In search of "personal care:" Challenges to identity support in residential care for elders with cognitive illness

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Abstract

In addition to meeting medical and bodily needs, personal(ized) care aims to address the biographical and social identity of the recipient. The term "personal care" contrasts most starkly with "impersonal care," which connotes bureaucratic and instrumental treatment. Care work always requires some adaptation to individual preferences and responses. However, typically, this is either an implicit or a secondary feature of care. With cognitive illnesses, such as Alzheimer's disease, however, the very capacity for maintaining a self (via language and memory) is threatened; thus, the extent to which care addresses the person *qua* person becomes especially significant: for the afflicted, personal care is identity care. This article is based on paid work and field research in a residential care setting; proponents claim that these quasi-institutional settings are conducive to the provision of personal care, and to collaboration between formal (paid) and informal (family) caregivers. Our research suggests that these goals are elusive, even in settings ostensibly organized to advance them. This partly reflects the ambiguous, contextual meanings of personal care. Despite its commonsense meaning, there is no simple or consensual definition of personal care. We develop a conceptual and empirically grounded typology and discuss the practical implications of various definitions for the fulfillment of the ideal. Barriers to personal-as-identity care are not confined to large, custodial institutions. Among those we find in residential care are instrumental definitions of care, which govern both the practice and public regulation of paid care; a functionally diffuse (familial) division of labor, which intensifies care work; and emotional demands of the care, which undercut family members' role in helping to translate individual meanings and practices of personal care. Even when all concerned are committed to

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cﾑ和 supportive of personal-as-identity care, there is ambiguity regarding whether to treat identity as object(ive) or as a process.

1. Introduction

Our purpose in this article is to analyze the meaning and provision of personal care for persons diagnosed with Alzheimer's disease in a small residential facility. Questions we address flow from this purpose: How do the daily routines and organizational structure of the facility shape how personal care is defined and provided? To what extent and how does the facility's care support or subvert residents' sense of personal identity? What distinctive problems arise for residents with cognitive illness, whose preference and autonomy are dependent in good part on the advocacy of and communication with others? The implications of these questions for researchers and the larger society are far-reaching, inasmuch as the fastest growing age group in the United States are those 80 and above, 15–20% of whom will be affected by Alzheimer's disease and related disorders (ADRDs; e.g., Fogel, Gottleib, & Furino, 1990). Historically, long-term care policy has neglected to support in-home, community-based care in favor of nursing home or "custodial" care, which is both more expensive and highly stigmatized. This bias is reinforced by Medicare reimbursements that feed the highly profitable, corporate nursing home sector (Lynch & Estes, 2001, 201–215). For many, the costs of "community-based" options, such as residential care (ranging from roughly US$25,000 to US$40,000 annually) are prohibitive. Yet those who can afford it seek out various assisted living or residential care settings which offer to provide care in a setting that approximates "home."

Since the 1980s, we have seen significant growth in the number of residential care or "assisted living" facilities. In an early review, Kane and Wilson (1993, vii) wrote that assisted living offers residents "individualized personal care in accommodations that offer more privacy, space, and dignity than are typically available in nursing homes, and at lower cost." Carder (2002) argues that the "social model" of elder care, promoted in residential settings, is achieving greater legitimacy and has come to be defined by the public and policy makers in terms of a "package" of principles and services. However, Carder finds that our understanding of critical roles and relations in such settings is limited. We ask, for example, what roles do residents' family members play in supporting (or challenging threats to) practices of personal care? To what extent and how does this model actually give care workers more control over and fulfillment in work or support recipients' sense of personal identity?[1] How does the *place* for care—defined both culturally and organizationally—shape the provision of personal care? We document and

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[1] Our focus in this article is on perspectives of care workers and family members. Elsewhere (Wellin & Jaffe, 2002), we attend more to the important and neglected role that older recipients themselves play in coping with Alzheimer's disease (see Cotrell & Schulz, 1993).

discuss barriers to realizing the avowed goals of residential care: After developing some contextualized meanings of personal care, we elaborate a definition that emphasizes identity support. Then, we interpret its suppression or absence in terms of the particular relations within this institutional model and the distinctive challenges of caring for those with chronic, cognitive diseases of aging.

2. Selling personal care, or delivering custodial care in homelike packages?

Consider this advertisement for the McKnight Terrace in Middletown, OH:

We offer a secure, home-like environment for those who have memory impairments. The Terrace is designed to address the special needs of these residents while allowing them to remain as independent as possible within a structured, familiar setting... Families will find the perfect combination of love, respect, and professionalism. Each of our staff members honors the life experiences our residents bring with them and we recognize and acknowledge their past and present contributions, whatever they may be.

In the ad above (for a place similar to that we studied), and generally in promotion of residential long-term care options, ambitious claims are made. Though inviting, these claims deserve skepticism from those—whether family or paid caregivers—who know the demands of such care. For example, the marketing of residential care promises to support "structure" and "continuity" in residents' daily lives as they move from home to paid care. This is said to help preserve their mental "functioning" and life satisfaction. But are not these goals problematic, even contradictory? On one hand, imposing a rigid structure on such daily activities as sleeping, eating, and sociability is at odds with helping support "continuity" in older peoples' lives. With aging, life patterns tend to become deeply ingrained for individuals yet more heterogeneous across individuals (O'Rand, 1996, 188–189). This heterogeneity reflects biography and cumulative choices, as these are molded by historical events, work roles, ethnicity, and kin-based cultures of care. In addition, "functional" definitions of health, although clearly relevant for organizing care, tend to undercut the holistic and flexible approach residential care has been said to promote. One's ability to practice bodily hygiene or to choose an appropriate outfit to wear is an element of health and social competence. Yet these abilities may seem trivial for those whose threads of self and biography are unraveling. This is especially true for those with cognitive illness, which implicates social identity and relationships as much as it does the body per se. Thus, communication and attachment in Alzheimer's caregiving are especially challenging, and instrumental, task-centered definitions are especially inadequate.

To deny this deeper mission in care work—the effort to address the existential and emotional distress of the older person—is to risk infantilization of older adults (Lyman, 1993, 68–70). Consequent losses—of home, independence, and autonomy—compound those of memory and command over language that are central both to subjective identity and to fully adult social status. In this context, we argue that the meaning and practice of personal care must therefore include *identity care* as a central mission, interwoven with other, more familiar dimensions. We will further argue that, in lay definitions, identity care is central to personal care. However, in our work and research into residential care we found widely divergent meanings and practices of personal care. Some usages are opposed to

commonsense meanings, such as those rooted in licensing regulations which focus on tasks of bodily care. However narrow, these regulatory meanings and rules shape both the provision of care work and people's eligibility to receive care in particular settings. We found that such regulatory pressures, in tandem with the devaluation and exploitation of caring labor (especially in for-profit settings), recreates many of the alienating dynamics which Diamond (1992), Foner (1994), and others have found true of nursing home care. Ethnography is a vehicle for excavating participants' perspectives on personal care, through events and stories that reveal their hopes and frustrations, as well as everyday routines (on the method, see Gubrium, 1995).

3. Research setting and strategy

This article is part of a larger, 6-year field study[2] of the division, relations, and philosophies of caring work in residential care facilities (RCFs) serving older adults diagnosed with Alzheimer's and other cognitive diseases. Our research strategy here is an intensive, multimethod case study of one RCF in a Midwestern city (on the method, see Becker, 1970; Hamel, 1993). "Lake Home" (a fictitious name) is a converted single-family home in an affluent suburb, opened in the mid-1980s. It was licensed as an eight-bed RCF in a Midwestern city. As a quasi-institution, Lake Home straddles the boundary between familial and institutional care. This requires all involved—house managers, caregivers, residents, and family members—to negotiate and justify care for particular residents.

Unlike many owner-operated "board-and-care" homes (Morgan, Eckert, & Lyon, 1995), none of Lake Home's owners live or work onsite. Rather, they manage a growing commercial entity, "Innovative Care Associates." The only licensing requirements are that Lake Home meet state standards regarding building safety and accessibility; admission criteria were that residents be ambulatory, able to feed themselves, and not require ongoing skilled nursing care. During our fieldwork, all residents were women. As mandated, Lake Home employed two staff members for each 8-h shift. Although the staff were required to get first-aid training at a local Red Cross, no other formal education or training was (as in some states) required. Wages ranged from just above minimum wage, for newly hired caregivers, to nearly twice the minimum for staff with the longest tenure.

The physical appearance of Lake Home conveys casual, suburban affluence. A modern ranch-style home set behind an abundant lawn, it housed two residents each in its four bright, carpeted bedrooms. Off the foyer is a large kitchen and dining area, where a rocking chair sits by a picture window, and a long table with a floral centerpiece seats ten. In the spacious living room, rural landscapes in oil hang above the fireplace; a fish tank gurgles in the corner. The two public rooms, kitchen and living room, are front-stage regions in which most of the residents' lives are carried out. As in nursing homes, there is a lazy rhythm to the days: it includes group meals, handing out of scheduled "meds" (medications), and organized activities. A large activity board in the kitchen displays few daily variations in the morning-to-evening routine: "Coffee Klatch," "Spic 'N Span," "Let's Lunch," "Fun 'N Games," "Sock Hop," "Able Aprons," and "Movie Night."

The first author took a part-time job as a caregiver during college, soon after Lake Home opened. He was responsible for assisting residents with meals, medications, outings, and all "activities of daily

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[2] The fieldwork and interviewing were conducted between 1986 and 1992.

living" (ADLs; except intimate tasks such as bathing and dressing) with which they needed assistance.[3] In addition, he assumed the range of caregivers' domestic tasks, including shopping, cooking, cleaning, and acting as liaison with family members to facilitate resident's placement and everyday adjustment. He held the position, working an average of three full shifts per week (a total of roughly 1200 paid hours) for 1 year. Wellin was part of the original cohort of employees hired at Lake Home, then among the first residential settings catering to Alzheimer's care in the Midwestern United States. For this reason he forged close ties with other staff members, whose excitement and commitment to residential care were strong.[4]

Collaboration between authors grew out of a course during which Jaffe encouraged and guided systematic field observation at Lake Home. Both entered "the field" the following year. With full awareness and consent of informants, we generated a database consisting of over 2000 pages of transcribed field notes, based on observations (with assistants) in three group home settings and 52 transcripts of in-depth, semistructured interviews.[5] Of these, 22 were with staff members, and 30 were with residents' family members. The Lake Home component of the database, on which we draw for this article, represents more than one half of the ethnographic data, all of which were collected by the authors.

4. Toward a grounded definition of personal care

Our richest source of insight for this article are the paid caregivers we came to know at Lake Home, many of whom had earlier spent years doing similar work in larger, more formal settings. They believed a residential setting would afford them more freedom to practice what many termed "care for the whole person." Roughly half of the caregivers were college-aged women, mostly white and middle class, pursuing careers in such clinical professions as nursing and occupational therapy. For them, Lake Home provided not only flexible hours, but an informal internship in which they could gain hands-on geriatric experience and professional references. Although their commitment was genuine, these women tended to see Lake Home as a training ground for other more medicalized institutions in which they expected to work in the future. Because of the relative novelty of residential Alzheimer's care when fieldwork began, it is likely that the number of caregivers in this collegiate category is larger than would have been found in most nursing homes.

The other group of caregivers, mostly women of color, was older and more experienced in care work. They had become frustrated with the routinized, hierarchical relations typical of elder care in

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[3] As male workers (in Wellin's case) and fieldworkers, we were excluded from these more intimate tasks at the request of the house manager, due to concerns that family members or residents might feel uncomfortable and object. This proved to be a trade-off: Though we lacked firsthand experience with bodily features of care that are relevant to this research, female caregivers discussed with us features of the work which they would likely have felt unnecessary to explain to female coworkers.

[4] This commitment was reflected in low staff turnover during Lake Home's first 3 years of operation. Most of the 8–10 staff members originally hired (either as full-time or occasional caregivers) remained on staff during this period. In later years, as the owners expanded into more homes, staff members were made to "float," that is, to work in whatever home had a vacant shift. This was one factor in the steady increase in staff turnover during the years of our project.

[5] In presenting quotations from field interviews, we have sparingly inserted bracketed terms. When we have done so, it is either to clarify ambiguity, created by presenting a short excerpt out of narrative context, or to provide context, based on field experience, that is not present in the interview transcript.

nursing homes (see Diamond, 1992; Foner, 1994) and been drawn to Lake Home to practice an ideal of care forged in prior jobs. Salaries at Lake Home were comparable to those at nursing homes, and benefits were often certainly poorer than for unionized aides. Therefore, it was not material reward but the autonomy and philosophy of care that attracted them. As Vera, a woman in her late 60s, explains, her ideal was not confined to elder care. She was also a licensed practical nurse and had worked in hospitals and the juvenile justice system. Vera's sense of care encompasses biographical interest and appreciation for troubles that extend beyond the immediate locale. She explained,

It is exactly what I liked and had already been doing all throughout the juvenile jail system—treating that person as a total person while you had them in front of you. You had to interview them. If you built up a rapport, you'd find out that there's no food in the refrigerator, there are two infants among the five children, they have been forced from school. You had to listen to and see the person, beyond what the formal questions might have been. [She then connected her perspective to care at Lake Home.] The managers wondered mainly about how did the clients rest. Were they having any problems with digestion? Had the food settled? Then [they worried about] their planned activities, keeping a running file regarding the activities for keeping them busy. And they worried about the families; what were their names and jobs and where did they live? And furnishing the rooms. That part didn't set right with me; we'd be told, "Be sure and tell whatever relative that we need to have her bed or her couch or her pillow." And I couldn't see where that was helping these [residents] to whom furnishings did not matter. They were seeking something that wasn't tangible, but that they wanted.

Eileen is another of the older caregivers with a strong commitment to care "for the person" and little patience that the routine and division of labor at Lake Home denied her time with residents.

I am a caregiver; to me, this means that you are to give care. And if there's anything else that's taking up three or four hours of your time, that's interfering. I'm not saying that you have to hold a resident's hand all day; but, in the meantime, there might be one resident who's sitting there, who's been depressed all day long and just would love for me to sit down for 30 minutes and tell her a story or take her hand. I do it all the time. In a way, it's a kid's world—you're going back into a kid's world, though you don't come out and let them think that you're treating them like a kid. They cannot remember but talk only about the past. Their husband or wife might have been dead for15 years, and their family is not sitting in the next room, and they're not all going to bed together in the house they were born in. They can't cope with that. You've got to make them think that it's not them by themselves. So I say, "We're all eating together here tonight."

Evelyn, another caregiver, spoke of "learning the ladies, one by one," which reflects her approach to personal care:

It means creating an emotional comfort, being affectionate, you know, hugging. A hug would get [one resident] to do something, where for another it would not even be appreciated at all. For one lady, showing interest in her pictures on her dresser and her nightstand, for some that'll win them over. You ask who is this in the photo, and it might get her off a sad or stubborn mood and onto something else.

These informants define personal care partly in terms of their awareness of residents' current lives and emotional losses, as well as their attempts to preserve dignity despite impaired memory. We turn now to constraints on caregiving, which are a subtext for the idealized images above.

5. Personal-as-in-bodily care and dynamics of distance

These fragile ideals of personal care, based on contextual knowledge and empathy, are in constant tension with practical work constraints at Lake Home. Caregivers' tasks and care relations are formed not only through interactions at Lake Home, but also by regulations and recruitment networks in the larger world of paid care work. Further, this occupational arena is not confined to the aged but extends to other groups of care recipients. Many families caring for ill members at home hire aides to provide "personal assistant services," either through home health agencies or, in some states, through Medicaid waiver programs. In these circumstances, control over and relations surrounding care may be distinctly different from those we have described.[6]

Paid in-home caregivers' working conditions and perspectives also bear the stamp of the disability rights movement, which has promoted a "consumer choice" model of personal assistance (Dautel & Frieden, 1999). This model, most applicable to adults living independently, mandates that services be rendered in the least intrusive manner possible, to maximize clients' autonomy and control. However they may be hired, through home health agencies or directly by recipients, "personal care assistants" are regarded, as in this profile by the U.S. Bureau of Labor Statistics, as service employees, responsible for "cleaning clients' houses, do laundry, and change bed linens. Aides also may help clients move from bed, bathe, dress, and groom. Some accompany clients outside the home, serving as guide and companion"(U.S. Deparment of Labor, Bureau of Labor Statistics, 2003, 335). In any case, the job status, presumed skill level, and wages are minimal.[7] For most of these workers, then, relations with clients and job evaluations are centered on tasks of hands-on personal care, subject (in many states) to medical authorization and oversight. Admission to Lake Home (and similar settings) also requires medical certification. Thus, the influence and status rankings of the medical model follow all concerned, even into places like Lake Home, in which medical personnel rarely appear.

Clearly, the appearance of an instrumental orientation to care work among paid caregivers in settings such as Lake Home is neither improvised nor reflective of their own ideals: in regulations governing home health and residential care, licensing and eligibility guidelines are largely determined by prescribed limits on the provision of and (for residents) the need for "personal care assistance."

As Diamond (1992) reveals in nursing homes, a task orientation tends to obscure, if not to demean, the socioemotional demands of the work, and the formation of bonds over time within care dyads.

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[6] Barker and Mitteness (1990) studied in-home care involving a single elderly recipient. They conclude that such relations—even if short-lived—may be mutually gratifying if the arrangement is in response to an acute illness or injury. They also conclude that longer term home care, even for older people with profound needs, often fosters kinlike relations and that the emotional tone and even rewards of the exchange are significant for both parties. This suggests that the exclusivity of (one-on-one) caring relations and the symbolic and practical supports the older person enjoys by remaining in the home allow for closer and more reciprocal bonds.

[7] The Bureau of Labor Statistics reports that the median hourly wage for such workers in nursing and personal care facilities was US$7.82 in the year 2000.

5.1. Bodily care(s) and dynamics of deference and distance

Relations between care workers and residents at Lake Home are shaped by (quasimedical) status rankings and regulatory guidelines embedded in formal policy. However, their perspectives and practices also reflect cultural qualms regarding autonomy and deference based on age, and their respect for norms of privacy. Assuming that caring work should be personalized (as for a "client"), it can also be seen, by either party, as "too personal," perhaps intrusively so. Thus, if paid carers perform intimate rituals of care—such as helping to wipe a resident's bottom—with a measure of detached efficiency, this may indicate recognition of the recipients' dignity and autonomy, rather than an instrumental conception of work. It would be facile to ascribe motives to care workers which are more fairly seen in terms of their cultural and situational constraints. The following vignette, told by staff member Jeanne, reflects both the inhibition against and potential benefits of transcending interpersonal distance:

> I would kind of try to stay away from real personal things [with residents]. I recall a time when a staff person was going out with a fella, and she would always come and want to talk about what had happened. They were having a lot of problems. A resident, Daphne, spoke up one time and said, "Why don't you drop him?" you know, because she had heard this a couple of times. And it would surprise us because you would think that she hadn't remembered. But sometimes she would, and then we would bring them in by that and say, "Well, Daphne, what do you think? Do you think she should drop him?" But as far as getting personal into *their* [residents'] lives, no; we might get personal into our own, but I can't remember anyone else, or myself, prying into that, trying to get more out of them. I would keep it pretty much general.

Thus, staff members' ideals of personal care stand in tension with the constraints of performing and accounting for work in occupationally defensible ways. Their reluctance to "pry" into residents' lives is driven by the sensitive nature, as well as the division of, caring work at Lake Home. Indeed, the dominant meaning and usage of the term "personal care" among staff at Lake Home is hands-on *bodily care*. In our staff interviews, only a minority (roughly one third) of respondents either mentioned "personal care" or used the term to describe residents' particular life patterns or needs. Even allowing for the fact that, as Tanner et al. (1996) note, it is difficult to describe such care "in general," this silence seems anomalous. If and when they use the phrase, it is made plural ("personal *cares*") which suggests that they generalize the tasks, rather than the relations, linking them and their work with residents. Common exceptions are references in which the term "personal" modifies "things" (objects) or "space" because family members and residents alike are vigilant in protecting boundaries of property and privacy—always at a premium in a total institution (Goffman, 1961, 12–74).

5.2. Individual versus cumulative care demands

Staff members' talk about personal *cares* takes place in the context of cumulative demands involving caring, domestic, and record-keeping work in a functionally diffuse division of labor. This quality of the work may be seen matter-of-factly, as when (staff member) Laura explains that her daily agenda is "to do activities with the residents, prepare meals, help them with their personal cares, administer medication. That's pretty much it. But [at Lake Home] there's a closeness, you know, a more personal touch than I think is in a nursing home."

Another phrase that many staff use interchangeably with "personal care" is "total care." Often used euphemistically, these terms connote both intimate practices like bathing and "toileting" and (especially with total care) the recipient's profound dependence upon the caregiver. The latter often resent the demands of "total care," both because it contains the most unpleasant tasks and subtracts from the limited supply of human resources (time and physical and emotional energy) in demand. These pressures produce a dual consciousness: staff members oscillate between talking and caring about residents, as persons, and shifting to an instrumental mode in which the latter are all but inanimate. "What makes it difficult" according to one staff member, "is the personality style, I mean, the disease state that they're in. The real agitated state is so hard to deal with unless you drug them. And also the cares, the personal cares, you know, the incontinence. [Staff] hate that." One can also hear both the negotiation and the sense of personal care as "dirty work" in the following statement by a caregiver, Darlene:

> [The owner] was adamant about cleanliness in the house, I mean, they were expecting us to do deep cleaning, walls and all that. Granted, it's got to be done, but I question whether the girls had time for that, especially when we were talking about so many incontinent people. I mean, you're giving a lot of personal cares [at Lake Home], so you could not get the residents involved in cleaning chores. You'd prefer [to admit] somebody that doesn't need too many personal cares done. Maybe you have a resident with a high level of personal cares but who might be more placid, with more peace of mind, you know. I see it as a trade-off.

In Darlene's statement, the emphasis on bodily over personal care is a response both to Lake Home's division of labor and to the struggle to attend to residents' individual needs, in favor of a minimal standard of care for the group. She laments the absence of more humane relations with residents and yet in the next breath, reduces them, in effect, to the tasks that their frail bodies impose on her. In turn, caregiver Stephanie reflects on the paradox that the very care tasks formally regarded as "skilled" (because they are done with and for the most dependent people) can be most difficult to integrate with the spirit of reciprocity that promotes personal-as-identity care:

> You're leaning more towards skilled care for some of these [residents], in the sense that they're incontinent. Some of these people can hardly ambulate; it's difficult to get them out of their bed. And because you're required to do so much work within a day, trying to get these people who are very slow moving—with severe arthritis, who are demented, and who don't want to get up—trying to get them on a schedule is very difficult. In the past, [Lake Home] had more people who were able to perform their own personal cares, could at least assist you somewhat. Now you get people who you have to dress them.

Overall, then, the absence of personal-as-identity care may reflect norms of deference, a reluctance to "pry," perhaps in compensation for the awkward intimacy imposed by bodily care. The absence also reflects an instrumentally defined division of labor which compels attention to the aggregate burden of particular tasks, rather than their sensitive accomplishment with individual recipients.

It is a national trend that residents of nursing homes and other care settings are (on average) becoming more frail in body and mind. Most residents arrive at Lake Home with needs that strain caregivers' ability to cope. This would be true if residents remained at a functional plateau but can become overwhelming given the progressive nature of ADRDs. In a home with eight older persons and two staff members per shift, a marked decline in even a single resident can upset the fragile balance between

various kinds of care and the relations in which they are embedded. As the next caregiver shows, the character of care and of relations with residents can change dramatically over time, in response to individual disease trajectories, the aggregate care burden within homes, and the market/demand for particular care settings within ICA [Lake Home's corporate owner]:

> When [ICA] had [residents] who technically were assisted living, who could dress themselves, do their own personal cares, then, yes, it was an easy home. But ICA seems to be getting a little more desperate in the people they're trying to take in because it's a competitive market out there. They couldn't get enough of those type of people anymore, and they started taking whoever they could get.[8]

To sum up, in the larger occupational sector of paid care, personal-as-bodily care is both commodified and divorced from more subtle, socioemotional dimensions that are assumed to require formal education few aides have. We found this to be true even in an ostensibly noncustodial setting and despite the limited relevance of formal (medical) expertise for identity-support care. So defined, personal care is subject to managerial control, both by agencies and by "consumers" (residents and family members) who, taking standardization as a proxy for quality, are unlikely to conceive of care as relational or to selectively negotiate how it's to be done. Moreover, personal care(s) must be documented for licensing inspectors, and violations in their provision—unlike those of socioemotional dimensions of care—expose facilities to stiff penalties. Given their subsidiary role in a quasimedical division of labor, care workers in residential care are denied the recognition and respect they merit as central actors in shaping the character and humanity of care. When overlaid with class and ethnic difference, the distinctive value and practices of personal care may not be visible in the eyes of paid caregivers, recipients of care, and their advocates.

6. Exemplars of personal(ized) care

Workers adopt various stances in their emotional identification and sense of "authenticity" on the job (Hochschild, 1983, 185–198). At Lake Home, many created deep relationships and communication with residents, however subtle, camouflaged, or simply undocumented the work may be. Their efforts to maintain authentic relations often support, at least in principle, personal-as-identity care. Here, Donna upholds the ideal of particularity in staff–resident relations and recognizes the emotional subtext of their ties to one another. Still, she is resigned to institutional routines she cannot change:

> That was really difficult for me—I hated to see some of the residents that I had worked with for months find out that they had to move [because of injury or deterioration in their condition]. They become so familiar with the home and setting, which is hard, and with an employee that they can really relate to and get along with, although it's not their family. You know we could not take the place of family, at all. But if you get someone in there who really understands the residents and they

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[8] A widely cited study of residential care, sponsored by AARP, reports: "Assisted living programs vary in their clientele, from those that mainly serve persons with only mild disabilities, requiring only meals and housekeeping, supervision of medications, and minimal personal care, to those with tenants who are almost all nursing-home-certifiable. In general, managers of assisted living indicate that their typical tenants are more disabled than the target group originally sought. . .Most. . .programs can and do accommodate tenants with cognitive impairments, mobility problems, and a need for assistance with ADLs. This may be done through third-party care provision, through 'pushing the envelope' of restrictive standards on a case-by-case basis, or by 'creative' interpretation of rules (Kane & Wilson, 1993, 112)."

know that you care, and you are not trying to take away their rights, and you continue to make them feel that they still…you know, that this is not the last step. Because, as soon as you make that switch—and I've seen that done—where employees have really made these people feel that this is the last step. Once you do that, it just sends them off into another…unreality.

Vera, described earlier, regrets that the spatial confinement and routinization of life undercut her ideal of personal care. She is especially frustrated by the shortage of spontaneity and time to establish biographical knowledge of residents. Vera detects a misplaced preoccupation among managers and family members with residents' physical property over their self-story/crisis.

They [managers] are crowding two persons into one room, crowding two personalities together, and that would cause a lot of friction in that one would be constantly calling for something during the night. Some [residents] remember, "Don't use that, that's mine," you know; they have that much recognition. But there was more emphasis on [keeping track of] their private things and keeping them occupied with activities. When I was finished with the food and the cleaning and all like that, I would just say, "Come on in the kitchen with me. Let's see what we can dig up." And one, she just lighted up so you just assumed her background was getting into the kitchen and doing. To me, there's not enough of that one-on-one [discussion] prior to the admission. But no one takes time to find out those things [about new residents, instead] it's "What does she like to eat, when is the family going to visit, and where are her personal things?"

Although they lacked detailed biographical knowledge, whether from family, friends, or the "resident profile" sheets documenting medical histories, caregivers wove biographical themes into their care work. Earlier, we saw that Vera works to elicit this knowledge, either from residents or, when present, family or friends. Cynics can argue with some justification that this effort is part of helping "manage" residents and the work routine. However, recognition of the recipient's life and prior roles lends dignity and texture to relations that otherwise can be alienating for all concerned. Vera captures her rapport with a resident, Charlotte, a former teacher:

Charlotte has a problem with her sight—in fact, I don't think she can see hardly at all now. But she's crying, laying there in bed, and she's thinking that she's talking to her husband in the next bed. But it's not. Now, to get Charlotte out of bed, you gotta kind of have a little angle. She knows what it is to keep a schedule. You see, this is where you find what this person was like before they came into Lake Home. Charlotte was a schoolteacher. So I say, "Charlotte, you know what it is to run a schedule. You taught school for many years; and you know that those parents have got to get those kids out on time, to get into your classroom, and you can't keep 'em waiting. Now, come on Charlotte; it is almost breakfast time, and, hey, we work for *the company*! We gotta get up and eat breakfast." She feels my respect in that, for the life she lived.

But Vera's ideal of personal care is not reducible to biographical knowledge or to any retrospective image of residents' lives or capacities. It also encompasses an immediate, intuitive rapport, an acute reading of moods, and a conspiratorial, jocular style that residents enjoy as a suspension of the routine and scripted nature of daily life. She insists,

Even if you say, "Well, that person won't know me again when he or she sees me," that matters not. There's something there and it's not along the medical lines. There's something there. One person I have

in mind, she would look at me and her eyes would light up. And I'd say, "When they're all out, we'll go in the kitchen." She would just beam. And she would be no problem. She'd sit and look at television because she was waiting for that time. So the thing is to be able to find something that hits that little hidden note. And you don't have to have them say, "I like that." You can see the expression on their face. It's very noticeable, but it's just the effort of being observant and the taking of time.

6.1. Appropriating biography and social control

Vera's story suggests that biographical awareness alone, without genuine empathy with residents, is of uncertain value. It can be cynically exploited by staff to manage residents and their resistance to institutional routines. And the ready explanation of "disease" can be used to pathologize behavior that is most conveniently read in that light. We detected a process we term *appropriating biography* when staff members invoked information—gleaned either from family or from the documentary material in residents' dossiers—that was critical of residents or could be used to make a case for their eviction from the home (see Goffman, 1961, 23–24). In one case, a resident named Evelyn was the target. Driven by anxiety and poor short-term memory to repeat questions and anecdotes, Evelyn was an irritant to staff; failure to respond and reassure her led to an escalating spiral of questions and demands. This syndrome, not unusual in intermediate-stage Alzheimer's disease, is usually responsive, if only temporarily, to kind words. Chatting animatedly with coworkers during a shift change, (staff member) Sally accounted for Evelyn's behavior this way:

> She was used to being catered to all her life, especially after her husband died, and she had three kids who catered to her when he was gone. You know she lived with her adult son until he got married at the age of 51 and feels like he just deserted her. I don't blame him. She's used to her whole world revolving around him, but I think her kids were just afraid of her. The son had to take over the pharmacy, after she couldn't handle it, and he works long hours. They're probably glad to get her off their hands.

Our research suggests the importance of distinguishing between workers' cultural images and ideals of care; the particular stocks of knowledge they develop (both about care work in general and about individual residents); and finally the extent to which they are free and inclined to exercise such knowledge on residents' behalf, rather than as a resource for social control. Care workers' lack of job status and control, combined with the regulatory constraints discussed earlier, understandably produce typifications (see Schutz, 1970, 111–122) of residents and caring relations which suppress their enactment of personal care.

7. Family members: caring about (but no longer for) the person who was

Tensions that divide kin from paid caregivers, as well as from the quiet crisis that their loved ones, the residents, are facing have been discussed. First are the shadows of medical authority and expertise cast over the illness career that brings all concerned to Lake Home. Second, we will show, are conditions of labor which family members see as eroding caring relations. The third tension is the emotional distance that family members need from the existential trouble they share, but cannot resolve, with the ill person.

By virtue of their concern and knowledge, residents' friends and family members can potentially play a vital role in supporting and mediating practices of personalized care. As Fisher and Tronto (1990, 40–46) help to clarify, realizing this potential is daunting because of the lack of integration between the *phases and relations* of caring. They distinguish between "caring about" (a general concern or priority, not requiring specific action) and "caregiving"(an intense, direct responsibility for another). Although integration of these phases may be good in principle, in reality, we saw a tendency for family members to distinguish between what Bowers (1988) calls protective versus instrumental care—caring about and caring for.

The work of loved ones, to begin mourning and reconciling present and past images of the ill person, often collides with the older person's desire to integrate the present with one's overall biography and (depending on their level of cognitive functioning) to *salvage a self* (Charmaz, 1987, 310–316). Residents' progressive "loss of self" calls into question not merely the practical adjustment to Lake Home for all concerned, but also deeper questions of how the troubled, ephemeral, and multifaceted self is to be made a shared object of care between intimates and strangers. During the period when residents are moving in, family members may be absorbed, even gladly, in the process of imparting the inventory of information about the resident that can readily be shared: favorite foods and outfits, rhythms of hunger and wakefulness, and recollections about a newly transplanted piece of furniture. These exchanges are polite, efficient, and *present-oriented*, as Melina recalls about her sister's transition to Lake Home:

> I remember, I said "I'll write it all down for you," because although my other sister took care of the financial matters, I was the one who took care of the personal side. I recall writing about four yellow sheets about Erika, her likes and dislikes, how to treat her. I wrote that flattery will get you everywhere, you know, to smile and shower attention and she'll be okay. She always loved folk dancing and traveled extensively. So I told them ethnic music, maybe slide shows about foreign countries, all of that she'd love.

Such consensus regarding time orientation may be rare, however, inasmuch as families and staff members are often facing opposing time horizons: family members toward a past that cannot be shared and must be insulated from today, the staff toward a succession of todays in which both past and future [*handwritten: Future*] are tacitly, although determinedly, avoided. Although we were rarely privy to encounters among family members prior to their placing an elder at Lake Home, we suspect that they also had been engaged in the work of reconciling divergent orientations to time, which in turn contain cherished (or contested) role relations. Here, Michael, the son of a Lake Home resident, describes the tumultuous turns in their relationship just prior to her moving in:

> During the [transition from home] she came to our house and stayed for three or four days, during which she was very accepting of me as her son and confidant. But she'd vent her frustration to my wife, my family: "They are doing something to me, the world is or somebody is, and I'm losing my freedom." None of it was directed at anybody; she was adjusting [to life at Lake Home]. Once or twice they needed to sedate her because they couldn't control her. But gradually she accepted it. I think the turning point was when I gave her a chance to prove to herself that she needed help.

Thus, he expresses awareness of her internal conversation and is moved, not by its fragmented quality, but rather by its logic of resolution, of coming to terms. Although crucial for both in their struggles to

cope with the changes in his mother's life, Michael was reluctant to share such a conversation with Lake Home staff. Doing so might violate his role as confidant and would only confirm and make public his mother's anxieties, which he hopes are subsiding. We found, as Bowers (1988) did about nursing home care, that many care workers try to share the emotional burdens of care with family members and residents alike. However, this partnership proves to be elusive. The family members' ability, upon placement, to lay down the physical and logistical burdens of care may allow for healing—for relational and biographical "repair work." In the transition to Lake Home, then, many welcome an instrumental division of caring labor because it insulates them from having to resolve divergent realities and time horizons. This is a potential virtue of paid care because, ultimately, family members' nostalgic and intense emotions become less supportive for the resident than are the attentive, accepting, present-tense orientation of personal care, as we have defined it.

7.1. Consuming care: home as facade and as practice

"Home" is a layered phenomenon. For example, Groger (1995) shows that, for those in nursing facilities, "home" is both a concrete *place* and an *image*, embodying cultural ideals of independence and comfort. The two may subjectively be congruent or not. In recalling the process of choosing Lake Home for his mother, Michael (quoted above) shifted from the densely plotted story of their relationship to the public language of care-as-consumption. It is clear in the narrative that follows that the meaning of personal care became transformed in the process, hostage to categories and images that reference custodial institutions. At first, Michael was elated to have discovered Lake Home:

> When I went to look at it, it was exactly what I had in mind; but I hadn't known this kind of thing existed, in which she'd have the dignity of, like, being in her own home, but also have the twenty-four-hour care. It was comparably priced to nursing homes. . .and she didn't need specialized care—and still doesn't; she's on no meds at all—that a nursing home would provide. A couple of the other residents seemed less advanced [in the disease progression]. So I thought, my mother's someplace in the middle of this peer group. My concern at that time was that she received some kind of stimulation for her mind. My impression of the cleanliness, of the care, of the food, of all the physical things was . wonderful. But I wondered, how much stimulation is going on here?

Q:	What kind of relationship did you hope to have with your mom, once she was settled in?
Michael:	I felt I would be her link to the immediate family. I am her immediate family—there is no one else. I would also be her link to her sisters who are living and to some extent a link to her friends, and to help those people stay in touch with her. I arrange visits from time to time so that family comes to see her. I try to keep the communication going, even if she can't. You'd try and see her every day and feel guilty because you couldn't and, on the other hand, you just want not to deal with it and not see her at all. I tried to strike a balance. I knew and admitted to myself that her primary community would have to become the people at Lake Home, that I didn't have time to do that anymore. That's part of what I was buying—is that community for her. And I feel convinced that exists; I feel very good about that. And whenever I can add to that when I come, I do.
Q:	When you say there's community there, what are you seeing or feeling that leads you to say that?
Michael:	There was a caregiver named Margaret. She's not there any longer, but she took a very personal interest in mom. There are others who I am convinced took a personal interest. They get to know her sisters and personal things about her. Even when I'm there visiting, [some] will come up and encourage mom. I don't get that with all the employees, nor do I expect it. But I get from enough of them that I know it exists.

In his appraisal of Lake Home, Michael partly adopts the language of commodification, celebrating the congenial physical setting and comparing costs. He regards "personal concern" among staff not as a feasible expectation, but rather as a gift he will cherish if and when it is bestowed. Nor, it seems, does he envision a role for staff members in "linking" his mother with her extended social circle. Therefore, it is difficult to connect the community he has "bought" and imagines for her at Lake Home with that outside its walls, especially because, as he concedes, he would often prefer "not to deal with it or see her at all." Michael embodies the very split between "home" as *facade* and as *sense of being*, which he ostensibly hoped to bridge at Lake Home.

Family members' sense of personal care as lost and to be mourned upon the residents' exit from home is also evident below. Melina spoke of her sister Erika's illness and ultimate entry into Lake Home.

Q: At this point, were you consciously trying to avoid placing her in a nursing home?
Melina: Oh God, yes, that was the whole thing.
Q: What were some of the most difficult emotional issues you faced in the period before admitting Erika to Lake Home?
Melina: It was hell, Erika was a very intelligent and accomplished girl; we were very close, traveled a lot. And to see her becoming someone else, I mean, the outer shell was there, but the inner self was beginning to deteriorate. She was becoming quite feisty, even swearing, and Erika had never gone beyond heck. She was a completely different person. To see, emotionally, that she could not bathe herself [was hard], and I would get help from [live-in caregivers] but she was upset and angry with me trying to help her with the personal things. Her reaction was really very emotionally upsetting for me. She never said "fear"...but I asked her what she felt, trying to speak rationally. But you cannot do that. She told the aides, "I think I'm going crazy," so it must have been terrible for her. I think that's the worst with Alzheimer's patients, when they're semiaware of what's going on. Tremendous fear and anger. That lasted three years at least.

Melina brightens when recalling her relief at believing that care at Lake Home would be informed by expertise and detachment, which she lacked: "They told what they were learning about the disease, and I got to feel like an expert in those years, the mid-1980s. When they opened, the staff were getting more training every month, so you felt they knew." Like Michael, Melina found diversion, a kind of refuge from her emotional turmoil, when entering into the stance of consumer. However, her expectations, if not her definition, of care were diminished in the process:

The place itself was so pleasant, not like a nursing home. What impressed me too was, in the beginning, they had these young people, the staff, who were very pleasant, helpful, eager. They were cooperating with the [local hospital's] Alzheimer's division. And I felt, how wonderful; they're really interested in knowing how to take care of these people, because the hospital's geriatrics center had gotten a grant or something and their day care center was very well organized. I thought it was wonderful because the nurse and social worker came and looked [Lake Home] over, and they were working, you know, in the field. That's what impressed me most.

Q: What kind of information did you want, and receive, from staff members about your sister's daily life?
Melina: You had to be a little careful. If you go and ask questions about what did she do today or how is she feeling, naturally, you're ruffling somebody's feathers. I didn't always know how to ask, and [staff] didn't volunteer. But they didn't have the time to volunteer. The topics would be like, did she color today, or did the foot doctor come, but not deeper than that. Let's face it, there were many changes [turnover] over a period of four years there. When I had more of a rapport with somebody [a caregiver], I'd talk to her more than the others. There were always favorites I had because they'd extend themselves; they'd come into her bedroom and put Erika on the john and then I'd sit with them and we'd chat.
Q: When over time you had questions, about the changes in the disease and how it was affecting Erika, who would you go to, to address those questions or concerns?
Melina: I went to the nurse, at the hospital program. No, I wouldn't have gone to anyone in Lake Home, because I felt that many of them were temporary, you know, just new at this. And the managers were really only involved in the financial dealings, and my sister handled that.

These statements reveal several important themes. First, for family members the decision to seek placement at Lake Home occurs late in their caregiving career; it comes after months or years of facing disruption, even stigma, in their other roles and activities. Often, the emotional toll on family members is such that they cannot simultaneously care for the older member and handle the practical and developmental tasks in their own families and lives (Globerman, 1994).

Even when their emotional resources are not exhausted, families feel remote from the process of caring in Lake Home. They defer to what they see as managers' quasimedical knowledge about the disease—which tends to obscure the emotional and relational dimensions of hands-on care and makes reference only incidentally to the particular troubles of their family member.[9] Distance from caregiving is also rooted in family members' uncertainty regarding their role vis-a-vis staff members; they tend to rely either on latent institutional norms (ranking caregivers below managers and owners) or, as in Michael's case, on connotations of extended family or community. In neither case do they feel permitted to participate closely in care or to act as critical consumers.

These narratives offer clues to understanding why family members so often maintained, indeed reproduced, a fiction about the "homeness" and quality of care available at Lake Home. They decry the distance between the present and a cherished past but seem resigned to a belief that "home" and "care" have been turned into commodities that have a fixed and public character. In this transformation, their definitions of personal care take on new shades of meaning: it becomes a theatrical set design of suburban domesticity, a haven from the emotional toll and conflict that preceded placement at Lake Home, or a sense of having bought a kind of expertise about the illness which is comforting, despite its uncertain benefits or even connection to the drama they are living through. Yet they also reveal a nascent awareness of the potential role and value of paid caregivers, whom they have, in effect, made the caretakers of the resident's identity. For all these reasons, caregivers need family members to develop what Tanner et al. (1996) term "the discourse of the particular." Ironically, however, they may experience the illness and transition to residential care as the disintegration of relations and of their conviction that such "particular knowledge" is extant or relevant to care. Family members may thus fail

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[9] Gubrium (1986, 111–151) analyzed the "public culture" of Alzheimer's disease, and argued that in this culture "...the stuff of Alzheimer's disease is made up of patient, disease, burden, alarm, and research. Focused attention on the caregiving particulars of 'making it' from hour to hour is not much in evidence." In this section we are noting the implications of this pattern for the family's collaboration in the provision of personal care.

to contribute what only they can and confront an institutional model that gives them too little reason to make the effort.

8. Personal care as identity care

Personal care is at once a central and an ambiguous concept in residential facilities. Its relational meaning and value are suggested, by way of contrast, by the critique of "impersonal care," which is synonymous with bureaucratic or custodial care. The moral valence of the terms is unmistakable. In a folk sense, personal care connotes an emotional interest or commitment beyond that which we expect when the care is either fragmented into discrete tasks or governed by bureaucratic rules. For many, the term also connotes warmth, even affection, in the caregiving encounter, in contrast to the "coldness" imputed to impersonal care. Care that is competent and provided equally to all recipients but lacks empathy or spontaneous adaptation is, in our view, necessary but not sufficient for personal care. Although not comprehensive, our definition builds on insights from other writers and practitioners and addresses recurring issues we discussed above. Key dimensions include subjective *awareness,* both of the recipient's present-tense demands and biography; *advocacy* on their behalf; and *authentic* (non-alienated) *commitment.*

Personal care, as developed here, requires active awareness of the recipient's preferences and responses and a willingness to adapt care practices accordingly. This presupposes sufficient rapport to understand these preferences via nonverbal or metaphorical allusions, and sufficient time duration to establish and share these subtle cues. Moreover, personal care is not merely a set of skills or procedures but rather a concerned consciousness. It requires cumulative awareness and synthesis of fragmentary knowledge about the recipient, from various sources, as well as the time and emotional presence to mobilize this knowledge when the caregiver perceives trouble or a need for resolution. Although the care may involve similar kinds of knowledge across recipients, it is conceived of and enacted in terms of their particularity. Third, with Benner (1994), we find that personal care contains an *ethic of patient advocacy*—the ability to exercise moral imagination, creatively helping patients to achieve holism and dignity despite dependence. Tanner et al. (1996, 217–218 emphasis added) arrive at a similar conclusion, centered on an analysis of what it means to "know" a patient: "Over time, nurses have developed an oral tradition to describe their knowledge about...intimate regions of physical and interpersonal care...However, it would be a mistake to think that this discourse could be made formal, explicit, general and objective, because it is the *discourse of the particular* [that is] so essential to clinical knowledge." This underlines the relational dependence of personal caring, when the recipient is impaired, upon others as sources of the particular knowledge that informs patient advocacy. In this vein, Strauss et al. (1997, 138) studied hospital care and analyzed the "biographical work" patients do, often with the support of medical staff (also see Gubrium and Lynott, 1985). They define this work as that usually done "by kin and close friends, to help ill persons maintain a sense of identity in the face of extended illness. Hospital personnel engage in this kind of work too, but usually with more distance and perhaps in a more calculated fashion to maximize the effectiveness of their trajectory [i.e., curative medical] work."

Finally, Freidson (1990, 151) has reflected on *nonalienated* labor, such as artistic or altruistic work. However, he also captures cultural ideals about personal care when he writes: "In contrast to alienated labor, labors of love are voluntary. Being freely chosen, they can be part of the workers' nature and allow

self-fulfillment. They imply motives for undertaking work that are not in the immediate and obvious sense, self-interested, that are beyond economy."[10]

As we have shown, in giving truly personal care, one is a detective and an advocate; has a conscious, creative awareness of the recipient; is informed both by biographical knowledge and emotional empathy; both listens for and tells stories—literal and metaphorical—that address trouble and lend support; and has a sense of intrinsic dedication to the work, as well as to particular recipients, that is not captured by a conception of work as a "job" or transaction. ADRDs, being chronic and progressive, deny "patients" and caregivers alike the hope of healing. Thus, the perception of efficacy or "skill" and expressions of gratitude by recipients that would confirm its attainment by caregivers are also in short supply. Nonetheless, with this "practical ideal" in mind, we have explored cultural and organizational barriers to its fulfillment. Our analysis of personal care helps illuminate the importance of familiar policy concerns such as the impact of staff turnover on quality of care (e.g., Aiken, Sloane, & Sochalski, 2001). However, it suggests as well a deeper moral and political examination of how we might summon institutional commitment to sustaining fragile relations of care over time.

9. Discussion and implications

We agree with Peter Berger (1963, 143–145) that critical analyses of social problems hold the danger of breeding "bad faith," a sense of inevitability or futility in the face of shared dilemmas. In fact, hopeful signs for improvements in care at Lake Home are everywhere visible in this account: Paid caregivers with strong convictions had left jobs in what they considered less humane institutions; family members had searched for alternative care arrangements and proved attentive and appreciative of the insights and struggles of paid carers; and residents drew strength from "personal caring" in withstanding the stress and loss of chronic illness.

Part of the predicament of caregiving at Lake Home is rooted in the multifaceted, subtly conflictual nature of identity itself. To the extent that care is oriented to preserving identity as fixed—an *object*—supported by the physical accoutrements of self (clothes, hairstyle) and home (furnishings, patio), it is unresponsive to the crisis of cognitive illness, as perceived by the afflicted. Seen as a *process*, the resilience of the self is based not only on fixed roles and relations. Instead, it is also a restless narrative—a search for order and honor in events we cannot control or that violate our sense of biographical and situational integrity.

Drawing on extensive clinical and research experience with afflicted elders, Miesen (1999, 58–82) describes those living with ADRDs as "in search of safety." Patients come to feel safe only intermittently and tenuously through interpersonal attachment with, and empathy from, others. Indeed, our experience suggests that (regardless of the presence or absence of kin ties) caregivers' reassurance and recognition of the older person's fragile self is the most powerful comfort they can provide. This lends an especially poignant meaning to the phrase *personal care*. A growing body of research (e.g., Cohen-Mansfield, 2000; Kitwood, 1996) is revealing how social cues and narrative support can mitigate and even partly compensate for the anxiety and confusion of ADRDs.

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[10] This we distinguish from Hochschild's (1983) concept of emotion work, which one enacts under external pressure—from supervisors or customers—as part of a labor process in the service sector.

Once we move beyond the sentimental aura surrounding "care," personal or otherwise, we confront several problems. We discuss three that reinforce the marginal status of care work. First, in our economy, we perversely tend to penalize rather than reward care workers, in terms of salary and prestige, relative to workers who have no direct responsibility to protect or nurture others (Cancian, 2000). This depression of rewards is due in part to what England and Folbre (1999) and others argue is the mutually reinforcing devaluation of caring tasks and of the particular people who typically carry them out: mostly women, often of color. The care penalty is also due to an inchoate cultural belief that labors of love—a category that overlaps with care—are an exception to our usual model of work (Freidson, 1990). The irony is sharp: In American society, we project ideals of sentiment and commitment onto care work, defining it as above or simply apart from other kinds of work. We enforce this ideal by denying workers the economic rewards and autonomy that would make it "rational" to do the work. We seem at once to glorify and demean the work of caring. As a consequence, family members and others are reluctant to develop partnerships with care workers, whose attachment to work settings (if not to the work itself) is understandably tenuous.

A second problem, as inchoate and contradictory as the first, concerns *family* as an idealized model for providing care. The family as ideal connotes relations of intimacy, particularity, and continuity through time. In our cultural ideal, families unify the various tasks, feelings, and traditions that make up care. In scholarly debates about care, this resilient ideal is often contrasted to the more detached, generic, and fragmented treatment we expect and often get from bureaucratic institutions (Stone, 2000). Because the critique of bureaucratic or "commodified" care is so powerful, it has ironically served to bolster ideals of private (i.e., familial) care. This is neither a motive nor an intention of those critics of institutional care who acknowledge family to be a key site of gender inequality and one increasingly strained by the demands of work as women pervade the paid workforce. In any case, we have argued that a familial model of care is problematic because the definition of personal care we develop is neither necessarily present in families nor easy for them to abide, given the emotional and organizational barriers involved.

The final problem is that of translating our particular, personal ethos and language of care into the public realm.[11] Care practices and ideals, embedded in significant relationships, are difficult to extract from or express across social contexts. When considering public care arrangements, people confront an unfamiliar, although densely coded, language. Behind its fuzzy pieties, this language may be laden with regulatory jargon or with marketing slogans whose lines we must learn to read between. Yet even in assuming a stance of critical consumerism, we become reliant on generic categories of appropriateness, quality, and expertise. These categories may be less likely to capture dimensions relevant to compassionate care than to distance us from relations—including those with care workers—on which ultimately we all depend.[12]

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[11] Wenger (1990) has studied the provision of personal care, but because she assumes the primary involvement of kin- and home-based care, she is less compelled than we have been to focus on processes of mediation and translation.

[12] Foucault (e.g., 1980) argues that, in modern society discourses of "expert," usually professional, knowledge is a pervasive source of social power. In this vein, we believe expert knowledge to be among the elements—along with ideologies of consumption and distinctions between the public and private sphere—shaping what Hochschild (2001) has called the *commodity frontier* in public care arrangements. This is a metaphor for the shifting boundary regarding culturally acceptable encroachment of the service economy into intimate relationships.

Acknowledgements

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