

*Paid Care-Giving for Older Adults with Serious
or Chronic Illness: Ethnographic Perspectives
Evidence, and Policy Implications*

Chris Wellin, Ph.D.

Department of Sociology & Gerontology,
Scripps Gerontology Center
Miami University
Oxford, OH

A paper commissioned by the National Academies Center for Education on
Research Evidence Related to Future Skill Demands. Washington, D.C.,
May 31-June 1, 2007

"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."

Emily K. Abel, *"Who Cares for the Elderly?"* (1991)

- This statement, capturing the challenge of providing care to older family members, is equally relevant to understanding paid care-work. Moreover, for LWCWs, the challenges are compounded by bureaucratic and regulatory constraints, and by a lack of cultural recognition and economic remuneration;
- The statement only implies instrumental caring *tasks* (e.g., helping to feed, dress, bathe, toilet, or groom the care-recipient); instead, it stresses the interpersonal and emotional relations in which the tasks are embedded. This insight is central to understanding and enhancing "person centered" care-work in the public sphere.

My agenda for today's presentation is to:

1. Review demographic context of societal aging, impact on illness/disability, and recurring issues and findings in ethnographic research on low-wage care work (LWCW) for older adults in the U.S.;
2. Summarize an ethnographic (i.e., contextual) approach to studying workplace skill—recognizing both cultural and organizational contexts, in conjunction with labor market and educational policy; and legacy of bio-medical model and status hierarchy;
3. Consider implications of this research for understanding future skill demands, and successful strategies for recruiting and retaining LWCWs.

Demographic and Labor Market Trends Propelling Interest in Paid Care-giving

- Conjunction of falling birth rates and increased longevity produces societal aging; lower fertility rates portend fewer family/kin caregivers in the future;
- With this demographic profile we see increased prevalence of chronic disabling conditions of late life: heart disease, stroke, diabetes, arthritis, cancers, and cognitive illness/dementias;
- By year 2025, more than 20% of U.S. population will be over age 60; fastest-growing segment are the “old-old” (over age 80), who will number nearly 14 million by the year 2040; costs of public reimbursement compel expansion of non-medical, community-based care options;
- Given limits of curative/therapeutic medicine in addressing chronic illness, elder care emphasizes bodily and socio-emotional care, to enhance quality of life for recipients. LWCWs (e.g., nurses’ aides and home health providers) projected to be among the ten occupations with greatest job growth in coming decades.

Demographic Profile of LWCWs

- According to data from the 2000 Bureau of Labor Statistics (BLS), there are over 2 million para-professional, LWCWs in the U.S.: including 1.3 million nurses' aides/orderlies/attendants; nearly 600,000 home health aides; and some 360,000 personal and home health aides;
- More than 80% of these workers are women; roughly half are women of color (12-23 % are foreign born); the majority are between ages of 25-54, nearly one quarter of whom have some college education;
- Median hourly wages of the workers range from \$6.82 for personal and home care aides, to over \$8 for Certified Nursing Assistants in hospitals or nursing homes; this translates into less than 20K annually; benefits are rare;
- The fastest growth is in "community-based" settings, rather than in hospitals or nursing homes; in non-medical settings, there is greater demand to integrate bodily care with socio-emotional support that is tailored to recipients' needs; this trend toward "person-centered care" was reinforced by the Supreme Court's 1999 passage of the Olmstead provision, under the ADA. (Note distinction between LWCW and routinization in many service jobs.)

Themes and Findings of Ethnographic Research on LWCW

Important to see *complexity* of care tasks based on: intimacy of contact; encroachment on adult privacy/dignity; variation among recipients in preference and ability; socio-emotional impact of disability; bureaucratic and regulatory constraints on flexibility in providing care;

Dominant tendency—reinforced by regulations, management and supervision of LWCWs—to focus narrowly on instrumental tasks rather than on relations with recipients. Fostering rapport and relations, however, are central to the motivations and fulfillment of LWCWs, no less than among those receiving care; however “skill” is often obscured because of assumption that these are natural, “instinctual” for women;

Under these conditions, LWCWs are not rewarded, but rather penalized, for performing work in more sensitive, “professional” ways; transmission of work skills, often sustained by oral tradition, is thus undermined both within work settings and among care-workers themselves; *cumulative*, *transferable* nature of skill is not recognized in worker training, evaluation, or compensation (See Wellin & Jaffe, 2004; Foner, 1994; Diamond, 1992).

Impact of Quality Care-Work on Recipients' Quality of Life

In institutional and community-based settings, LWCWs provide over 80% of the direct care; in the latter settings, they also provide nearly *all* of the social contact, support, and empathy, especially for those lacking “informal support” from family or friends; a majority of people, within care dyads, define relations in the context of friendship or fictive kinship;

For residents *with* informal support, care-workers are invaluable partners in helping to maximize residents' autonomy and control, achieving continuity of care despite changes in health status or in administrative turn-over; this sharing of burden has repeatedly been found to enhance residents' relationships with family and friends;

Sharing and sustenance of biographical knowledge and stories—life narratives—is essential to adapting to disability (see e.g., Kleinman, 1988); this is true even for those with serious cognitive illness. In community-based settings, LWCWs inherit and embrace this dimension of care, provided they are supported and permitted to do so. Sharing of such knowledge among LWCWs is rare.

Factors Shaping Recruitment and Retention of LWCWs.

Only half of Certified Nursing Assistants are in the occupation two years after certification. Factors that have repeatedly been found to affect recruitment and retention of LWCWs reflect the relational, person-centered mission discussed above;

Among factors associated with higher recruitment and retention (lower turnover) are: lower number of beds; lower staff/resident ratios; non-profit status; high quality care (i.e., low numbers of care deficiencies); and involvement of all care staff in ongoing training and resident care planning (e.g., Castle & Engberg, 2006); realistic orientation and peer mentorship also effective;

In turn, care-workers' most commonly noted reasons for leaving jobs include "lack of opportunities for advancement, instability of working hours, emotional strains of the job, and lack of input into the development of care plans" (Atchley, 1996).

Finally, there is some evidence that cultural and ethnic similarity enhances recruitment and retention; this applies to staff/resident relations, but even more strongly to *within staff* relations. A large proportion—perhaps more than half—of staff hires are made via informal referrals; often, these are embedded in ethnic ties and communities (e.g., Filipina in Northern California, Latina in Florida).

Current Policies of Training/Certification of LWCWs

Current training of LWCWs stress instrumental tasks, basic medical knowledge (e.g., first-aid), resident safety and regulatory rules in care settings; minimal and superficial attention is devoted to psycho-social care skills; these are necessary, though not sufficient, to preparing for excellence in the practice of care-work;

Training and certification requirements vary widely, with Certified Nurses' Assistants requiring somewhat more training than home health aides; state requirements range from a few days of on-the-job training and a GED, up to 150 hours of supervised training and a high school degree.

Some workers are given in-service training in basic nutrition, infection control, body mechanics and safe-transfer techniques (to combat record high rates of occupational injury and accident liability). Less commonly, staff are oriented to resident rights and ethical concerns, dementia care, family stress and communication, and spiritual counseling.

Implications of Ethnographic Research for Training and Retention of LWCWs

Though for some, LWCW provides an entry level rung in a health care career, for most it is a longer-term career choice; the work represents an occupational anomaly: high commitment/sense of mission, with low occupational stability and rewards;

With the shift to community-based care, we see expansion of *both* techno-medical *and* psycho-social demands of care. Further, in nursing homes and elsewhere, we see more serious forms of disability (e.g., dementias), which complicate the provision of all care tasks and services;

LWCWs are strongly motivated to provide “person-centered” care, often trading—off higher wages for the opportunity to enjoy more holistic relations with care recipients;

This commitment can “anchor” enhanced training in basic human development/adult aging; communication skills to support integration of formal and informal care systems; and specialized content in dementia care, palliative care, and spirituality; finally, LWCWs should ideally be included in ongoing assessment and refinement of care planning for recipients with whom they work; this has been shown to be a strong desire among workers, and is perhaps the most powerful way to apply their knowledge.