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Abstract

In addition to medical and bodily needs, *personal(ized)* care involves the biographical and social identity of the recipient. Care-work always requires some adaptation to individual preferences and responses. But typically this is either an implicit or a secondary feature of care. However, with chronic, cognitive illnesses such as Alzheimer's disease, the very capacity for maintaining self (e.g., memory and language facility) is threatened, and so the extent to which care addresses the person *qua* person becomes especially significant: For the afflicted, *personalized* care is identity care. Our analysis is based on paid work and field research in "quasi-institutional" residential care settings for the elderly; such settings claim to support collaboration between formal (paid) and informal (family) care-givers. We find that, despite its sentimental folk meaning, there is no simple consensus regarding the meaning or practices of *personal care*. We first develop a conceptual and empirically grounded definition; we then discuss its diverse meanings for the various groups involved in paid elder care and reflect on their practical implications for the fulfillment of the ideal. Our research shows that obstacles to personal-as-identity care are not confined to large bureaucratic or medicalized institutions. Among the obstacles we find in residential care are instrumental definitions of care among paid workers and the public at large; a "familial" division of labor lacking special provision for such care; and emotional demands of the care, from which families seek relief. Even when those concerned do orient care to preserving identity, there is tension regarding whether to treat identity as object(ive) or as process.

In this paper we examine residential care for older people diagnosed with chronic forms of dementia. Alzheimer's Disease and related disorders [ADRDs] afflict between 15-20 percent of those aged 80 and older, the fastest-growing age group in American society. Among the oldest-old, those aged 85 and over, more than 15 percent of men and 27 percent of women were living in nursing homes in 1993 (Morgan and Kunkel 1998, 89); these trends are on the rise. On the one hand we are facing demographic pressures of an aging society, with an increasing incidence of chronic and often cognitive illness. On the other hand, these demands are colliding with a widely disparaged, medicalized model of institutional care. Despite the increase in women's paid work in recent decades, most elder care is still provided by family caregivers at home (Doty 1986). So it is they, often working daughters, who pay the price for the inadequacy of long-term care policy in the U.S. This dilemma is well-known and slowly this institutional landscape is changing. Yet as a society and as researchers we need to magnify this broad canvass; we also need close-up portraits of elder care in new institutional settings, and of how roles and relations are changing for those involved.

Selling Personal Care, Delivering Custodial Care in Homelike Packages

This research provides a unique vantage point for addressing questions that, despite their relevance, are rarely addressed in research on paid care-giving: To what extent, and how, does care support the recipient's sense of personal identity? And, how does the "place" for care—defined both culturally and organizationally—shape the provision of *personal* care? Answers appear to be coming from the large and growing "market" for public care-giving. Consider this advertisement for the McKnight Terrace in Middletown, Ohio: "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 honor the life experiences our residents bring with them and we recognize and acknowledge their past and present contributions, whatever they may be."

During years studying elder care, we witnessed both the power and, too often, the absence of what we understood to be personal care. In the ad above (for a place similar to that we studied), and generally in promotion of "noninstitutional" long-term care options, ambitious claims are made

for *residential care*. Though inviting, these claims deserve skepticism from those who know the demands of such care, whether it is provided at home or within overtly institutional nursing homes. But neither the claims nor everyday life in these quasi-institutions have been scrutinized closely, maybe because so many people—family members, care workers, older “residents,” even researchers—want so badly to believe them. 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 aren’t these goals problematic, even contradictory? On the 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 tendency reflects biography and cumulative choices, as these are molded, in turn, by historical events, work roles, ethnicity, and kin-based cultures of care. Also, “functional” definitions of health, though clearly relevant for organizing care, tend to undercut the holistic and flexible approach residential care claims to promote. One’s abilities to choose an appropriate outfit to wear or to practice bodily hygiene are elements of health and social competence. Yet these problems may seem trivial for those whose threads of self and biography are unraveling. This is true for those with cognitive illness, which implicates social identity and relationships more than the body per se. 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 public personhood. In this context, we argue that the meaning and practice of care must therefore include *identity care* as a central mission, interwoven with other, more familiar dimensions. However, we found widely divergent meanings and practices of personal care, in our work and research experience with residential care. These may have connotations and consequences that are opposed to commonsense meanings. Still, the public meanings mediate both care work and even access to paid care.

In this paper, we use this salient distinction in caregiving – *impersonal versus personal care* – to interpret relations in one “quasi-institutional” setting. Specifically, we document and analyze a tension in paid caregiving, involving careworkers and family members acting as advocates for institutionalized care recipients. For example, although in principle they reject nursing homes as too

“medical” and bureaucratic, few family members were directly involved in or responsible for care, even in a setting ostensibly more flexible and receptive to them than are “custodial” institutions. We found as well that careworkers themselves tend to invoke the rhetoric of personalized care, more than they cultivate the roles or relations required to sustain such care.¹ Our problem, then, is twofold: first to develop a grounded definition of personal care and then to 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.

Limits of Familial Care in an Aging Society

Alzheimer’s disease and related disorders (ADRDs) afflict between 15-20 percent of those aged 80 and older. In the past, ADRDs were dismissed as “senility,” an inevitable part of growing old; Gubrium (1986) recounts continuing ambiguity surrounding the organic and clinical markers of Alzheimer’s. But in a culture that prizes adult independence and competence, these diseases are a source of terror and, given the costs of long-term care, public alarm. Alzheimer’s and related disorders are progressive, but their course and timetables vary across individuals. The period between diagnosis and the terminal phase of these illnesses can last five or more years.² Although some one-fifth of persons over age 80 have cognitive limitations, some three-quarters are cared for at home, by spouses or adult children (i.e., daughters) (Doty 1986). But most spouses and adult children ultimately exhaust their capacity to provide care (Aneshensel, et al.1995).

In seeking housing and care options, families find a rather barren institutional landscape. Historically, U.S. 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 feed the highly profitable, corporate nursing home sector. For poor and many middle-class families, the costs of intermediate options such as residential care (ranging from roughly \$25,000 to \$40,000 annually) are prohibitive. Yet those who can afford it seek out various assisted living or residential care settings such as Lake Home (the setting for this study), which offer to provide minimal medical and bodily care in a setting that approximates “home.” A “quasi-institution,” Lake Home claims to straddle the border between familial and institutional care; this requires all involved – house managers, caregivers, residents, and

family members—to arrange and justify care for particular residents.

In our field work, we came to see the importance of what is *not* often discussed or expressed in these encounters: namely, whether and how living at Lake Home helped residents and their kin to cope with the anxiety and loss of cognitive illness. The demands of care for older persons with ADRDs make central what is often a peripheral part of care. This is the effort to help recipients preserve personal identity and dignity in the face of a chronic and progressive condition. Such disorders impose losses that are not only medical or “functional,” but also existential. On the basis of extensive clinical and research experience with afflicted elders, Miesen (1999: 58-82) describes those living with ADRDs as “in search for safety.” Patients come to feel safe only intermittently and tenuously through interpersonal attachment with, and empathy from, others. Indeed, our experience suggests that (whatever their relation to the recipient) caregivers’ reassurance and recognition of the older person’s fragile self is the most powerful and complex comfort they can provide. This lends a special and poignant meaning to the phrase *personal care*. Thus, communication and attachment in Alzheimer’s caregiving are especially challenging, and instrumental, task-centered definitions of caregiving are especially inadequate. A growing body of research (e.g., Cohen-Mansfield, et al. 2000; Kitwood 1996) is revealing how social cues and narrative support can slow, and even partly compensate for, the anxiety and confusion of Alzheimer’s disease and related disorders. Beyond the immediate case, however, *personalness* is a generic dimension in caregiving. And it should be instructive to consider a setting in which both the importance and the challenge of providing personalized care are especially great.

Research Setting and Strategy

This paper draws upon a five-year field study³ 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 is an intensive, multimethod case study of an RCF in a mid-western city (on the method, see Hamel 1993; Becker 1970). Lake Home (whose true name we conceal, along with those of informants) opened in the mid-1980s. It was licensed as an eight-bed RCF in a mid-western city. A converted ranch house in an affluent suburb, Unlike many owner-operated “board-and-care” homes (Morgan et al. 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 skilled nursing care. During our fieldwork, all residents were women. As mandated, Lake Home employed two staff members for each eight-hour shift. Though staff were encouraged and paid to acquire first-aid training at a local Red Cross, no other formal education or training was (as in some states) required. Wages ranged from \$3.75 (then the minimum wage), for newly-hired caregivers, to nearly \$6 for staff with the longest tenure.

Chris Wellin took a part-time job as caregiver soon after Lake Home opened and was responsible for assisting residents with meals, medications, outings, and all “activities of daily living” (except “personal cares” such as bathing and dressing) with which they needed assistance.⁴ In addition, he assumed the range of caregivers' domestic tasks, including shopping, cooking, cleaning, and acting as liaison with family members in order 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 1,200 paid hours) for one year.

Collaboration between authors began as both entered “the field” as ethnographers interested in understanding subjective experience for people with Alzheimer's and how their interactions with caregivers, family members, and one another shaped their attempts to preserve self. Along with other members of the research team, we generated an ethnographic data base consisting of over 2,000 pages of transcribed field notes, based on observations 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 data base, on which we draw for this paper, represents more than one-half of the ethnographic data.

A Continuum of “Personal(ized)” Care

Our richest source of insight for this paper is the paid caregivers whom we came to know at Lake Home, many of whom had earlier spent years doing similar work in more bureaucratic settings. They came for what they believed would be greater freedom at Lake Home to practice what they 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 work they believed in with flexible hours, but an informal internship in which they could gain “hands-on” geriatric experience and letters of reference from managers. Although their commitment was genuine, these women saw Lake Home, in part, as an approximation of other, more conventional and more medicalized institutions in which they expected to work in the future.

The other distinct group of caregivers was older, more experienced, mostly women of color. They had become frustrated with the routinized, hierarchical relations typical of elder care in nursing homes (see Diamond 1992) and been drawn to Lake Home in order to practice an ideal of care forged in other places. Salaries at Lake Home were comparable to those at nursing homes, and benefits often poorer, certainly than for unionized aides. So it was not material reward, but the autonomy and philosophy of care that attracted them. As Vera, an African American women in her late 60s, explains, her ideal was not confined to elder care. She was also a licensed practical nurse and had worked in the juvenile justice system. We asked her about the origins of her definition of care, Vera explained,

It is exactly what I liked and had already been doing all throughout the juvenile jail system. Which meant treating that person as a total person while you had the person there in front of you. Regardless of whatever. You had to interview them. If you gave them a good interview and built up a rapport, you'll 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 elimination? Had the food settled? Then [they worried about] their planned activities, keeping a running file regarding the activities for keeping them busy, and about the families—what were their names and jobs and where did they live. And then the part about furnishing their rooms. That part didn't set right with me; we'd be told, “Be sure now and tell whichever relative that we need to have her bed or her couch or her pillow.” And I couldn't see where that was helping these persons [residents] to whom furnishings did not matter. They were seeking something that wasn't tangible, but that they wanted. I would ask the staff members who had been there for a while about the ladies, because they knew quite a bit. The other part I just learned from the one-on-one with the clients.

CW: Ah. So you would ask them questions about their background.

Vera: I would ask different questions, but not for them to think I was asking a question.

Sometime I would just make them think that I knew, you know. I would say, "I saw a lovely blouse today and it was pink. And I remember that's your favorite color." And the person'd say, "No, you forgot. I like yellow." Or something, you see, to start up that conversation.

Eileen is another of the older caregivers with a strong commitment to care "for the person" and little patience when the 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. You catch yourself actually holding hands, playing games. 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 start only talking about the past. Their husband or wife might have been dead for 15 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 going to have dinner all together here tonight."

Toward A Grounded Definition of Personal Care

Vera and Eileen offer glimpses of their ideal of caregiving; for us, it is a touchstone. "Personal care" is at once a central and an ambiguous concept in caregiving. 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. If care is competent and provided equally to all recipients, but lacks empathy or expressions of concern, this would be necessary but not sufficient for personal care. Our definition, still evolving, incorporates insights from various writers and practitioners. Among the key dimensions of our definition of personal care are the following. Personal care

requires:

1. active *awareness* of the recipient's preferences and responses regarding instrumental care and a willingness to adapt care practices accordingly. Stone (2000: 101-102) argues that the tension between "specialness and fairness" is among the core issues in evaluating care in the public sphere. By specialness, we interpret Stone to mean "favoritism" among caregivers for particular recipients. Though surely an important problem, it only partly captures our problem of understanding the interpersonal relations and organizational conditions which allow care to be tailored to a particular person
2. 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, as well as the time and emotional presence to mobilize this knowledge when s/he perceives trouble or a need for resolution (as Eileen explained, about feelings of loneliness and grieving). Thus, although the care may involve similar kinds of knowledge across recipients, it is conceived of and enacted in terms of their particularity. It is common for both the distress and the caring response to be expressed metaphorically; for example, Groger (1995) shows that, for the institutionalized elderly, "home" is a layered phenomenon—both a concrete *place* and an *abstraction*, embodying cultural ideals of independence and comfort. Care involves responses to appeals like this one by a resident, Marge, who in a conspiratorial whisper insisted: "They've got the wrong girl; unlike these other people who are very far gone, I still feel like I can do an awful lot. I'm hoping that you can help me. If you could only find a place for me—I don't care what it costs, I don't care if it's empty, I don't care if it's a clean place or a dirty place. Just a place where I can get back to where I was." Care informed by such knowledge need not, therefore, take the form of directed conversation, but can be expressed through empathic listening and supplying cues to connect and honor a fragmented self-narrative
3. from Benner (1994), we learn 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 informal practical discourse 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 this particular knowledge

4. in this vein, Strauss and colleagues (1997:138) studied hospital care and analyzed the “biographical work,” patients do, often with the support of medical staff. 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 in order to maximize the effectiveness of their trajectory [i.e., curative medical] work.”

5. Finally, Freidson (1990: 151) has reflected on *non-alienated* labor, such as artistic or purely altruistic work. But 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.” Vera, quoted above, embodies the *rationality of caring* (Waerness 1996).

In giving personal care, then, 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 isn’t captured by a conception of work as a “job” or transaction. What distinguishes care at Lake Home, along these dimensions, from that in other places are matters of emphasis. Alzheimer’s and related disorders, 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. Elder care, though dependent upon present-tense intuitions about residents’ feelings and responses to their immediate milieu, also requires awareness of a longer “life trajectory.” This includes family and work roles, ethnic and class experience, and how the loss of self is refracted and managed through these identities. With this “practical ideal” in mind, we turn to cultural and organizational barriers to its fulfillment.

Personal as in Bodily Care and Dynamics of Distance

Next we contrast the ideal of personal care, which owes so much to perspectives of paid caregivers, to everyday practice in the division of labor at Lake Home, of which personal care is only a part. As a group, careworkers hold meanings of personal care inherited from the occupational divisions and regulatory guidelines that have shaped long-term care in the U.S. But their perspectives, and the practices they inform, also reflect cultural qualms regarding autonomy and deference based on age. For example, granting that caring practices should be personalized (as for a “client”), they 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 evince recognition of the recipients’ dignity and autonomy, rather than an instrumental conception of work. It would be easy to ascribe to careworkers motives that are better understood 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. 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 just 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, you know, 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 lives, no; we might get personal into our own at times. But I can't remember anyone else, or myself, you know, prying into that, trying to get more out of them. I would keep it pretty much general.

This reluctance to delve or “pry” into residents’ lives is driven by the sensitive nature, as well as the division, of caring work at Lake Home. And by an effort to respect norms of privacy.

Nonetheless, the primary meaning of personal care for staff at Lake Home is, “*hands-on*” *care of the body*. In our open-ended staff interviews, only a minority (roughly one-third) of respondents either mentioned this term or alluded to how they respond to residents’ particular life patterns or emotional needs. Even allowing for the fact that, as Tanner et al. (1996) note, it is difficult to perceive or articulate such care “in general,” this silence seems anomalous. Many

caregivers drew invidious comparisons between Lake Home and nursing home care: They celebrate the “homelike” atmosphere, responsiveness to family, and “personal touch” a smaller facility permits; yet they appear to conflate the benefits for family members and for themselves as workers with those of residents. 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. A search through our staff member interviews revealed that the terms “personal” and “personal care,” if spoken at all, are virtually always used in this, more instrumental, sense. Common exceptions are references in which “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). Also, staff members’ talk about personal *cares* takes place in the context of cumulative demands involving caring and domestic work in a functionally-diffuse division of labor. This quality of the work may be seen matter-of-factly, as when 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 as euphemisms, these terms connote both intimate practices like bathing and “toileting” and (especially with total care) the recipient’s nearly total *dependence* upon the caregiver. Caregivers may resent the demands of “total care” because it both contains the most unpleasant tasks and subtracts from the supply of human resources (time, physical and emotional energy) in such great demand. These pressures produce a dual consciousness in which staff members switch back and forth 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], lots more than South Lake Home, so you could not get the residents involved in those cleaning chores, maybe dusting. First of all you're going to say, yeah, you just want [to admit] somebody that doesn't have too many personal cares. 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, one can see how the emphasis on bodily care over personal care is a response both to Lake Home's division of labor and to the struggle among staff to attend to residents' individual needs, in favor of a minimal standard of care (transcending the "personal") 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 caring tasks formally regarded as "skilled" (because they are done with and for more dependent elders) most strongly hinder formation of caring relations and, thus, the potential to fulfill ideals of personal 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. As far as the clients go, in the past, they had people who were more able to perform, like I said, their own personal cares, could at least assist you somewhat. Now you get people who you have to dress them.

These pressures also involve the tyranny of the clock, in which the challenge of synchronizing multiple tasks is increased by the therapeutic benefits ascribed to keeping up daily routines. As Tricia explained,

You get everybody up, because all of the residents required some care getting them up; whether it was informal directions or whatever, they all required something. Getting them dressed and getting them all out to breakfast. Because of the way the menus were set up there were very seldom days where you didn't actually cook a meal for breakfast. If third shift had a bad night, then first shift does the baking and catches up. If you've had a resident that was up all night, or up and down, or if somebody who was sick or whatever, then you baked whatever they didn't get to,

which means breakfast is later. I didn't find it to be that big a deal, but then you clean up from breakfast, deal with everyone that is on any kind of toileting schedule, do a morning activity like read the paper or do remembrance, and it was time for fixing lunch.

Liz takes pride in resisting this rhythm, but maintains a task-oriented stance with residents, which shades into infantilization (Lyman 1993: 68-70):

I take the extra five or ten minutes to, you know, listen to a resident if they have a concern, whereas some other staff may not. I take... I do my job right; it's so easy, with the cares, to just skip something, just like pretend you did it, whereas I couldn't do that. I go out of my way to fill their day with enjoyable activities and stuff. I sometimes bring stuff from home to make it more enjoyable.

In the statement that follows, we see that staff members' attention to the maintenance of the body can itself be a form of resident advocacy, as well as a critique of what all concerned may regard as family members' negligence. There are also financial pressures that enter in, which are felt no less sharply because of Lake Home's relative affluence.

Violet's false teeth are coming out. She looks like a pumpkin. They're missing you see, and should be fixed. But the funds are tight right now because they didn't sell her home yet. And we're not allowed, because of cost, to let the podiatrist do her feet. And she's gained so much weight, we need clothes. Staff is bringing clothes in for her, from like secondhand stores. So we feel so bad for her because the family is not cooperative.

Overall, then, the absence of personal-as-identity care may reflect a kind of deference or reluctance to "pry," perhaps in compensation for the awkward intimacy imposed by bodily care. The absence also reflects a division of labor that reduces care to tasks and, for the caregiver, reifies the aggregate burden of particular tasks, rather than their sensitive accomplishment with recipients.

Personal Care(s) as a Regulatory Artifact

Caregivers' perspectives on tasks and relations are formed not only through interactions at Lake Home, but also by recruitment networks and regulatory rules in the larger world of paid care-work. Further, this occupational and political arena is not confined to the aged, but extends to other groups of care recipients. Many families caring for aged members *at home* hire aides to provide

“personal assistant services,” either through Medicaid or, in some states, through waiver programs promoting community-based care. In these circumstances, control over and relations within care are distinctly different from those we have described.⁶

Paid 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 and Frieden 1999). This model mandates that services be rendered in the least intrusive manner, to maximize clients’ control. Such workers are either hired through home health agencies or directly by recipients; but in either case, their status, presumed skill level, and wages are the lowest. For most of these workers, then, relations with clients and job evaluations are both rigidly confined to tasks of “hands on” personal care, subject (in many states) to medical authorization and oversight. For families struggling with Alzheimer’s disease, access to “day care” programs or residential facilities 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, careworkers’ instrumental approach toward “personal cares” in settings such as Lake Home is neither improvised nor reflective of their own ideals: In regulations governing home-health care 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 or “assistance.”

Given America’s institutional bias in long-term care policy, the demand for options such as Lake Home is intense. Because of the expense of placement and obligations of filial care that typically delay placement until a breaking point (Abel 1990a, 1990b; Aneshensel, et al. 1995; Corbin and Strauss 1988), residents arrive with needs that strain caregivers’ ability to cope. This would be true even if residents remained at a functional “plateau,” but becomes 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—including emotional care (Cancian 2000)—and the relations in which they’re embedded. As this 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:

When they had people who technically were assisted living, who could dress themselves, do their own personal cares, then, yes, it was an easy home. But again, ICA [Lake Home's corporate entity], I think, is 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 those type of people anymore, and they started taking whoever they could get.⁷

In the larger occupational world of paid care, personal-as-bodily care is both commodified and divorced from other, more valued, dimensions, even outside of bureaucratic settings 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 who, in the name of 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 socio-emotional dimensions of care—expose facilities to stiff penalties. Even divorced from their subsidiary role in a quasi-medical division of labor, careworkers and the bodily features of their work are denied the recognition and respect they merit as central actors in shaping the character and humanity of care. When overlaid with racial and ethnic differences, the distinctive value and practices of personal care are obscured in the eyes of paid caregivers, recipients of care, and their advocates.

Vignettes of Personal(ized) Caring

Workers, of whatever sort, adopt various stances in their emotional identification or sense of “authenticity” at work, each with distinctive risks and consequences (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 ties between them. 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 about seven or eight months find out that, really, they had to move. They become so familiar with the home and setting 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 know that you care, and you're 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, an African American caregiver in her late-60s, regrets that the spatial confinement and medicalized overtones of care at Lake Home undercut her ideal of personal care. She is especially frustrated by the absence of time to establish biographical knowledge of residents. Here she tells of tensions between two residents, a conflict most staff-members dismissed as part of “the disease.” 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 of a recognition. But there was more emphasis on that and their private things and keeping them occupied with the games. When I was finished with the food and the planning 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. I'm 68. If anything would happen [forcing me from home], if they didn't give me something that was connected with the earth, growing things in the earth, they would have a problem from me. 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 lack detailed biographical knowledge, whether from family, friends, or the bland “resident profile” dominated by medical histories, caregivers weave biographical themes into their care-work. Earlier we saw that Vera works to elicit this knowledge, either from residents or, when present, those close to them. This is but one strand of the tacit skill Diamond (1992) terms “mother’s wit” in his ethnography of nursing homes. Cynics can argue, with some justification, that this effort is part of helping “manage” residents and the work routine. But 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:

I'll go into Charlotte's room and put the light on and say, "Good morning." 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 in school; she was a teacher. What I find helpful with Charlotte is I try to bring up something in her lifestyle that she can relate to today, although she's not teaching. 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." Yeah, it works out better that way. I think she feels my respect in that, for the life she's lived.

But Vera's ideal of personal care is not reducible to biographical knowledge or 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. I could tell from the times that I would go home and I would come back, and especially this one person, 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.

Appropriating Biography and Social Control

In a taxonomy of staff members' meanings of personal care, 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 always ready explanation of "disease" can be used to pathologize behavior that is most conveniently read in that light. We detected this process, of what 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. But it takes a toll on caregivers, who are short on time and have little evidence that their efforts are appreciated (let alone reciprocated) by recipients. Chatting animatedly with co-workers during a shift change, 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 the kids were just afraid of her all those years. 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. When [the son] drops her off from outings, he can't wait to leave.

Family Members: Caring About (But Not For) the Person Who Was

Boundaries that divide family members from paid caregivers, as well as from the quiet crisis that their loved ones, the residents, may perceive, have already become apparent. First are the shadows of medical authority and expertise cast over the illness career that ultimately brings them all together at Lake Home. Second are conditions of labor, which families realize are constantly undermining caring relations. Over time, hope among most family members that they might come to see paid caregivers as partners or as extensions of themselves dwindles or dies. It falls victim to a parade of new staff members and to recognition that the most precious human resources available to their loved ones are squandered in an organizational model that denies caregivers security or flexibility.

The third boundary is the *emotional distance* family members need from precisely the existential trouble they share, but cannot resolve, with the ill person. The work of loved ones, to begin mourning and reconciling present and past images of the ill person, frequently collides with

the older person's desire to integrate the present with her 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 the deeper question of how the troubled, ephemeral, and multifaceted self is to be made a shared object of care between intimates and strangers. Early on, family members may be absorbed, even gladly, in the process of imparting the inventory of information about the resident that can more easily be shared: favorite foods and outfits, rhythms of hunger and wakefulness, 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 that 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 slideshows 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—the family member toward a past that can't be shared and must be insulated from today, the staff toward a succession of todays in which both past and present are tacitly, though determinedly, avoided. Though we were rarely privy to encounters among family members prior to their placing an elder at Lake Home, we suspect that they, too, had been engaged in the work of reconciling divergent orientations to time that, 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 confidant—her son. 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. Though crucial for both in their struggles to cope with the changes in his mother's life, Michael would be unlikely 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 no longer real. We found, as Bowers (1988) did in nursing home care, that many careworkers try to share the emotional burdens of care with family members and residents alike. But 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 they may *welcome* an instrumental division of caring labor because it insulates those concerned from having to resolve divergent realities and time horizons. This is a potential virtue of paid care because, ultimately, the nostalgic and emotionally freighted concerns of family members become less relevant for the resident than the attentive, accepting, present (tense) orientation of personal care, as we have defined it. So the importance of family involvement, and the cost of its absence, vary depending upon their temporal place in the disease trajectory: The importance is greatest following placement, when family capacity is low.

Consuming Care: Images of Home and the Work of Community

In recalling the process of choosing Lake Home as his mother's care facility, Michael shifted from the densely plotted story of their relationship to the public language of care-as-consumption. It is clear, in his and in the family narrative that follows, that the meaning of personal care becomes transformed in the process, hostage to categories and images known (and feared) from custodial institutions. At first, Michael was elated:

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 receive 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?

DJ: What kind of relationship did you hope to have with your mom, once she was settled in?

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.

DJ: When you say there's community there, what are you seeing or feeling that leads you to say that?

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 the relative cost. He is happy too that his mother *qualified* for admission, according to the medical and functional criteria for placement. In the next breath, however, he voices doubt (“Is there stimulation around here?”) that this is a sound principle for creating a “community.” He also has trouble seeing “personal concern” as a feasible expectation of staff members in this institutional model, rather than 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. So it's 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. This sense of

personal care as a capacity which is somehow lost and mourned by family members upon their loved ones' exit from home is also evident below. Melina spoke of her sister Erika's illness and ultimate entry into Lake Home.

CW: At this point, were you consciously trying to avoid placing her in a nursing home?

Melina: Oh God, yes, that was the whole thing.

CW: What were some of the most difficult emotional issues you faced in the period before admitting Erika to Lake Home?

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, 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 [used the word] 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 semi-aware of what was going on. Tremendous fear and anger. That lasted three years at least.

Melina brightens when recalling her sense of relief that care at Lake Home was 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-80s. When they opened, the staff were going to in-services every month, so you felt they knew. I was terrified of this disease, was starting to worry about and doubt my other sister, because it can run in families." Like Michael, Melina found diversion, a kind of refuge from her emotional turmoil, when entering into the stance of consumer. And 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. And at that time, they were cooperating with the 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 a little bit more organized. I thought it was wonderful because the nurse and social worker came and looked it [Lake Home] over, and they were working, you know, in the field. That's what impressed me most. You see, my relationship with Erika was not the same [as it had

been] and I had lost expectations. As I understand it, they would have [rejected] anyone who was not able to navigate on their own more or less. You had to have a doctor's report. The only problem with Erika, besides her Alzheimer's, was the beginning of incontinence; they can't handle too many personal needs like that in a residential home.

DJ: What kind of information did you want, and receive, from staff members about your sister's daily life?

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 they 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.

DJ: 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?

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' quasi-medical knowledge about the disease. This tends to obscure the emotional and relational dimensions of "hands-on" care and makes reference only incidentally to the particular "personal" troubles of their family member. Distance from caregiving is also imposed by uncertainty regarding their role vis-a-vis staff members;

this leads family to rely either on latent institutional norms (that rank caregivers as 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. Holly, a caregiver, told us,

Some families are very worried about the changeover in staff and the changeover in management of the houses—different managers every three to six months at our house. And they are worried that things may not be done correctly for their mother. And they ask, you know, how long have [we] been here. And they say that the staff should be paid more so then they will stay longer, and the residents will get better care if they had consistency.

These narratives offer clues to understanding why family members so often maintained, and actually reproduced, a fiction about the “homeness” and personal care being practiced at Lake Home. On the one hand, they decry the distance between the present and a cherished past; on the other, they accept with resignation 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: Personal care becomes a theatrical set design of suburban domesticity, or 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 at Lake Home need family members to develop what Tanner and colleagues (1996) term “the discourse of the particular.” But, ironically, they may experience the illness—and later transition to residential care—as the disintegration of relations and of their sense that such “particular knowledge” is either real or relevant to care. Thus, as consumers of care, families too often fail to contribute what only they can give, and they confront an institutional model that gives them too little reason to make the effort.

Personal Care as Identity Care

The concept of self is the organizing principle for our daily experience and connects us to the larger constellation of ties that make up our social worlds. We may experience our selves either

as changing or stable through time, as contradictory, often as fragmented or somehow in need of repair. Yet we nonetheless perceive an internal essence that we can morph and renew through a succession of social encounters. Our selves depend on confirmation from others of our desired identities and refuge from rejected identities, embodied in others, which we seek to avoid. Charles H. Cooley, the social psychologist, wrote of the “looking glass self,” arguing that we have as many reflections—as many selves—as we do significant others in our minds. John Hewitt (1984: 106-114) distinguishes the “biographical” from the “situational” self, arguing that the importance we attach to each and their linkages vary according to the social context. At a party, we and others may have little concern with our biographical selves, but rather be absorbed with establishing (situational) confidence and rapport with people whom we expect never again to see.

Part of the predicament of caring relations at Lake Home is rooted in the multifaceted, subtly conflictual nature of identity itself. Even if one were possessed of a core identity, assented to by a gallery of dear old friends, it would still be difficult to sustain this social “object” should our memory fail. As we faced this ordeal, the looking glass would crack. We would likely discover that we are known by each of those others in distinctly different ways and that each has an emotional stake in preserving the shard s/he uniquely knows, and is reflected in. To the extent that care is oriented to preserving identity as fixed—an object—supported by the physical accoutrements of self (clothes, jewelry, hairstyle) and home (furnishings, patio), it is less responsive to the crisis of cognitive illness, as perceived by the afflicted. Seen as 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 and that violate our sense of biographical and situational belonging. Selves cannot be pinned down. Thus, to revisit our central theme, personal-as-identity care implies knowledge of and support for the biographical self. However, it also requires acceptance of the person who is unmoored from biographical anchorage, along with whatever emotional turmoil and giddy catharsis may follow. Clearly personal care of this kind exposes the importance of conventional concerns about staff turnover. But it requires as well an explicit institutional commitment to sustaining fragile relations of trust and attachment over time.

Implications for Care-Work

We agree with Peter Berger (1963) that critical analyses of social problems hold the danger of breeding “bad faith,” a sense of inevitability or futility in face of share dilemmas. We believe that the elements for better care at places such as 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 and proved attentive and appreciative of the insights and struggles of paid carers; residents drew strength from “personal care” during their ordeal. What remains is for us to challenge the priorities and funding policies of the present system of long-term care in the U.S., as well as the morality of our system of occupational status and rewards, in the spirit of comparable worth. The organizational innovations needed to improve care are within reach.

Contradictions in our research opened up further questions, which arise in a different form in studies of paid child care.⁸ When care recipients are unable to speak for themselves, due to limited cognitive or physical capacity, how and with whom are we to *translate* their usually tacit personal preferences about care? This is a daunting issue inasmuch as those receiving the care may be incapable of remembering episodes of care (however “personal”) and even may resent the care if it is seen as symbolic of the loss of adult autonomy and status. Further, is it realistic to expect such personalized care, given that minimal requirements of safety and dignity are denied still to many persons? And given the effort and difficulty of translating individualized care preferences, what kind of institutional arrangements do we seek and trust to maintain *continuity* in caring? These goals are especially elusive when, as with Alzheimer’s disease, the course of illness is variable and progressive over time.

More generally, 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 as 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 (1998) and others argue is the mutually reinforcing devaluation of caring tasks and of the particular people who typically carry them out: relatively poor women 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 carework, defining it as above or simply apart from other kinds of work. We go on to 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 careworkers, whose attachment to work settings (if not to the work itself) they know to be tenuous. In this a crucial alliance is lost, since *working families* is a group that includes, not only caregiving families, but also paid caregivers themselves, who constitute a large and growing segment of the new service economy.

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. Ideally, families have a special tendency and obligation to *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, Diamond 1992). Because the critique of bureaucratic or “commodified” care is powerful and resonant, it has 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 that family is a site of gender inequality and is increasingly strained by the demands of work as women have entered the paid workforce. In any case, we have argued that a familial model of care is problematic precisely because the definition of personal care we develop is neither necessarily present in family relations 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. Care practices and ideals, embedded in significant relationships, are difficult to extract from or express across social contexts. When considering public care arrangements, families confront an unfamiliar, though densely coded language. Behind its fuzzy pieties, the commodified language of care 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 are 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.⁹

Notes

1. We focus our ethnographic data on contrasting and contextualizing perspectives of careworkers and family members, rather than the important and neglected role that older recipients themselves play in this process (see Cotrell and Schulz 1993).
2. Because of the long periods of time involved and the variable trajectories of cognitive illnesses, longitudinal research is especially important and revealing. For example, in this research we are concerned with older adults in the “intermediate” stage of illness, usually between two and five years into the illness “career.” The demands for care and emotional responses (especially of family members) we describe are therefore most characteristic of that stage. For examples of studies that incorporate change over time, see Aneshensel et al. (1995) and, though less explicitly, Corbin and Strauss (1988).
3. The fieldwork and interviewing were conducted between 1986 and 1992.
4. 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 important in this research, female caregivers discussed with us features of the work which they would likely have felt unnecessary to explain to female co-workers.
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 in order to provide context, based on field experience, that is not present in the interview transcript.
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. 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 Activities of Daily Living (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 and Wilson 1993: 112).

8. Problems of “translating” and monitoring care via family mediators also arise in studies of paid childcare. But their limited social power and legitimacy, rather than diminished capacity, renders recipients vulnerable. Tuominen’s (2000) research on “in-home childcare” provides valuable points of comparison with the present work. For example, in both cases the work is devalued (in status and wage terms), spatially dispersed in ‘homelike’ places, and subject to regulations that undercut collective mobility. However, unlike elder care, childcare: has strong obligations and sanctions regarding parental involvement, is part of a longer (i.e., school) institutional “career” that is prospective and not stigmatized as living in a nursing home is, and is likely to be more integrated, geographically and politically, within neighborhoods. This combination of factors has the potential to promote strong personal and political alliances between child care workers and parents of the sort that we do not see between careworkers and residents’ spouses or adult children.

9. Foucault (e.g., 1980) argues that, in modern society, discourses of “expert,” usually professional knowledge are an important means of mediating power. Our work reflects the importance of his critique, and we believe expert knowledge to be among the forces (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.

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