in connection with the organization and funding of nursing home care. This source is also unique in having connected the daily struggles and routines of care, directly to the bureaucratic categories and demands of Medicaid and Medicare, in reflecting the project of institutional ethnography (e.g., Smith, 2005). Moreover, Diamond—the protagonist who, as a male, tended to elicit especially candid responses from field informants—also deals with the training, skills, work culture, and the emotional tenor of life among nursing assistants (Wellin, 2012). His account of the training process reveals the dominance of basic scientific and medical material (e.g., first aid training, anatomy and physiology, and medical terminology). Trainees, many of whom had modest formal schooling, language barriers, and children to support were encouraged to continue on for degrees as LPNs, a goal that was beyond the reach of most. In turn, little of the practical, challenging human contact involved in the work found its way into the training. He notes that one day, after a rote memory exam and the completion of supervised clinical rounds, students asked the teacher what to do next. The reply: "Why don't you go back and do some psycho-social stuff," is a comical request to the students who had haltingly been trying to get to know residents all day. Reviewing the 2004 version of the National Nursing Assistant Assessment Program practice

exam reflects that little has changed in the composition of the test. Out of sixty multiple-choice questions, half concern physical care skills, twenty-three concern the role of the nurse aid (e.g., communication, client rights, legal, and ethical behavior), and only eight are devoted to "psychosocial care skills" ("emotional and mental health needs," "spiritual and cultural needs"). Another resonant theme in the book is that of "Mother's wit," a folk term among Diamond's colleagues that connotes the intuitive, deft handling of the physical and emotional vicissitudes of the work (see also Hochschild, 1983):

> Mother's wit requires a host of unwritten emotional, physical, and interpersonal skills. But it also involves working with residents under a specific set of rules and regulations; trying to make sense of them and make them livable; trying to bridge everyday needs and external control. Take away Mother's wit and the industry is left without the women and the work that hold the building up, mediating between its base in everyday caretaking, and the superstructure of ownership that has been built upon it.
>
> (p. 237)

Foner's (1994) *The Caregiving Dilemma* extends Diamond's book in several important respects. Foner's is a more conventional ethnography, in the sense that her field role—as a volunteer and observer—enabled but did not commit her, as Diamond's did, to a distinctive perspective or participant voice. A woman, she was also less conspicuous, and was permitted to float more freely and thus paints a panoramic view of "Crescent View," a 200-bed, non-profit nursing home near New York City. A cultural anthropologist, with special expertise in ethnicity and immigration, Foner was naturally drawn to the Jamaican, Latina, and other ethnic groups in the very diverse LWCW staff. Where Diamond made mention of the great diversity of the LWC workforces in Chicago, there was little sense of ethnic traditions in caregiving as sources of meaning or support for workers. In fact, in some parts of the United States, one sees striking examples of ethnic employment *niches:* in the Bay area of San Francisco, for example, a majority of LWCWs in assisted living/residential care are Filipina; in cities such as Chicago, Detroit, and Milwaukee, African-Americans are preponderant in care work; Latinas are likely to be especially numerous in Texas, Florida, and southern California. There is suggestive evidence that recruitment and retention of such workers is strengthened when there are chains of referrals, to which those hiring give preference. In addition, in Foner's account, ethnic solidarity among LWCWs fosters more light-hearted, informal social gatherings and rituals than one finds in other accounts, and there is little evidence of racial/ethnic animosity, since the day shift care staff is divided between English-speaking Carribeans and Latinas, with African-Americans comprising only 20% (p. 18).[3] Foner's case suggests the utility of exploring ethnic cultures (which, in turn may shape views and norms of kinship) as mediators, which may promote interdependence at work and collective responses to grievances. Foner concludes that LWCWs are more help than hindrance to one another, and this solidarity and morale seem on balance to enhance the quality of care. In fact, the attempt to link staff working conditions with resident quality of life has become a theme for reform in nursing home care, and Foner provides clues and encouragement in this direction. Other of Foner's suggestions to enhance quality of care and life for all concerned are to include aides in care conferences (where they can play vital roles in reaching medical as well as socio-emotional goals); another is to hold in-service training outside of the work shift (so as not to disrupt the routines of care dyads), and be led by neutral trainers who are outside of the facility's authority structure; still another is to designate "primary assignments: each day and evening shift aide would become the facility expert on one or more residents—medically, psychologically, and socially—and represent the resident's interests with other staff" (p. 160; also see Paraprofessional Health Institute, 2003).

Trade-Offs for Care Workers in Home and Community-Based Settings

Before concluding with implications of the argument for training and education, we turn to LWCW in home and community-based settings. There are more than one million home health workers in the United States (Sommers, 2007), reflecting growth in numbers driven by combined effects of societal aging, the impact of the Olmstead Decision,[4] and efforts by state governments to reduce LTC expenditures (Foner, 1994, pp. 153–155). Trade-offs for LWCWs, in terms of relative work conditions and rewards in hospitals/nursing home and community-based care, can be severe. Demographically, as Montgomery, Holley, Deichert, and Kosloski (2005) showed, home care workers are more likely to be urban/suburban than rural; to be Latino or foreign born, rather than African-American (roughly half are white); to be older, with a mean age of 46 (vs. 36 among nursing home aides); and to earn less than hospital or nursing home aides (averaging some $12,000 per year as of 1999 for full-time, year-round workers, with higher hourly wages for part-time employees). It is hard to reckon what the average time and gasoline investment are for those traveling widely to serve multiple clients, but this investment is typically uncompensated. Thus, because they often work longer than 40 hours per week, the compensation for home health workers is even worse than is immediately apparent.

A sharp dilemma for home care workers is that, in resisting the more rigid, bureaucratic constraints of institutional care and seeking to provide care that is tailored for individuals, they pay a heavy price: in addition to the logistical and financial costs, they submerge their own quasi-professional status and identities more deeply, since they labor in isolation, without peers, within clients' social spaces. Rivas (2002), quoting a home health aide, sharpened the point:

> It's being able to put yourself in a situation where you are almost not seen . . . where the recipient of care is so able to do what he wants . . . it almost feels like, "I'm doing this," and you [the aide] are not even in the picture in

> his mind . . . When the person's so in tune with what they're doing, what he wants to do and feels really good, and you're almost non-existent and yet you're there but somehow not there . . . [When they can do something] without even realizing that they're doing it because you're there, that's quality work right there.
>
> (p. 175)

A distinction worth making is that, while workers such as the informant have rejected bureaucratic rules, schedules, and supervision, they have not necessarily forsaken *medical or technical* components of work. As Aronson and Neysmith (1996, p. 61) made clear, "Home health care services encompass a wide array of health and social services and employ a variety of care providers. Services may cover acute, rehabilitative, supportive, and palliative types of medical care, may be provided on long- or short-term bases, and are staffed by a range of professional providers (e.g., nurses, physiotherapists, nutritionists, social workers, and medical technicians)." This category of employment also involves "personal care" or "personal assistant services" that require less training and aim to maintain people at a functional plateau, in-line with the "independent living" model usually associated with younger disabled adults. So, whether/how home care workers can embrace techno-medical skills and knowledge, as a vehicle for mobility and other collective goals, is an important question. As hospitals discharge people more quickly; as more people receive care in the community, via private pay or waiver programs; and as disability rights/independent living agendas increasingly dovetail with government pressures to cut costs (especially sharp under the Affordable Care Act), systemic distinctions between care work processes and demands in varied settings are eroding (Kane, 1996).

Implications of Ethnographic Research on LWCW for Education and Training

In concluding, we draw together some of the implications of the foregoing for recruitment, training, and retention of LWCWs. There is a disparate but substantial literature in the area of training recommendations for LWCWs, much of which is distributed online or locally, by groups such as the *Direct Care Alliance* and the *National Network of Career Nursing Assistants.* My remarks draw on discussions with directors of these organizations, as well as on published material. It may be helpful to organize the discussion so as to address three key questions: (1) *What does the review of ethnographic research suggest are especially important challenges and objectives in the area of worker education and training?* (2) *How do the broader, structural labor and policy conditions of LWCW limit adoption of successful approaches to education and training?* and (3) *To what extent and how do skill demands in LWCW reflect broader changes in the service economy? If there are common trends or objectives—for workers and employers alike—what appear to be promising alliances or policies for enhancing quality of care and work life?*

What Does the Review of Ethnographic Research Suggest are Especially Important Challenges and Objectives in the Area of Worker Education and Training?

LWCWs will not maximize educational and training benefits, of whatever quality, until we address the poor job quality that continues to be endemic (Dawson, 2007). The median hourly wage for LWCWs was just under $12 in 2017 (according to the Bureau of Labor Statistics), "significantly less than the median wage of $19 for all U.S. workers." If we assume full-time, year-round employment, average annual incomes in 2017 were $22,000 for home health and personal care aides; and $27,650 per year for nursing assistants, based on a median hourly wage of $13.29. Yet these figures overstate what many workers earn, since more than half of the home-care workforce is employed part time . . . "A typical home health aide in New York City works 30 hours per week and earns approximately $13,000 per year" (Dawson, 2007, p. 3). In addition, these workers have among the highest rates of occupational injury in the nation.

Direct care staff in elder care are also seeing increasingly frail residents, especially in nursing homes, and such care requires integration of technical/medical tasks, quasi-medical knowledge (of areas such as dementia care, nutrition, and effects of prescription drugs), with a "person-centered" philosophy and practice of caring (e.g., Folkemer & Coleman, 2006; Rahman & Schnelle, 2008; Sloane, Zimmerman, & Ory, 2001). There is substantial convergence between these needs and motivations and preferences of direct care workers. It has been noted (e.g., Gipson, 2007; Wellin & Jaffe, 2004) that many LWCWs have family care experiences, with grandparents or others, through which they are "called" to care and discover personal fulfillment. Supporting the provision of such care requires a shift in training orientations, from the instrumental, task-driven approach described by Diamond (1992) and others, to one focused more on sensitive communication (with residents as well as other members of residents' social and clinical networks), team-building, critical thinking and problem-solving, and health related knowledge—in addition to personal/bodily care skills. This is precisely the agenda laid out by advocacy and public policy groups that work closely with the direct care workforce (Paraprofessional Healthcare Institute, 2003b).

The same professional/advocacy groups promote modes of teaching and learning that depart from conventional classrooms, in favor of *Adult Learner-Centered Education.* In this approach, trainers acknowledge and tap students' practical life experiences, and locate the learning process, and focal problems, in the practical work situation rather than in more detached classroom settings (Paraprofessional Healthcare Institute, 2003b, pp. 6–7). Such training, if offered in the learner's work site (often but not always by nurses), can help solidify mutual respect between staff and administration, and enhances workers' sense of safety and support in the work organization. For this reason, innovative approaches to training direct care workers often forge a close linkage between staff recruitment, training, and retention, in order to create what are termed *Employers of Choice* (Paraprofessional Healthcare Institute, 2003a).

How do the Broader, Structural Labor and Policy Conditions of LWCW Limit Adoption of Successful Approaches to Education and Training?

Even the most enlightened approaches to education and training will fail unless conditions—in the labor market and in employing organizations—that undermine continuity and quality of care are addressed. There is an acute need to approach a living wage for such workers and to attach employment to basic fringe benefits such as health insurance and supplementary pensions, which a majority of workers now lack. There is every reason to expect that, were these goals achieved, many LWCWs would be able to achieve the tenure required for sensitive, competent, and fulfilling work. To some extent, greater compensation and career stability would check the downward social estimation of the work, especially in the eyes of clients and family members who, despite mistrust of paid care, have compelling reasons to make common cause with LWCWs. It is also increasingly clear (Kemper et al, 2008) that concerted efforts at *culture change* in nursing homes (such as the Eden Alternative and Greenhouse Models, mentioned above), which aim to create a more collaborative, team-orientation in which direct care staff enjoy greater affirmation of their knowledge and ongoing professional development, are essential complements to enhancing economic compensation if we are to reduce turnover.

Unfortunately, however, efforts to increase wages for such workers are blocked by powerful public policy constraints that override the interests and wishes of employing organizations, no less than those of direct care workers themselves. Conventional assumptions about labor demand and costs do not apply to LWCW, given that "primary financiers" distort and undercut "effective demands" for care work (Paraprofessional Healthcare Institute, 2001). Federal and state "third-party" payers (i.e., Medicaid and Medicare) effectively set wages by virtue of their reimbursement rates, and they have strong pressures to limit costs. As of the year 2000, "long-term care expenditures for the elderly alone totaled $123 billion—60 percent from public sources (primarily Medicaid and Medicare), 4 percent by private insurance, and 36 percent by out-of-pocket and other sources" (Paraprofessional Healthcare Institute, 2001, p. 2). Moreover, despite the massive profits in the LTC system, "the financial viability of the entire industry is currently endangered, in part by passage of the Balanced Budget Act 1997. [Between 1999 and 2001], 20 percent of all Medicare-funded home care agencies closed, and five of the ten largest for-profit nursing home chains entered Chapter 11 bankruptcy" (Paraprofessional Healthcare Institute, 2001, p. 2). In sum, the current structure and funding of LTC in the United States create enormous barriers in addressing recurring labor conditions in LWCW.

Apart from these macro-level funding and policy constraints, there are more proximate, "meso-level" obstacles to wide-spread adoption of better education and training programs. Though it would be ideal—both for policymakers and advocates for LWCWs—to define and promote universal goals or "best practices" in this area, such a goal is, for several reasons, elusive. Identifying and assessing training approaches and practices is made difficult by wide state-level variations,

both in licensure and other requirements for employment, and in mandates regarding continuing education and training. Although there are "registries" of LWCWs in, and reciprocity agreements between, many states, there are many departures from the basic federal standard, and a lack of consistency across care settings. The standard for direct care staff in *nursing facilities* was established in 1987, as part of the Omnibus Budget Reconciliation Act passed during the Reagan Administration. It requires 75 hours of training, and 12 hours of in-service training per year, and passage of a "competency test" within 4 months of employment (Institute of Medicine, 2001, p. 197).

Inadequate or ad hoc standards regarding who provides training (e.g., employers, the Red Cross, community colleges) and wide-state-level variations in training only exacerbate these problems. Moreover, training requirements and policies in *residential care/assisted living* are set by states, rather than federally, and these vary widely. Hawes and colleagues (cited in Institute of Medicine, 2001, p. 204) "found that 20 percent of licensed board and care homes and 33 percent of unlicensed homes did not require *any* staff training. Of the facilities that required training, most did not require training to be completed before staff began providing care."

Clearly, as vital as formal education and training efforts are, there are issues of labor politics and collective action that cannot be ignored if we are to gain traction on this problem. For example, the ethnographic literature supports the contention that *tenure* in particular care positions and relationships is a key mechanism in achieving a high quality of care, and staffing ratios are clearly another. Some states and labor organizations have attempted to establish job ladders/wage premiums based on tenure, as well as mandated staffing ratios, attempts that vary independently from particular training or licensing requirements. We need to work toward consensus, across states and in connection with distinctive care settings and groups of care recipients, regarding these standards.

To What Extent and How do Skill Demands in LWCW Reflect Broader Changes in the Service Economy?

An implication of the ethnographic research is that providing instrumental/bodily care, with knowledge and skill, is a necessary but not sufficient criterion for excellence in working with the chronically ill or disabled, of whatever age. Instead (reflecting the disillusion that has followed the advent of Managed Care in recent decades), we see greater demand for collaborative, person-centered, holistic treatment—a social model—throughout the health care system.

Human resource consultants (e.g., Houston & Ferstl, 2007), analyzing the job skills that will increasingly be in demand in the years to come, note the importance of sensitive communication skills, independent problem-solving capacity, and comfort with social/cultural diversity in the workplace. Other key competencies include adaptability—the ability and willingness to cope with uncertainty—and self-management. These traits are clearly relevant to paid care work, and very often present—especially where supportive supervision, staffing ratios, and job tenure are favorable. This analysis suggests that while formal educational skills

and credentials (literacy and numeracy) will continue to be important factors in training and rewarding care workers, they are unlikely to be decisive in framing and pursuing policy agendas in the years ahead.

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Notes

1 For example, drawing on data from the National Center for Health Statistics, Quadagno (2005, p. 315) noted that "among those age 75 and over, 52 % suffer from arthritis, 42 % from hypertension, and 36% from heart disease. Alzheimer's and other dementias afflict nearly 9% of those between 80–84, 15% of those 85–89, and 29% of people age 90 and above" (p. 156).

2 See the U.S. Department of Health & Human Services report (2006) on the challenge and necessity of recruiting and retaining more social workers in LTC.

3 See Berdes and Eckert (2001) and Lepore (2007) for important discussions of race relations in caring relationships.

4 The decision mandates that, "states are required to place persons with disabilities . . . in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with . . . disabilities."

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