

In research on dementia care and housing transitions, only rarely are residents themselves present as active informants. This is a costly omission, inasmuch as manifestations of dementia, perceptions of care settings, and residents' experience of such transitions are both complex and highly variable. In this article, drawn from a larger study of the social organization of care in residential care/assisted living (RC/AL), we develop a detailed, ethnographic narrative that combines first-person reflections by, and observational data on, a single resident—a focal case. The account suggests that for older adults with mild to moderate dementia, awareness of serious impairment among coresidents can be both distressing and stigmatizing. We further argue that assumptions about and attributions of dementia by staff members, compounded by immediate demands of caregiving, may create a self-fulfilling prophecy resulting in residents' resistance and withdrawal. The case also suggests that, to the extent this interactional dynamic is present, distinctive goals in RC/AL, such as enhanced self-determination among residents, are undermined.

Keywords: assisted living; housing transitions; identity; narrative gerontology; dementia care

June's Troubled Transition: Adjustment to Residential Care for Older Adults With Dementia

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The biomedical model of dementia suggests inevitable and inexorable decline resulting in a loss of self (Gubrium, 1986; Lyman, 1989). However, this model emphasizes the tragic end-point of dementia, rather than the process—often spanning years—in which the afflicted person actively attempts to maintain core roles and identities despite cognitive impairment.

When we began our fieldwork, research on dementia was dominated by medical terms and concepts, and by concern about caregiver burden (Mace & Rabins, 1981; Zarit, Orr, & Zarit, 1983). Ethnographic research with older adults and their caregivers was rare, and many doubted whether the afflicted had self-awareness or a coherent story to tell. However, despite methodological and ethical challenges, recognition grew that it is essential for understanding the manifestation and treatment of such illnesses that we include impaired older adults as research informants (Beard, 2004; Cutchin, Chang, & Owen, 2005; Loue, 2004). In recent years this research has flowered: for example, Belgrave, Allen-Kelsey, Smith, and Flores (2004), Beard (2004), and Kitwood (1996) have mapped the cultural and experiential dimensions of dementing illness, and psychologists such as Miesen (1999), drawing on clinical practice, have shown how honoring and responding to utterances—however fragmentary—and forging emotional attachments with those affected can mediate and often buffer the anxiety and sadness that accompany dementias.

Furthermore, it is apparent that research on the onset and course of dementia is enhanced when explicit attention is paid to the socioenvironmental context of care. Researchers and clinicians alike accept the utility of Lawton's (e.g., 1980) path-breaking work, a major premise of which is that competence does not inhere in the person alone but, rather, is adaptive, shaped by the degree of fit between individual capabilities and proximate challenges and supports (both physical and social). This model is one of *environmental press* (Lawton, 1980; see also Olness and Loue, 2004; Schaie and Willis, 1999). In policy terms, this premise has been central to claims that residential care/assisted living (RC/AL) is an optimal setting for dementia care: As Morgan, Eckert, Piggee, and Frankowski (2006), Carder (2002), and Zimmerman, Sloane, and Eckert (2001) discuss, residential care promises to support a more flexible *social model*, in which residents' privacy, autonomy, dignity, and self-determination can be preserved for as long as health permits. Ideally, these conditions enhance identity support, which is central to quality of life for residents and their loved ones (Wellin & Jaffe, 2004). However, whether and how residents in fact perceive and exercise these benefits has only begun to be explored empirically.

Research into adaptation has varied in terms of its focus on assessing the *model of RC/AL*, as opposed to the *subjective adaptation of persons to the model*. In a recent example of the former, Cutchin, Chang, and Owen (2005) used a semi-structured questionnaire to tap important dimensions of the assisted living experience. Among their findings are (a) that residents' community contacts decrease after admission, (b) that it is important, when assessing involvement in activities, to distinguish significant, or purposeful, activities from others in which residents merely fill time or maintain generic interactions, and (c) that the role of staff members, in mediating activities and shaping residents' quality of life, needs to be explored and theorized more fully. Brandi Kelley-Gillespie, Liese, and Farley (2004) compared older adults' perceived quality of life in nursing homes versus RC/AL. They found the severity of depression and anxiety to

be lower for residents in RC/AL. However, because the informants had been living in nursing homes prior to entry into RC/AL, their health and residential trajectories may have been quite different than the subject of this article (who had been dwelling independently in the community). Thus, whether and how residents adapt to the RC/AL model appears to be mediated by the circumstances in which they make the transition. Similarly, Ball et al. (2004) used qualitative interviewing to reveal the multidimensional nature of a key concept that defines the social model in RC/AL, that of *independence*. Other researchers, whom we follow, have used qualitative data to explore the subjective process of adaptation. Morgan et al. (2006) have analyzed ethnographic and narrative data to reveal how the expression of personal choice and agency in RC/AL is shaped by residents' particular biographies, including their social networks, events that precipitated moving from home and community, and earlier constraints on autonomy prior to entry into RC/AL. This argument echoes Gubrium's narrative study (1993), in which he found the meaning of nursing home residency to be highly variable and contingent, shaped by older adults' routines, roles, relationships, and health trajectories before entering nursing care. In this continuum of topical and theoretical concerns, the value of narrative approaches is particularly great as one moves toward the second theme (subjective adaptation). A defining goal of narrative inquiry, in short, is to understand "the continuity and wholeness of an individual's life experience" (Clandinin & Connelly, 2000, p. 17).

Residential care, a relatively recent component of the continuum of care, is an ambiguous model both culturally and organizationally: bridging home life and nursing/institutional care, it contains aspects of both. Also, many RC/AL facilities are informally designated, if not licensed, to provide special care for particular groups. Sloane, Zimmerman, and Ory (2001) estimate that some 40% of residents have at least mild cognitive impairment, and confirm that a growing percentage of settings offer specialized dementia care (roughly one quarter, particularly among newer and larger facilities). However, these and other authors (Parker-Oliver, Aud, Bostick, Schwarz, & Toffe, 2005) conclude that researchers and clinicians have yet to agree on common definitions, criteria, or measures of well-being in such settings, and that research strategies are needed that are better able to capture the subjective nature of residents' adaptation and perceived quality of life.

Our agenda is to address this gap in the literature. Drawing on the constructionist tradition in gerontology (see Gubrium & Holstein, 1999), we highlight how the confluence of social losses, relationships, and organizational contingencies creates turning points in the struggle over selfhood. Although we recognize our role and power in the construction of this account (Jaffe & Miller, 1994), we blur our individual identities by the use of the pronoun "we" in order to privilege the voice and perspective of a woman we call June Turner.¹ In short, we offer an illness narrative (Kleinman, 1988) to counter the master narrative of dementia as inevitable loss and social death. Finally, we discuss implications of June's narrative for research and practice in residential care.

THE RESEARCH SETTING, PROBLEM, AND APPROACH

Against the backdrop sketched above, our goal is to understand how the meanings of memory loss and bodily decline are constructed in the context of the social and organizational relations of caregiving. Drawing on a multiyear ethnographic study of residential care for people diagnosed with dementia, we present a coconstructed narrative and interpretation of the experience of one resident in an effort to recount how the loss of self associated with dementia occurs. In the larger case study of which this is part, we collected extensive observational and interview data, spanning 3 years, on many aspects of the social organization of care in the setting we call "Lake Home" (Jaffe & Wellin, 2002; Wellin & Jaffe, 2004). Licensed as a specialized dementia care setting, Lake Home is a suburban ranch home on the outskirts of a Midwestern city. Eight residents—all women—occupied the home's four bedrooms; the expansive living room contained a stone fireplace, tropical fish tank, and picture windows framing a stone patio and manicured lawn. Two staff members were present during three shifts around the clock.

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Specialized dementia care settings were not yet common as we began fieldwork. We were interested in the everyday social construction of dementia care, and in the political economy in which this for-profit agency marketed itself, recruited residents, and expanded its role. In a sense, the unit of analysis in the larger study was the RC/AL model itself, as an institutional response to demands of dementia care. Many RC/AL facilities claim expertise in dementia care, and are licensed, as Lake Home was, according to regulations that govern who can be admitted. These guidelines are defined not in terms of cognitive or communicative ability but, rather, in terms of medical and legal liability; to be admitted, residents (all paying privately) must not require more than a minimal amount of skilled

nursing care, must not be incontinent, be ambulatory and able to feed themselves. We became increasingly conscious of the wide variation in cognitive ability among residents, and of the impact this variation had, both on the process of care and on residents' efforts to create bonds with one another.

Why have we returned to these data after some years? June Turner, our protagonist, was exceptionally lucid and candid with us in recounting her earlier life and her ongoing efforts to maintain autonomy and agency at Lake Home (Morgan et al., 2006). In articulating the more general process of resisting and accommodating daily constraints, June became, for us, what Morgan et al. (2006) term a "focal case." Stimulated by developments in narrative gerontology (see Bury, 2001; Gubrium, 1993; Kaufman, 1986; Kenyon, Ruth, & Mader, 1999; Kidder, 1993), we saw the value of reconstructing and contextualizing her narrative in chronological and experiential order.² June's narrative helps to reveal social aspects of the dementia experience from the standpoint of the older person who, ostensibly, suffers from dementia (e.g., Beard, 2004). We say "ostensibly" because the diagnostic markers and clinical manifestations of dementias are highly varied and ambiguous (Gubrium, 1986). During the intermediate stages of such illnesses, which often span years, the afflicted face such problems (in various combinations) as memory loss, difficulty in processing language or managing steps in practical household tasks, loss of balance or coordination, and a lack of attention to, or concern about, norms of public behavior. These deficits understandably trigger acute anxiety and grief for those with self-awareness, emotions that often are rooted as well in practical losses—of loved ones, home, and control over daily routines.³

Such losses were sharply felt by June Turner in her months at Lake Home. June was one of nearly three dozen residents about whom we collected data during the case study. Our data, in addition to notes based on weekly visits and conversations with June, include interviews with her attorney and confidant; field discussions and semi-structured interviews with staff members; and entries in a daily shift report in which staff members documented residents' health status, care demands, and behavior. We follow Goffman's lead in examining the *moral career* that unfolds along with the experience of institutionalization (1961). In rendering June's story, we are alert, as Goffman was, to understanding "moral experiences—that is, happenings which mark a turning point in the way in which the person views the world. . . . The self in this sense is not a property of the person to whom it is attributed, but dwells rather in the pattern of social control that is exerted in connection with the person by him- [her-] self and those around him" (1961, p. 168). Now it's time to meet June.

JUNE TURNER'S BIOGRAPHY

Widowhood and Loss of Independence

Born in 1899, June Turner had already lived a long, secure life when her husband died in 1985. Before retirement, the two had for

decades shared a home on a quiet residential street in a suburban community and pursued their careers, he as a traveling salesman and she as a bank worker. They never had children or close ties with their extended families. June's main social contact after her retirement was Loretta Cummings, a neighbor. June was easy to like, and also to respect, with her regal bearing and graceful laugh.

June Turner met Tom McDermott two years after her husband died. McDermott was an attorney her neighbor had recommended. Mrs. Cummings had become June's only contact with the world and had begun to realize that June was getting into trouble with the Internal Revenue Service. Mrs. Cummings contacted McDermott to help get June's finances in order.

Initially, June would not permit McDermott to enter her home. They spoke through a screen door as he stood on her front porch. McDermott was able to get June's taxes squared away and she finally trusted him enough to invite him into her home. He discovered that she had allowed the gas and telephone service to lapse. She was using electric space heaters for comfort in cold weather and slept on an old couch in the living room. As McDermott described it, "The place was a chaotic mixture of trash and personal items. . . . She would save everything. She was a compulsive saver of Styrofoam packages from the grocery store."

As June's trust in Tom McDermott increased, he convinced her to let him attend to other affairs. Her finances were in disarray, so June asked McDermott to establish a trust, with him as trustee, in order to dispose of her property after she died. Still, McDermott could not persuade June to move out of her house. As winter enveloped the Midwest, McDermott felt helpless, knowing that June was relying on space heaters for warmth and existing on canned ham, soda, and cold cereal.

In late January, June found herself in a life-threatening situation and McDermott faced an ethical dilemma. June's legs developed severe infections. In her upstairs bathroom she made a bed for herself and for three days she lay on the floor, unable to get up. Tom McDermott debated his legal and moral responsibility: Should he honor June's request that he do nothing? Should he ignore her plea and call an ambulance? Ultimately, he contacted the police department and an emergency squad arrived. June was taken to the hospital and, though angry at Tom, she asked that he continue to oversee her care at the hospital.

The infection under control, June was transferred to the county geropsychiatry ward where she remained for several weeks. Meanwhile, McDermott was meeting with the staff of the geropsychiatry center to try to figure out what was best for June. While at the center, June talked a great deal about the past, her childhood, married life, and her job. She could not remember her illness or being trapped in her bathroom at home. She didn't believe Tom McDermott when he told her about the condition of her house when they met. According to him, "Her mind seemed to have been able to just shut all of that out." Nevertheless, the staff told McDermott that as long as home health aides could be retained to make sure she was taking her medicine and eating well, he could honor June's wish to return home.

Once home, June regained her mental acuity and refused to allow the home health aides into her house. She and McDermott had heated discussions about her lack of cooperation with the treatment plan. According to the attorney, “she was very independent, and that was very important to her—that she be in control. That [meant] being in control of access to the house. She didn’t like the aides coming in.” Looking for help, McDermott contacted a local case management agency and began working with Susan Miles, a social worker. The two explored alternative living arrangements for June because, according to Tom, “It was pretty obvious she was not going to be able to live in her house.”

Ms. Miles urged Tom to contact Innovative Care Associates (ICA), a for-profit corporation that operated and ran several small group homes. One, “Lake Home,” they learned, was specially designed for residents with dementia, so when June emerged from the geropsych ward with a diagnosis of probable early-stage Alzheimer’s, McDermott and Miles decided to visit. Still, McDermott doubted that June had lost her memory. She knew exactly where her bank accounts were and frequently reminded Tom to make sure that no account exceeded the FDIC insurance limit. He simply didn’t think she could care for herself in a way that would preserve her health. While he respected her wishes, he also thought that he had “some sort of moral obligation to try to get June in a situation that would be better for her.”

Of his first visit to Lake Home McDermott recalled, “It was not institutional looking at all. It was a house. Bedrooms looked like bedrooms rather than hospital rooms, and the living room was decently furnished; the physical plant seemed to be good.” As for June’s needs, McDermott thought Lake Home was ideal: “It was important to me that she be someplace with round-the-clock staff on duty, because I had seen what she would do when she didn’t have some supervision. I wasn’t sure that she really would qualify for a more independent type living environment.” Buoyed by the sense that Lake Home was an answer to June’s practical problems and his own moral dilemma, Tom discussed a possible move with June. Ultimately, she agreed to give it a try.

June moved to Lake Home in May, but her attorney remained cautious: “I was frankly nervous that she might insist on going back to the house, which wasn’t sold until September. We weren’t sure it would work out and didn’t want to give her any reason to think that people were taking away her home.” Tom McDermott’s initial concern focused on June’s adaptation to Lake Home, but he concluded with relief that “All I have to do is look back to what she had before she came there.” Indeed, it had been almost a year of care and conflict, bargaining and negotiation between June and Tom McDermott. Thus, a number of paths converged at Lake Home. For Tom McDermott and other loved ones and guardians of people with dementia, Lake Home certainly seemed like a godsend. All would be spared what they thought of as the living death of the nursing home and they could finally enjoy a respite from caregiving. For staff members, too, Lake Home represented a potentially pleasant, even liberating alternative to the rigid, top-down working conditions of nursing homes and psychiatric wards (Wellin, 2007;

Wellin & Jaffe, 2004; Zimmerman, Sloane, & Eckert, 2001). Lake Home represented a collective solution to a number of individual problems. But what did June think? Was Lake Home a godsend for her?

Arrival and Early Adjustment to Lake Home

We met June at Lake Home in May of 1988, just after her arrival. The first time we saw her she was sitting outside on the patio in a floral dress and sunglasses. We spoke to staff members about her and one thing they agreed on was that the relationship between June and her roommate, Emma, was strained. June was Emma’s new roommate, and although Emma had been lonely and wanted someone to share her room, apparently there had been hostile exchanges between them.

Our first encounter with June revealed that she was very sharp; she gave us a firm handshake, and in the half hour that we spent with her we were impressed by how lucid and alert she was. While she found aspects of the transition to Lake Home to be difficult, she had a sense of humor that was a bit sardonic. Asked how things had been going, June smiled wearily and said that she’d been having a good deal of trouble getting along with her roommate. She spoke of “the other lady in my room,” who, she said, was nasty and territorial. The “other lady” didn’t want June to put her things in the drawers or in the closet. June expressed her wish, however, that she could get to know the other residents more. Thus far she said she’d only been able to talk with “the help”; she said the “girls who work here” had been nice, but what she really wanted was to know and interact with the other residents. She made it clear that getting to know them was difficult because, she claimed, some could not be understood. Still stoic, June declared, “I’m sure I’ll adjust.” When we visited the following week, June was preoccupied with Cora—another new resident—who was distressing to be near, constantly

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clicking her dentures and even chasing another resident around the living room. How sad it was, June felt, that Cora’s mind was gone, and how fortunate that she, at 88, was “still in pretty good shape.” June also identified people whose behavior at meals offended her: “Emma’s food’s all over her when she eats; she eats ice cream with her hands!” When asked if Cora and Emma were exceptions, she said “Most of them are like that.” June leaned close, with piercing eyes, and said, “You see?! That’s what we have to deal with around

here; *that's* what we have to talk to." June drew close as if telling an important secret, and her stage whisper only added eloquence to her plea. "She comes up with all kinds of things, and I can't make heads or tails of 'em. You see, I'm the kind who likes to speak my mind; I just say right what's on my mind, and this is quite different from some others." And with this she tilted her head toward Cora and laughed. June implied that Cora was choosing to be less than forthcoming by her gibberish. "When you can't talk to people, it changes your life," she said.

A week later, she declared, "Coming here was the worst decision I've ever made in my life." We asked if there were particular things that she'd liked to do at home and missed at Lake Home; she reflected and said, "But I'm not *allowed* to feed the birds here." There were two chairs on the front porch, and we asked June if she enjoyed sitting to watch the birds in the stand of trees on the boulevard. She replied, "Sometimes, but they don't let you just sit out there by yourself; one of *them* [staff members] has to be out there with you. Maybe they think I've got a motorcycle out there, and I'll hop on."

We queried June about her relations with other residents, a topic that preoccupied her. Some weeks after her arrival she declared, "You *can't* know these people." Another resident, Gladys, chimed in to say "Well, we're all acquainted, but we don't know each other." Asked when she'd be able to get past that awkward stage, June answered, "Never. We never do." We commented that mealtime was usually sociable. June agreed, but said, "The owners don't allow us to talk at the dinner table. No. They [pointing to staff in the corner, doing paper work] talk to each other some, but they seem a lot more interested in feeding us and cleaning up than they do about talking to anybody. Sometimes they've been nice to me; they'll go out of their way for you." But June regarded them more as employees than friends or confidants.

For their part, staff members wondered aloud if June would be long for Lake Home because, they said, "She's so high level." This reflected their sense that, being so lucid, June was ill-placed at Lake Home. She complained bitterly about field trips that she'd been required to take, such as one to the zoo. She wasn't given a choice, the drives were long, and the trips were too strenuous for a woman in her late 80s. "Sometimes they make you play games, and if you refuse, if you don't get involved, they treat you like there is something wrong with you. They'll bring out a ball and throw it back and forth." We volunteered that that sounded like sort of a childish game and she nodded, adding that she "wanted to fly the coop" as soon as she could.

We asked her whether she had come to feel differently about herself as a result of her time at Lake Home. "Yes, I suppose I have . . . like the young man [the foot doctor]—after he treated me I wanted to tip him, but that's impossible here because I haven't a nickel. I have no money of my own that I could use to do such a thing." This is one way in which she felt less than independent, less than adult, which undermined the pleasure she usually took with visitors.

A Taboo Subject

At times, when residents acted in eccentric ways or expressed in tense or incongruous emotions, one was tempted to broach the topic of dementia. After one episode, when June was clearly troubled and searching for an explanation, we asked if she were aware of the term *Alzheimer's disease*—one which we had never heard uttered at Lake Home, except among staff. We discussed the disorder and its behavioral signs and symptoms. June agreed that there were several people at Lake Home who would fit into that category. She said she could tell those people who were afflicted, "When you really get to know them." June seemed both relieved and troubled to broach the topic, to which she'd made so many glancing references.

June's "Secret" and Gradual Withdrawal

A few weeks later we learned from the house manager that June was often incontinent of bladder during the night. This only compounded our puzzlement, since admission guidelines prescribed that residents be afflicted with some kind of dementia, but that they *not* be incontinent. June, it seemed, violated both. Suggesting that June's presence at Lake Home was *due* to her incontinence, the manager quickly added that June was "paranoid." She continued, "She's also paranoid and delusional; you know she locked herself in her room [before placement in Lake Home] for days, and [because of her incontinence] her clothes were foul." Of course, this referred to McDermott's story of June's reclusive period at home. It was offered as the "official" evidence that she was mentally incompetent, and thus as an ad hoc rationale for why June had been admitted to Lake Home. In a way that others have noted (Mitteness & Barker, 1995), June's bodily failing had been generalized and stigmatized.

We found her alone in the living room, dressed in a rumpled nightgown though it was mid-afternoon. We were all uncomfortable, sensing an ill-timed intrusion. June apologized, saying, "This is just one of those things that's so unlike me—sitting here dressed this way." We asked whether she had insisted on remaining in her nightclothes, and she said, "No, it's that I don't have enough clothing here. I have so few things to wear, and they [staff] always want to put me in my very best things."⁴ We asked June whether she wanted to save her good clothing for another occasion, and she said, "Oh no, it's not that; you see I'm wet all the time. I have no control whatsoever over my kidneys." By this time June was often refusing even to get out of bed or get dressed. She'd decided, after being denied re-entry to her room on occasion after breakfast, that she wasn't going to leave her room in the first place. Staff members thought, perhaps correctly, that June was refusing to put on her clothes because she didn't want to ruin them by soiling them (a point she'd made to us as well), but she changed her nightgown frequently, in keeping with her sense of dignity and personal hygiene.

At a staff meeting, Trudy, the house manager, had given a stern talk about how necessary it was that Lake Home be sanitary and "presentable," especially given that prospective clients and family members were granted impromptu tours. Trudy made it clear that

staff were to clean and disinfect all areas where residents had urinated. This discussion shifted to June. It seemed that, at any given time in the house, a problem-resident was designated and became a target of staff members' ire. In practical terms, June created trouble because she resisted house routines, sought the seclusion of her room (especially during the day, when she had it to herself), and created more dirty laundry for staff. Worse, rather than being grateful for their tolerance of her incontinence, June resented the staff, seemed in fact to use her bodily failing as a kind of protest against her presence at Lake Home. A staff member angrily reported June to have said, in reference to her incontinence, "They're getting paid for it [cleaning up after her urination], let them do it." The house manager had even bartered, in effect, with June, seeking to exchange some favor or privilege, if only June would cease what Trudy suspected was willful behavior. Exasperated, Trudy reported: "I think she's just playing at being confused like this, and I'm not going to play that game anymore." The house manager directed the staff to continue to chart all of June's transgressions, especially the incontinence, but also her refusal to get up in the morning. Locking eyes with everyone to underscore the gravity of the situation, Trudy instructed staff to "Chart *everything*; when in doubt, just write it down." She also said, softening her hard-line, "I know it seems harsh, but think of the time you spend cleaning." We commented that other residents had suffered from incontinence yet remained in the home for long periods of time. Trudy countered, "But they're cooperative; they'll wear their Depends and everything." An "official" interpretation of June's behavior had been constructed and was soon discussed with her attorney and social worker.

At a subsequent field visit, June's social worker, Susan Miles, was present. Susan had questions about why June seemed so despondent. The house manager pulled out the "shift log" and began reading: "On Monday, wouldn't get out of bed except for meals." Turn the page: "Wouldn't leave her room." Turn the page: "Only up for meals." A growing dossier was attesting to what a picky eater June was, compounding her other demands on staff. Trudy acknowledged that June was angry and upset, and the conversation turned to competing hypotheses about the reasons for her anger. They went to great lengths to absolve each other of any guilt, and finally located the reason in June's incontinence. Entries in the chart declared: "Refused to dress." "Refused to have her

bedclothes changed." "Refused to come out of bedroom." While incontinence rarely led to evictions from Lake Home, "refusals" of various sorts could be fateful. June's condition and behavior were defined as malicious within the context of the work lives and demands of the staff members. Worse for her, June's struggle—oscillating between hiding from and defying staff members—poisoned what was already her precarious sense of place and acceptance within Lake Home.

A Rare Alliance, but Trust Misplaced?

One day, several months after arriving, June said, "I really don't trust the elderly people around here, though there was *one* who I got pretty close to." Rather than refer to her friend, Gladys, by name she said, "The person that sits by the window." June said that, among other things they had in common, she and Gladys were both Lutherans. She said, "I've tried to go out of my way for her, to help her in any way that I can. But that's probably over now." It turned out that June thought that Gladys had told a lie: "She's not who I thought she was and I'm not going to go out of my way anymore." Apparently, after returning from an outing, a staff member had asked Gladys whether or not they'd eaten and Gladys replied that they hadn't. But June declared that, "All we'd done all day was eat! We had popcorn—which I hadn't had in ages—and lemonade." In the absence of any explicit discussion of dementia as a cause (as noted above), Gladys' dubious report had shaken June's trust. This was a turning point. She repeated, "I thought there were some that were different, but I guess that's not the case. Now I'll keep to myself, live my own life. It's simpler not to trust anybody."

Losing Heart, Gaining Clarity About Her Place at Lake Home

Three months after June Turner's move to Lake Home, Trudy invited us to go back to June's room to visit with her and added, "You know she's trying to die in there. She hasn't been eating much; if she eats lunch then she eats no dinner. She's lost seven pounds. She's trying to die." With trepidation we walked back to her room. She greeted us and said she would like to get to her house, to dispose of some of her belongings. In fact, Tom McDermott had sold her house, which Trudy suspected to be at the root of June's depression. June insisted, "I'm not depressed or miserable; I'm a fighter—whether I win or lose." But there was no mistaking the general air of depression around June, and perhaps sensing our concern June said, "Don't mind me. I just get down in the dumps. . . . Yesterday I was out, and I got *so* lost; I've never been so lost in all my days."

She said, "I have another problem that's been on my mind. Sometimes I just hide under my yellow blanket; I try to stay warm and just hide under there. But they always come and want to change the bedclothes. I just hate this place, because that's all you are to them. Every five minutes they'll ask—from across the

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room sometimes—‘Do you have to go to the bathroom? It’s time to go to the bathroom.’ How would you like it if strangers came, and you were talking to them, and someone came in and said that to *you*? I know that I have the problem, but it’s worse when they rub your nose in it. You hear your name, and you wonder if it affects you, how it affects you. If they’d tell me straight, then you could defend yourself, if you need defending.” Reflecting for a moment, trying to put it all together, June said, “It’s just like a prison. This is a very peculiar place to live.” As she spoke June busied her hands with a task, cutting stockings off of her pantyhose so that she could wear the lower part to cover up her feet and lower legs. This way she would not soil the panty part. Staff members had suggested this as an activity of sorts, though one centered on June’s spoiled identity as an incontinent and incorrigible old woman.

A Self in Service to Others, June Helps the “New Ducks” Learn to Swim

Still, June sought other ways to define herself. New residents arrived at Lake Home and she told us that it was her role to help “the new ducks” adjust, adding, “After they’re on their own, I have little to do with them.” She seemed not to see this role as transitional, leading to close or enduring relationships; it was rather like a public service that was fulfilled when the new resident’s early days passed. We saw June assume this role with Marjorie, a new arrival who anxiously asked us, “Who *is* there to talk to in this place?” We introduced her to June. Marjorie then posed a series of questions to June; “How do *you* like it here? Do you think I should stay?” June replied, “It’s not the most pleasant place I’ve ever been in. And I *know* you’re depressed; I’ve shed a lot of tears myself here. But you’ll get used to it—you have to try because there’s no choice. Your family must want you here or they wouldn’t have sent you. The time *will* go by.”

The role of helping Marjorie seemed to lighten June’s burden for a time; it was a role that she took on, and through which she could speak, freely and without a sense of coercion. Conflict and protest seemed to fortify June’s sense of integrity and identity. But that strategy was costly in terms of her social ties and emotional stress. Still, after more than 6 months at Lake Home June conceded that “One thing that I’m not thinking or talking so much about, and that’s death.” After more than a year’s residence, and gall bladder surgery, June’s feisty self was little in evidence. She seemed increasingly reserved and resigned. By our final visits, nearly 2 years after her arrival, it wasn’t clear whether June recognized us. She could manage only tired, terse responses to our attempts to converse.

TURNING POINTS IN JUNE’S MORAL CAREER

Although June did not welcome the move to Lake Home, she made good faith efforts over many months to find an authentic place and sense of community there. Decades of independent life

with her husband, followed by her solitary years of widowhood, left her unprepared to adjust to the rigors of life as one of eight women in congregate housing. It is worth noting, as Rubenstein, Kilbride, and Nagy explain (1992), that many older adults choose and cultivate a “culture of living alone,” one that entails the exercise of mundane routines and choices—including controlling the access of people to one’s home and acceptance of lower standards of cleanliness—and whose termination may be mourned, despite declines in health or vigor.⁵

Still, Lake Home came to encompass her social world, and a vehicle for avoiding the more dreaded specter of nursing home residency. More, the formal rationale for her placement at Lake Home—her forgetfulness and struggles to manage financial and other mundane affairs on her own—became increasingly tangled up with attributions of dementia, which were both contested by staff members and hidden from June. Later, her incontinence became, by turns, a private shame, a public stigma, and a weapon by which she registered her rejection of and withdrawal from interpersonal relations.

Consider June’s situation, as she saw it. Although at first considered sharp, articulate, and “high level” by the staff, June became unhappy and puzzled about many aspects of daily life: She found neither privacy nor solitude and felt Lake Home also denied her the presence of others with whom she could converse in meaningful ways. A person of principle and propriety, June’s social world came to seem twisted: her roommate rifled through other’s belongings and ate with her fingers but was treated with weekly outings with a personal companion. Yet June, honoring social conventions—but lacking family supports—was restricted and isolated.

June nurtured a friendship with Gladys, but at the moment Gladys’s credibility faltered (by misreporting the events of a field trip), June’s faith was shaken. When asked about why she was maintaining her distance from people, she responded, “I don’t trust this place.” Two years after arrival, June’s resilience was sapped; she seemed reserved and resigned. To what extent, readers may wonder, was her decline simply explained by failing health? Would she have fared even worse in another setting? We can only reply that the narrative reflects June’s conscious, even passionate efforts to find a sense of place and friendship at Lake Home. Her struggle was marked not (or not solely) by her faulty memory or body. Rather, it was shaped by barriers to communication with other residents, and by sanctions by staff members that reflected both conflicting work demands and frustration as they confronted, with June, the limitations of their operative assumptions and interventions regarding “dementia care.” However strong staff members’ desire, ideally, to forge ties with and provide “total care” to residents, their functionally diffuse division of labor—which included domestic and clerical work that in a larger bureaucratic setting would have been apportioned to separate jobs and employees—made this nearly impossible. This is among the tensions and limitations of the model of RC/AL, at least in small settings such as Lake Home (Wellin & Jaffe, 2004).⁶

CONCLUDING REMARKS

We hope the narrative can be useful as a pedagogical tool, for engaging students and practitioners alike in dilemmas of long-term care policy and caregiving, which are less visible in other modes of research (Wellin, in press).⁷ The sequence of events that brought June to Lake Home are commonplace among people of advanced age, living alone, with few close friends or extended family members. Part of the cultural context of aging—particularly in the United States, given the institutional bias in its long-term care policies—is the protracted effort to manage at home independently, fearfully awaiting the accident or medical episode that represents a tipping point toward residential relocation. So it was with June. She was forgetful, stubbornly independent, and emotionally vulnerable after the death of her husband. Had she accepted a live-in caretaker, or acted earlier to move to a retirement community with a “continuum of care,” she might have prolonged her independence and sense of control. Instead, the combination of an acute illness (the infection in her leg), an inability to manage or organize her suburban home, and the chaos in her finances converged on her. Her attorney’s understandable worry about her safety—whether compassionate or paternalistic—was also a catalyst.⁸

Upon arrival at Lake Home, however, June’s forgetfulness and determination to preserve control took on new meaning and implications in the context of the shifting, often instrumental definitions of disease that were operable among staff. In spite of the formal (i.e., medical) account of probable dementia, staff initially viewed her as alert and competent; they voiced ambivalence about whether Lake Home was a good fit for her. Later, June’s resistance to being treated as a compliant object of staff labor or as a demented woman produced ever stronger efforts to control her and, in effect, to blame her for her troubles.

The narrative of dementia has largely been a caregiver story—one of fear, frustration, exhaustion, stress, and protracted grief (Mace & Rabins, 1981; Zarit et al., 1983). We sought to create a story that had not yet been told, with a shape whose contours were not clearly drawn or known prior to our fieldwork. Elsewhere (Jaffe & Wellin, 2002; Wellin & Jaffe, 2004) we analyze other institutional tensions and features of social organization in residential care. Given the growth of residential care as a relatively unregulated sector of the long-term care system, and the Supreme Court’s recent *Olmstead* decision (mandating that people with disabilities be housed in the least restrictive environment available), scenarios such as that described here are likely to proliferate in coming years. In turn, the practical adaptations people make to such settings and their subjective quality of life are topics of growing interest, both to researchers and to practitioners.

June’s placement and experience at Lake Home brings into greater relief the limitations of the medical/institutional model in providing guidance for dementia care. Yet the account also reveals the limitations of the smaller-scale, avowedly *social model* residential care has come to represent. Did June have dementia? Who can say? If she did, or was thought to, why did staff view her as able

to make conscious, strategic decisions about her behavior? Why weren’t they more forgiving? If she didn’t have the disorder, or was thought not to, why didn’t staff react to her situation with greater understanding? In any case, the therapeutic response centered on control for its own sake, practice without theory, a shifting definition of June tailored to be consistent with the needs and interests of others. But June’s Lake Home caregivers were not, or not wholly, responsible. Though we do not hazard recommendations regarding regulatory changes in RC/AL, we believe accounts such as this can and should inform this nascent policy debate.

June’s is an interesting case because of the ambiguity and resistance she presents. In it one sees how the imposition of control limited the possibilities for June and reinforced the conditions under which her decline seemed inevitable and consistent with organizational ideology. In June’s case, we can also see the possibilities of alternative organizational and personal responses—in which the recognition of social and mental vulnerability leads to greater efforts to support individual identity and collective community rather than undermine them in the name of organizational or profit-related expediency. If the master narrative of aging revolves around decline, then certainly the narrative of dementia is elaborated around the concept of loss—of economic resources, productivity, caregiver energy and well-being, adulthood, and selfhood. Moreover the public spotlight and alarm that dementia receives, highlighting the narrative of loss, only reinforces the hegemony of aging-as-decline. One way to challenge the ideology of aging as decline is to re-examine squarely the conventional image of the prototype, the *person* with dementia. In June’s story one sees alternatives to loss: frustration, struggle, hope, and strength. These elements are obscured by the long shadow of the medical model and the cultural model of aging as the unraveling of the fabric of life. These manifestations of selfhood are also often rendered invisible by those who speak for people like June Turner but who have never set foot on the terrains where the meanings of dementia and old age are created and navigated (Coenen, 1991). The ethnography of dementia can reveal the existence of alternatives, possibilities in which we all have a stake.

NOTES

1. All names of persons, settings, and agencies are fictitious.
2. Recent years have witnessed increasing scholarly attention to narrative gerontology (Gubrium, 1986; Kaufman, 1986; Kenyon, Ruth, & Mader, 1999) and narrative studies of identity (Ochs & Capps, 1996; Peacock & Holland, 1993). Much of this work has focused on *illness* narratives (Bury, 2001; Kleinman, 1988; Riessman, 2002). In summarizing this corpus of work, Bell (2000) argues that narrative studies have served to critique biomedical and professional definitions of disease and illness and have advanced our knowledge of suffering, “of grasping the complex inner language of hurt, desperation, and moral pain (and also triumph) of living an illness” (Frank as quoted in Bell, 2000, p. 139). There has been lively debate regarding the status and interpretation of life history and narrative

data (Bury, 2001). Peacock and Holland (1993) conclude that two approaches have been dominant though similarly myopic in their emphases: the life-focused and the story-focused approach. While the former focuses on the narrative as a "datum for learning about the external reality" of the life lived, the latter "tends to take a formalist perspective that gives primacy to the form of the narrative itself" (1993, pp. 369–370). If the first is overly objective in its aims, the second tends to equate narrative with pure subjectivity. We steer a middle course, integrating first-person reflections, field interviews, and archival data. Another example of this approach is that of Deppen-Wood, Luborsky, and Scheer (1997). Wallace (1992) cautions that narrative reflections, such as we report here, should not be assumed to be natural or inevitable for older adults, but rather a response to particular interactional and narrative challenges, such as conversations or field interviews.

3. Upon admission to Lake Home, June Turner's health status was consistent generally with a definition of "mild dementia," as described by Sloane, Zimmerman, and Ory (2001): "Cognition and language: Unreliable memory for recent events; lack of initiative for healthy daily tasks; inability to reliably manage finances, meal planning, or shopping; inability to carry on a good conversation, MMSE (Mini-Mental State Examination) score 18+; ADLs, Walks, eats, and toilets independently; may need supervision with dressing and bathing" (p. 244). However, as the narrative makes clear, June's verbal facility exceeded the norm described above.

4. Since staff often had to conduct tours for prospective clients, residents, like the house itself, had always to be "presentable" during business hours.

5. Olness and Loue (2004) address similar issues of coping with cognitive impairment in the community. Rather than extended narratives, they construct hypothetical cases to analyze practical issues and challenges that arise.

6. In the state in which this research was carried out, some 40% of these settings contain fewer than 12 beds. In some states, facilities this small are rare, in part because the profit margin is small and especially sensitive to vacancies.

7. Kane (1995) argues that developments in long-term care policy are blurring distinctions between home care, residential care, and other arrangements; the relevance of our account is thus not restricted to RC/AL.

8. Many older adults in the community receive help with such tasks from personal assistance services, which are now reimbursable in some states via Medicaid waiver programs. No such option was available for June at the time.

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