

An Ethnographic Study of Stigma and Ageism in Residential Care or Assisted Living

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Purpose: This study explored aspects of stigmatization for older adults who live in residential care or assisted living (RC–AL) communities and what these settings have done to address stigma. **Design and Methods:** We used ethnography and other qualitative data-gathering and analytic techniques to gather data from 309 participants (residents, family and staff) from six RC–AL settings in Maryland. We entered the transcript data into Atlas.ti 5.0. We analyzed the data by using grounded theory techniques for emergent themes. **Results:** Four themes emerged that relate to stigma in RC–AL: (a) ageism in long-term care; (b) stigma as related to disease and illness; (c) sociocultural aspects of stigma; and (d) RC–AL as a stigmatizing setting. Some strategies used in RC–AL settings to combat stigma include family member advocacy on behalf of stigmatized residents, assertion of resident autonomy, and administrator awareness of potential stigmatization. **Implications:** Findings suggest that changes could be made to the structure as well as the process of care delivery to minimize the occurrence of stigma in RC–AL settings. Structural changes include an examination of how best, given the resident case mix, to accommodate care for persons with dementia (e.g., separate units or integrated care); processes of care include staff

recognition of resident preferences and strengths, rather than their limitations.

Key Words: *Dementia, Long-term-care environments, Residential care settings, Stigmatization*

Stigma—the assignment of negative worth on the basis of devalued group or individual characteristics—is an ever present yet often ignored component of life for older adults. The sad truth is that, in our society, older adults are stigmatized because of myths and stereotypes associated with the very fact of being old. Further, the signs of disease or discredit associated with aging (e.g., memory loss, wrinkled skin, and functional impairment) contribute to negative evaluations that may become the core of personal identity. In this way, stigma infuses the body and soul of the individual, so that the person accepts being devalued.

Stigmatization has three interrelated components. First, dominant cultural beliefs link undesirable characteristics to labeled persons. Second, labeled persons are placed in distinct categories so as to separate “them” from “us.” Third, the labeled persons experience status loss and discrimination that result in unequal outcomes (Link & Phelan, 2001). Dominant cultural beliefs come into play at the societal level, as people become stigmatized for conditions over which they themselves have no control; this existential stigma affects the mentally ill, the aged, and Native Americans, for example (Falk, 2001).

Labeling has consequences both for those who are and those who are not yet stigmatized. Research among institutionalized older adults who are labeled and stigmatized as incompetent are likely to accept others’ definitions of them as incompetent (Grogger, 1995). Furthermore, individuals who perceive themselves as the object of stigmatizing attitudes and

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behaviors may become depressed, experience poorer function and self-confidence, have decreased social interaction, and lowered self-esteem (Charmaz, 1991; Frable, Platt, & Hoey, 1998; Hausdorff, Levy, & Wei, 1999; Link & Phelan, 2001; Link, Phelan, Besnahan, Stueve, & Pescosolido, 1999; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; MacDonald, 1988; Rosenfield, 1997). For those who are not yet stigmatized, they fear that they may acquire a stigmatizing condition—a phenomenon known as stigma consciousness (Pinel, 1999). For example, in long-term-care (LTC) settings, people who are aware that they have started to decline cognitively or physically may become defensive or avoid contact with others, fearing that their loss may become known and that they will then be labeled or not accepted (Blum, 1991; Charmaz).

The state of being stigmatized contributes to a spoiled identity in which a person is seen to have a failing, shortcoming, or handicap (Charmaz, 2000; Goffman, 1963; Jones et al., 1984). Stigma based on age is an important type of devalued, spoiled identity (Kohli, 1986; Zebrowitz & Montepare, 2000), also referred to as *ageism* (Levy & Banaji, 2002). Ageism, according to Butler (who coined the term), is “a process of systematic stereotyping of and discrimination against people because they are old” (Butler, 1975, pg. 12). The definition implies both an attitudinal and behavioral component (Kane, Priester, & Neumann, 2007). Age-stratification theorists argue that ageism is part of a social system and that members of society develop a predilection toward ageism as early as childhood, with images of the old as a homogenous group that is dependent, lonely, frail, and incapable of socialization (Bengtson, Burgess, & Parrott, 1997; Kane et al.; Riley & Riley, 2000). Because of societal behavior, including segregation of older adults into institutions or forced retirement at age 65, these ageist attitudes are reinforced in adulthood (Levy, 2003). Thus, it is no surprise that ageism is common, experienced by as many as 80% of Americans older than 60 years of age (Palmore, 2001).

Disability as it relates to cognitive and functional decline is a common stigmatizing trait for older adults (Falk & Falk, 2001; Goffman, 1963; Kane et al., 2007), especially because there is evidence to suggest that society’s response to disability differs substantially by age. According to Kane and colleagues, older adults are seen as frail and vulnerable people who need protection whereas young individuals with disability accept risk as the price of free social participation. As a result of these differing attitudes, public programs for younger disabled people in large part fund community care options and independent living, whereas programs for older disabled people fund nursing home (NH) care (Kane et al.). Thus, it is no surprise that one of the shortcomings reported of LTC personnel is that they

do not take the time to watch, stand by, or assist residents, but instead themselves make the bed, prepare the meal, and perform all tasks. This behavior is in opposition to the promoted goals of LTC, which are to improve or maintain health and functional abilities. Such promotion requires an attitude that encourages residents to do things for and by themselves.

LTC facilities house a subset of older adults who are physically or cognitively impaired upon entry and who may be most vulnerable to the negative effects of stigmatization and ageism. Unfortunately, despite their purpose to provide services and care to those in need, stigma and ageism occur even in these facilities. Decades of research in different types of LTC settings highlights the structural features that promote depersonalization, which in turn create stigma (Diamond, 1992; Dobbs, 2004; Goffman, 1961; Gubrium, 1975). Goffman’s (1963) classic work, *Asylums*, points out that certain features of institutional living, such as conducting all aspects of life in the same place under a single authority, having daily activities personally witnessed by many others, following rules and schedules, and having all activities brought together into a single rational plan designed to satisfy official aims of the institution, are largely responsible for depersonalization in LTC. Dobbs found many of these same features to be present in her ethnographic study of a residential care or assisted living (RC–AL) facility.

Research in NHs has shown that attention is often paid to dependent behaviors rather than to independent behaviors; that “elder speak” or baby talk within the NH lowers self-esteem; and that negative attitudes of staff toward older persons result in lower quality of care (Diamond, 1992; Gubrium, 1975; Kane, Kane, & Ladd, 1998; Pasupathi & Lochenhoff, 2002). These attitudes also operate among older adults themselves and their families prior to entry into a LTC facility, and in part account for the disdain felt toward LTC. For example, those who choose independent living in a retirement community, instead of a different LTC option, may be motivated to mask or hide the need for assistance as they age. Similarly, those who select RC–AL may want to appear less helpless than those who need NH care (Whittington, Ball, & Perkins, 2005).

Within the socially constructed reality of LTC, the older person struggles to manage self-esteem and personal identity. In settings with multiple levels of care, the relatively more able persons compare themselves with those who require more care, and who carry a heavier load of stigmatizing traits. They often perceive these residents as less capable and competent, and they recognize the possibility of relocation to the next level of care as decline progresses (Fisher, 1990). LTC managers further recognize that a resident’s obvious physical and cognitive disabilities could be a barrier to attracting new residents who might be repelled by such

Table 1. Facility Description

Facility Description	Valley Glen Home	Franciscan Home	Huntington Inn	Middlebury Manor	The Chesapeake	Laurel Ridge
Type	<16 beds	<16 beds	Traditional	Traditional	New model	New model
Ownership (all private)	Owner-operator	Owner-operator	Owner-operator	Family owned	For-profit chain	For-profit chain
Years in operation	11	17	34	14	9	16
Region	Suburban	Suburban	Rural	Suburban	Suburban	Suburban
No. of beds	8	8	32	35	100	112
Resident age range (years)	78–95	71–87	69–103	59–102	49–102	56–100

Note: Facility names are fictitious.

characteristics; consequently, the facility may segregate and hide these residents (Carder, 2002; Fisher).

Another stigmatizing trait that is commonly found in LTC settings is being seen as a member of a lower socioeconomic class (Diamond, 1992; Gubrium, 1975; Kane et al., 1998). Diamond's study found many instances in which residents who were financially sound and had saved money throughout their lives became penniless as they "spent down" and qualified for Medicaid. For most residents, to become poor was devastating. Even worse was when other people in the NH knew they had spent down.

Many of the preceding examples reference NHs; few address the issue of stigma in the RC-AL setting, which has grown rapidly as a supportive environment for older adults and now houses as many as 1 million individuals (Zimmerman et al., 2003). RC-AL settings are nonmedical, community-based residences that are not licensed as NHs. They provide 24-hour supervised care and assistance in activities of daily living, and they respond to unscheduled needs for support. The RC-AL industry purports to be a more homelike, social model of care that is an alternative to some of the medical and institutional care that is provided in NHs. The core of the philosophy of care in the RC-AL setting is to promote resident autonomy, dignity, and privacy through such care practices as one-bedroom apartments with kitchens, risk agreements, and flexible schedules for meals, sleep times, and wake times (Chapin & Dobbs-Kepper, 2001; Zimmerman, Sloane, & Eckert, 2001). Because of the RC-AL philosophy and values to promote resident autonomy and dignity, the extent to which it is attendant with unanticipated stigma is a relevant concern with implications for care and well-being. Thus, our purpose in this article is to examine stigma in the RC-AL setting.

Methods

Participants

In this study we examined the concept of stigma within six RC-AL communities in Maryland participating in the Collaborative Studies of Long Term Care (CS-LTC), Transitions From Assisted Living:

Sociocultural Aspects (J. K. Eckert, Principal Investigator). We purposively selected the six RC-AL settings in which data were collected from the sampling frame of the CS-LTC, reflecting the diversity of RC-AL settings: We used two "small" residences (<16 beds), two "traditional" residences, and two "new-model" residences. Traditional and new-model settings both have 16 or more beds, but the new-model residences were purpose-built facilities constructed after 1987, tend to have a registered nurse or licensed practical nurse on staff, and assist persons with more care needs. Further information about the CS-LTC facility types can be found elsewhere (Zimmerman et al., 2001). We selected the facilities to achieve diversity in terms of physical setting, background of residents, and source of payment (whether private pay or Medicaid). We selected resident cases for participation as those most appropriate for a study focusing on transitions: those who had or were most likely to experience a transition in the recent or upcoming months. The final sample for the analyses for this study included 309 participants (153 residents, 80 staff at various levels, and 76 family members) across the six facilities. Table 1 presents the characteristics of the six facilities and their residents.

Data Collection

We collected observation and interview data from April 2002 through December 2006. Research staff asked questions about daily life in RC-AL, how residents came to live in this setting, how they settled in, and how they experienced major and minor transitions over time. It is important to note that ethnographic data collected for this project focused broadly on resident transitions into, within, and out of RC-AL, not specifically on uncovering instances of stigma. We also examined facility transitions that affect a resident's life and care in RC-AL. Examples of facility transitions include the death of an AL manager, staff reorganization, new ownership of a facility, remodeling and physical expansion, and the development of a dementia care unit.

A semistructured interview guide allowed ethnographers to ask follow-up questions, thereby

expanding on informants' responses. Some individuals (including residents, staff, and family) were interviewed several times over a period of months, providing opportunities for a deeper examination of some topics, which also contributed to the trustworthiness of what we heard and learned. Family members provided information in cases of cognitive impairment.

Research staff tape recorded and transcribed the interviews, which ranged in length from 20 minutes to 3 hours with an average length of 1 hour and 15 minutes. In addition, the research staff recorded the ethnographer observations as ethnographic field notes. During active fieldwork, one ethnographer spent approximately 8 hours per week in each smaller facility and two ethnographers spent approximately 16 hours per week in each larger facility. All procedures were approved by the Institutional Review Boards of the University of Maryland Baltimore County and the University of North Carolina at Chapel Hill.

Analysis

The interview data from the 309 study participants resulted in 338 field notes or observation periods and 353 ethnographic interviews. We entered the interview transcripts and field notes into a database using Atlas.ti 5.0 for data management, coding, and analysis. Our initial analysis involved collaborative coding of the interview transcripts and field notes. Two-person coding teams, composed of investigators, ethnographers, and research assistants, independently coded the project documents by using a coding scheme that emerged inductively through review and discussion of the documents. Team members then met to reconcile differences in assigned codes. We reviewed and revised the coding scheme as necessary through periodic discussion during project meetings. We entered the coded documents into Atlas.ti 5.0 for further analysis.

We used three strategies to search the document database (field notes and formal interviews) for passages related to stigma. First, we conducted a word search to locate key words related to the concept of stigma, including *they*, *others*, *elderly*, *Alzheimer's*, and the word *stigma* itself. Second, we ran a query for passages that had been coded as *assessment of residents, dementia/cognitive impairment, medical/health/functional status, power struggles*, and *inappropriate behaviors*. We read narratives associated with these coding categories within the context of the entire case documents to ascertain whether they illustrated examples of stigmatizing actions, attitudes, and behaviors. Third, project ethnographers recalled situations involving stigmatizing actions, attitudes, and behaviors from their fieldwork, and they used word searches to locate the precise excerpt in the interviews. The

examples of stigma resulting from these analyses were then reviewed and discussed by the entire investigative team. Presented in this article are themes related to the experiences and settings in which stigma plays a part in the RC-AL setting.

Findings

Four overarching themes relating to stigma emerged throughout the field material: (a) ageism in LTC; (b) stigma as related to disease and illness (physical and cognitive); (c) sociocultural aspects of stigma; and (d) RC-AL as a stigmatizing setting.

Ageism in LTC

Some family members, staff members, and other residents had negative attitudes about aging that resulted in a generally ageist worldview. An exemplar of ageism from a family interview reads as follows: "Mr. Hill and the girls [these being RC-AL staff], they really care about the patients. They have patience. Old people can be nasty." The daughter went on to explain how difficult it was to work with older people. We also observed staff members communicating with residents' family members about care decisions without input from the residents, regardless of the residents' cognitive ability. In other instances, staff expressed ageism by interacting with residents by using infantilizing elder speak. In the following example, a staff member describes interactions with a cognitively impaired resident.

She doesn't speak . . . except to say—sometimes she says "yes" or "uh-huh" so like that, but she can follow most of what we tell her. We usually speak with her and we tell her, "You're a good girl."

One resident expressed ageism when describing how he felt about RC-AL:

Well, and of course, looking after an old person can become rather tedious and often times distasteful. And I think that a lot of people would rather, you know, farm them out, to some place where they get all the care they need, without imposing on the rest of the family.

When asked "why do you say distasteful?" by the ethnographer, the resident replied as follows:

Elderly people have accidents and have many personal needs that have to be attended to. They're incontinent and I'm sure that some people find that rather distasteful to have to look after an elderly person who has frequent incidents with—well, you know what I'm trying to say.

We also had examples of how family members actively try to protect their relative from the stigma

of ageism. Some expressed concern about the way health care professionals spoke to their relative. These families made sure that their family member was included in all discussions pertaining to his or her care and treatment. This excerpt from an interview with a family member illustrates the point:

I know they [administrators] ask me to pay the bills; you know, they thought it would be better if I paid the bills for my mother to stay over there. And I said, “my mother is quite capable of paying bills.” And I really refused. I *hate* it when they come in—doctors come in and they act like someone elderly—they don’t see them, they’re invisible. I think that is absolutely asinine. And I insist that they talk to my mother.

Another example was when the son of a resident relentlessly pursued treatment for his father’s sudden inability to swallow. Because of his persistence, his father relearned how to swallow and had his feeding tube removed. The son felt that the facility staff and his father’s physician showed age bias toward his father by not taking action to wean him off of the feeding tube.

Stigma as Related to Disease and Illness (Cognitive and Physical)

Stigmatizing labels and reactions were common in relation to disease and illness. The first of these is related to residents with cognitive disability. For example, an observation was recorded of Alan, who had been without a dinner partner at his two-person dining table since his wife left the facility. One evening he was seated with Charlotte, a resident with apparent cognitive difficulties, where upon he demanded that she be moved, stating, “How dare they put me with a woman with dementia!” The activities director replied, “You have control of your own chair and not over others.” With that, he refused to eat and left the room.

In another community, a resident was asked, “What kind of people do you think assisted living is best [suited] for?” The resident gave this response:

Assisted living is best for somebody like me—some of them in here don’t belong in here—they belong in a nursing home, or whatever you call it, where you have problems with your head—or something like that—I think. Now that’s my opinion . . . a lot of them —I say—don’t know what they are saying—don’t know what they are talking about—and I just think they should be separate from us.

We saw frequent concern about aging and forgetfulness in others and denial of the possible expression of these traits in oneself. This interview with an administrator illustrates the intolerance often

expressed by some residents toward those with dementia:

I guess you know when we reach 80 years old we’re not going to be very tolerant either. But plenty of times, now—I mean it’s certainly not the exception, it is the norm, that residents who aren’t cognitively impaired, they absolutely will not tolerate those who are. So I’ve been given ultimatums plenty of times, from other residents: “look, do something about it or I’m out of here.”

Some residents and their families showed discomfort in talking about dementia, in some cases considering it to be a contagious disease. One resident who wanted to form a group to visit the dementia special care unit in one of the new-model RC-AL settings was rebuffed when the daughter of another resident said, “Oh, no, she can’t go—we’re not going to allow her to go near those people.” Similarly, family members very often believe that their relative is not as cognitively impaired as the other residents of the facility, even though that is not necessarily the case.

There were examples among the staff of ways in which stigma could be avoided or lessened for residents with dementia. For example, staff used information about a particular resident’s preferences to relabel this combative resident as one who was “fun to interact with.” In doing so, the staff eased the resident’s transition into the setting. This seemed to be a conscious effort on the part of the staff to relabel the person as fun, rather than as the disease from which she suffered.

In some instances, dementia as a form of stigma could affect others in a positive way. For example, the woman who wanted to organize a group to visit people on the dementia care unit felt empowered to be helpful to those with dementia. She explained why she wanted to organize the group: “I like being helpful to people. There are lots of people who really need some cheering up . . . hopefully we’ll have some more people to help.”

The second stigma is related to those residents with physical disability. For example, a staff member described how a resident did not like to go on outings because she did not want to be seen with other residents using wheelchairs. A family member had this to say about her relative:

She has a thing about being in a wheelchair. So if she ever gets completely wheelchair bound—if she ever gets so she can’t walk with a walker, I think that would be another let down for her because she feels the people in wheelchairs can’t do nothing for themselves.

In one of the new-model homes, the interviewed staff member explained that people who are incontinent of bladder are for the most part accepted

by residents and staff because so many people have incontinence, but residents can be cruel at times to the people who are incontinent of bowel and those who cannot feed themselves. In one case, the RC-AL facility itself was not accepting of those who defecate themselves; a staff member describes that a resident had gotten to the stage to where she [defecated] in the bed so she was discharged to a NH.

In another new-model facility, the staff complained to the administrator that one of the residents was too overweight to lift and was bordering on being a three-person lift, and they recommended that the administrator discharge this person. The administrator agreed with the staff and defended the decision as one of abiding by the regulations, because the facility's license would not allow for more than a two-person assist. It is this very language of calling someone a "two-person assist" that depersonalizes them (Diamond, 1992; Goffman, 1963; Gubrium, 1975). One RC-AL director, when asked if residents try to hide their decline, responded "definitely." He went on to say this:

But again, it's so hard when you're dealing with the human mind that they don't want to see themselves decline, some of them understand and get frustrated by the fact that they are declining. A lot of them sink into a depression because of that—and we give them Prozac to make them happy because they are declining.

Sociocultural Aspects of Stigma

Several incidents of stigmatization that we observed were related to sociocultural characteristics. Our data indicated that attitudes involving social class and stigma ran across all three types of RC-AL settings, although in some cases they were presented more as a matter of fact. For example, an administrator of a traditional facility praised the smaller RC-AL communities for the role they provide to the lower socioeconomic class:

They [smaller RC-ALs] have a tremendous role to play ... the population that has the four or five, or six hundred dollars a month—or SSI or a small Social Security check. Those people could not afford the Marriott's and the Sunrises of the world ... [if they went out of business] who would take them for \$500 or \$600 a month? We can't here.

One resident, cognizant of her own "higher" social class by virtue of marriage and the special treatment she receives, alluded to the subtle ways stigma is transmitted:

I don't like the way they treat the residents here. It's a shame. ... If they (staff) don't like you, they find a way to mistreat you without using their

hands. ... They treat me pretty well because of my husband; he was a judge. Doctors and judges and their wives are treated differently. The girls [referring to the staff] know the difference.

This resident placed much of the blame on what she called "the upper echelon" of the RC-AL setting, meaning all levels of administration, and even "the echelon on top of them." She confirmed her appraisal, by explaining that a care aide plans to quit because "poor residents don't get as good care."

Another resident, admittedly somewhat class conscious himself, felt demeaned by the administrator, solely by virtue of his living in RC-AL. He states that the Executive Director needs to be reminded that residents are consumers, actually the employer, and tells us that

... maybe at the next staff meeting, maybe he [Executive Director] should remind them that they are here to serve us, and we are not charity patients, we are not institutional patients. We are here of our own accord and we can leave any time we want to and we pay a good bit for the privilege. They should be reminded of that from time to time.

Class issues related to stigma were not only indicative of relationships between staff and residents. One resident referred to members of her RC-AL home as "mentally slow" and attributed this to the fact that "many of the people have never been out in the world, demanding their rights." She was proud of her status, considered herself a level above many others, and treated "slow" and unworldly residents accordingly. In another instance, a female resident was critical of a table mate who chose to change her seat in the dining room because "she wanted to sit with the PhDs," shunning her former table partners for a more educated group.

Another sociocultural category we observed relating to stigma was gender. Women who wanted to sit with men at the dining table were criticized by both residents and staff for being "on the prowl," although it was perceived as natural for men to want to sit with women. Staff members, in general, were more tolerant of men's idiosyncrasies than women's. They were also more apt to use titles for male doctors (one a professor, the other a dentist) but referred to a woman with a doctorate by her first name.

Race and ethnicity were also the focus of stigma. In one setting, a family member seemed fearful of her relative's potentially negative behavior when she was describing her transition into assisted living: "I don't think she was ready for Black people yet." We also uncovered that foreign born, recent immigrant staff members were sometimes perceived as having attitudes of care toward the elderly residents that were different from the attitudes of "Americans." A

niece who oversaw her aunt's care offered a cogent example and hinted at stigma.

You know—there are certain cultures that don't give a lot of empathy to older patients—you know what I'm saying. You know they figure, you're old, you're just old. . . . You know some cultures think that when you get old—you know, this is it. You don't need all that care, that's what I'm trying to say. . . . They don't have—the warm bedside manner—no, they do not. Maybe one or two of them. But I find out if you complain too much on them, they sort of like stand off from you—you know what I'm saying.

One care staff from the Philippines explained that the American practice of institutionalizing elders is itself stigmatizing:

We in the Philippines, old people live in their own home, in their children's home. . . . Sometimes it's sad [care in RC-AL]. They feel old, I cry because the poor people. It's different. . . . It's a sad thing.

RC-AL as a Stigmatizing Setting

Some able residents told our fieldworkers that RC-AL was an oppressive environment that they oppose and that staff members “dehumanize” them. For example, on occasion, residents reported that their daily pleasures were negatively affected by facility or state rules and regulations. In some of the settings there was a rule that residents were not allowed to keep cigarettes, alcohol or over-the-counter medications in their rooms. As one resident explained, “Do you know that [facility staff] saw me—I bought an extra thing of Tylenol at the grocery store—and she said, ‘you have to put that in the nurse's office.’ And I said, ‘I don't choose to do that.’” These are things that an older person living independently would never have experienced in a private home. Residents also complained about state regulations that infringed upon their independence and quality of life:

Dr. Smith: They won't let me even have a stove that gets hot. As a matter of fact I don't, I think it's a state law against water temperature. The water is just warm enough not to be regarded as cold.

Ethnographer: You can't get a hot shower?

Dr. Smith: I can't get a hot shave or a shower.

Some residents saw the RC-AL setting as a generally stigmatizing place. A resident in one of the new-model settings said she was angry that her children moved her into this “place.” She made this statement:

Well, my children, particularly Susan, wanted me to be in a safe place because I had, had a very bad fall

and I was unconscious for two days when I was living alone, and nobody knew it. But I keep telling her now—I'm fine now and there is no reason for me to be here. And that's what everybody says in the place. They all say—why are *you* here?

In a related example, we observed the use of generic activities programming and other amenities based on a stereotype of generational preferences rather than individual preferences. A family member interviewed about his father's care said this about activities in one midsize community:

When he first got there, you know he said that he felt that his dignity basically is being degraded by the things that they want him to do, like bounce a ball on the floor. You know, take an apple and make it into a face with some toothpicks or something. I don't know. But you know that stuff that you would give little kids to do. He just felt like—that's ridiculous. Here's a guy who sat and drank Martinis all his life and played golf. Now they wanted him to make Mr. Potato Heads and bounce rubber balls.

Some facilities have policies that create stigma for residents who experience physical or cognitive decline, such as strict criteria to transfer a person from one level of care in response to decline. This transfer occurred in a larger RC-AL community that has a dementia unit, but it could not have happened within a setting that accommodates multiple types of frailty in the same common space.

In contrast, there also were situations in which administrators acted to prevent or avoid stigma from occurring. One such example is that of an administrator of a smaller home who decided against admitting a male resident in what was currently an all-female home, to avoid the possibility of one of her residents with dementia being stigmatized for disrobing behavior. As an all-female home, it was a safer and less critical place for such behavior than would be the case in a larger setting that housed members of both sexes.

Discussion

The findings that we present in this article were derived in a study focusing on transitions. In that context, the first types of experienced stigma occurred in the transition to RC-AL, and they are the stigma attached to ageism and sociocultural aspects of the person, which the individual carries into the setting from the community. Understood this way, the RC-AL setting is not curative of societal stigma. This point is reflected by the fact that three of the themes (ageism, disease and illness, and sociocultural issues) are societally based and not unique to RC-AL settings. However, such images of

the old as frail, dependent, and incapable of socialization (Bengtson et al., 1997; Kane et al., 2007; Riley & Riley, 2000) could potentially be either enhanced or reduced within the RC–AL setting (Falk & Falk, 1997).

Once a person is living there, the RC–AL facility as a stigmatizing setting operates separately from the matter of transition, as it is more a characteristic of the environment. Stigma related to transitions a person makes while within the setting is most evident in the theme of disease and illness. Because disease and illness is so pervasive in RC–AL settings, it is likely to cause stigma consciousness (the fear of acquiring a stigmatizing condition).

Efforts to combat such stigma could build off the strengths-based perspective used widely in the social work discipline (Chapin, Nelson-Becker, & MacMillan, 2006; Koenig & Spano, 2006). Indeed, some of the research in this area has been applied to older adults in LTC (Chapin, 2007; Chapin et al., 2006, Fast & Chapin, 2000), and it aligns well with the goal of reducing stigma in RC–AL settings. On the basis of this approach, staff members are advised to build on resident strengths (such as sense of humor) rather than focus on problems and limitations (such as combativeness). A poignant example of staff use of this approach in this current study is the staff member who relabeled a combative resident as being fun to interact with. Other principles to combat stigma include fostering the staff–resident relationship and facilitating reciprocal relationships so as to bolster informal supports and social interaction (Chapin et al.; Fast & Chapin).

The strengths perspective suggests a two-step process. First, cognitive reframing can help staff members recognize their prejudice related to more cognitively and functionally impaired residents and how it affects the care they provide. Then, supervisors can help staff identify the strengths and positive characteristics of each resident. Once strengths are identified, staff can promote them to the resident as well as to the resident's social group, which may result in a positive new reality for a person who typically would be stigmatized. The strengths-based approach positively frames the differences between people that foster stigma.

The most pervasive stigmatizing attitudes and behaviors appear in the context of dementia and cognitive decline. This finding is of particular concern because two thirds of the residents in RC–AL settings have probable dementia and 90% have some degree of cognitive impairment (Zimmerman et al., in press). Attention increasingly has been paid to the stigmatizing matter of dementia, with some cultures recommending a change to basic language to combat stigma (Whitehouse, Maurer, & Ballenger, 2000). For example, the Japanese government has instituted a campaign to change the words used for dementia from *chi ho* (demented) to *ninchishyo*

(cognitive symptoms; Whitehouse, 2006). Canada also has started a campaign to eradicate the French term *démence*, which is demeaning, and to identify alternative language and labels for persons with dementia.

RC–AL providers themselves may address stigma related to dementia through their structure of care. That is, settings that include only one level of care avoid the inherent threat of residents moving “back there,” but this is not the recommendation emanating from decades of experience in NH settings (Grant, 1996; Ragneskog, Gerner, & Hellstrom, 2001; Teresi, Holmes, & Monaco, 1993; Wiltzius, Gambert, & Duthie, 1981). Thus, although the structure of one level of care has the potential to reduce stigma by avoiding segregation, and to enable able-bodied residents to interact more frequently with those who are less able (Calkins, 2003), the attendant disadvantages are less cognitive and social stimulation for those without cognitive impairment and increased agitation for those with impairment (Grant; Ragneskog et al.; Teresi et al.; Wiltzius et al.). A better alternative, if resources allow, is to provide dementia care in settings dedicated to that population; unfortunately, these settings are typically more costly and do not necessarily provide better care than integrated settings (Magaziner & Zimmerman, 1994; Reimer, Slaughter, & Donaldson, 2004).

The process of how services and care are delivered in RC–AL settings also can affect stigma, particularly the role of staff members. Administrative staff are in the position to decide about resident admission and discharge (e.g., related to change in functional and cognitive status), and these are transitions that have stigma associated with them (Mead, Eckert, Zimmerman & Schumacher, 2005). This article has illustrated ways in which administrators have made an effort to accept residents who may be more difficult to care for, and also who have stigmatizing traits such as lower socioeconomic status (i.e., one home was praised for its provision of care to lower-income populations). To the extent that good care and finances allow, policy makers may want to facilitate and providers may want to adopt practices to provide more inclusive care.

In reference to stigma in daily life, stripping residents of their autonomy and offering activities that are not age appropriate is degrading and could potentially reach into the core of personal identity. Learning about a person's preferences at the time of admission, and structuring opportunities around such preferences, is supportive of personal identity and indicative of good NH care (Deutschman, 2005; Tellis-Nayak, 2007). Findings from these analyses suggest that it is important in RC–AL settings as well, and it can combat stigma. In fact, devoting effort into the provision of activities that are desired by a resident population is perhaps more important

for RC-AL, as it is consistent with the values of autonomy, dignity, and respect that are the core of its mission.

Notwithstanding limitations in research design associated with conducting fieldwork in six settings in a single state, our study has clearly identified that stigma is alive and unwell in RC-AL settings. Although RC-AL was developed in large part as a reaction to the perceived institutionalized and stigmatizing care offered in NHs (Kane & Brown-Wilson, 1993), evidence from this study reveals that stigma lives on in this setting. With its expressed purpose to support resident autonomy and independence, RC-AL may be the perfect environment to better understand how the “stigmas” associated with age, health, and personal characteristics can be better understood and combatted.

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