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Bradley J. Fisher
Southwest Missouri State University

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Bradley J. Fisher

Southwest Missouri State University
Department of Sociology, Anthropology and Social Work

Illness career descent is a process involving the downward trajectory of chronic illness and the residents' downward movement through the organizational structure of the retirement facility. This structure can be conceptualized as a "descending" hierarchy where residents experience downward mobility through successively lower statuses. These conceptualizations are grounded in three years of participant observation and interviews with over 150 residents at a multilevel care retirement facility. Downward mobility, within the facility, entails relocation to more regimented and stigmatized residency situations. The individual's goal is to slow down the pace of this illness career timetable. Descending hierarchical structures within facilities for the aged exacerbate the effects of the residents' declining health by disrupting social networks, decreasing control, and negatively affecting the resident's self-concept.

There are a variety of living arrangements for the elderly which form a housing continuum (Thompson, 1982), a health-care continuum (Koff, 1982), and a continuum of institutional totality (Markson, 1982). While there has been considerable research on the dynamics of living and dying in nursing homes

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(Gubrium, 1975; Tobin and Lieberman, 1976; Gustafson, 1978), less research has concentrated on older people at multilevel care facilities as they progress through their illness careers. Multilevel care facilities offer a research advantage since they encompass a broad range of the housing/health-care continuum within a single institution or facility.

Marshall (1975) focused on residents in bilevel care facilities and how their dying careers could be understood as a "terminal status passage". Morgan (1982) focused on the health-care careers and negotiation processes for residents within a bilevel care facility as they resisted relocation to the skilled nursing section. He described the conflictual nature of interactions between residents and staff as "...bargaining between those moving through the career and those with control over the career" (1982, p. 40). The residents' downward movement from semi-independent living to the nursing facility was characterized as being taken "...away from social independence and toward a medically determined way of life" (Morgan, 1982, p. 40).

These studies and others, demonstrate that illness can be viewed as a career or a process with a beginning, intervening stages, and an end (Manning and Zucker, 1976). Some illnesses move upward toward recovery, and others move downward toward further deterioration and forseeable death (Strauss et al., 1985). Among the elderly suffering from chronic illnesses, illness careers generally move downward (Strauss, 1973). Within multilevel care facilities, designed to accomodate the residents' increasing health-care needs, there is an organizational structure which shapes the residents' experiences of their illness careers. As their health declines, residents are *moved down* through the levels at the facility which has been referred to as illness career descent (Fisher, 1987).

This paper develops a complementary focus to prior research by examining the process of illness career descent and how it is built into the organizational structure of a trilevel care retirement facility. The social structure of such a facility can best be conceptualized as a "descending hierarchy". Relocations downward are the benchmarks of the typical illness career for residents at the retirement facility. Residents attempt to prevent or postpone relocation while staff members monitor resi-

dents' behaviors to evaluate when relocation should take place. There is an inherent conflict between consumers and those who control the provision of services in medically oriented settings (Roth, 1963; Goffman, 1961; McCoy, 1988; Zola, 1972). The structure of the multilevel care facility and its emphasis on health evaluation and relocation has a negative effect on the residents and their interactions with staff members.

Methods

For three years, I investigated the social and cultural factors affecting elderly people's ability to adjust to life in a retirement facility, Rolling Meadows.[1] Qualitative data on the retirement facility were gathered through participant observation in a variety of roles including (in chronological order): activity volunteer, facilitator of a "men's life-history" seminar, consultant/ombudsperson for residents, and as an openly declared social gerontologist doing research. Each of these role transitions granted me deeper access into the lives of the residents (and to some extent, the work lives of the staff) and built up the necessary trust to complete such a study.

In addition to participant observation, interviews were conducted with both staff and residents. Open-ended interviews were conducted with over 150 residents at the retirement facility providing information on residents' perceptions of and experience within the facility and their attitudes toward self. These interviews, lasting between 60 and 90 minutes, focused on the residents' responses to declining health of self and others, the adjustment process, placement within the facility, finding friends within the facility, interactions between residents and staff, loss of control over life activities, and the advantages and disadvantages of living within the facility. Open-ended interviews with the full range of staff members provided information concerning the formal structure of the facility and procedures for relocating residents. While interviews were conducted with both staff and residents, this paper purposely emphasizes illness career descent from the residents' point of view.

Description of the Setting

Rolling Meadows is a modern retirement complex offering multi-level care by combining a residential (230 units) and a nursing home (70 beds) facility. At full capacity, Rolling Meadows can house 300 individuals. In the residential section, residents rent their apartments rather than "buying in" with a lump sum as required by continuing care contracts at other facilities. Everything within the retirement complex is geared to the health condition of the people served there. Currently, the average age is 84.

There are three distinct types of residency: Semi-Independent Living,[2] for those who can maintain their own apartments with minimal supervision; Intermediate Care, for those requiring moderate supervision and 24 hour nursing service availability; and a Nursing Center for those requiring skilled nursing care. The various residency classifications are separated spatially: Semi-Independent Living (SIL) is available on floors 1, 2, 3, and 5; Intermediate Care (IC) is on the fourth floor; and the Nursing Center is a separate building attached to the back of the residential section. This formal segregation of residency classifications is further reinforced by separate dining facilities and activities for each group.

Findings

The Organizational Structure of the Retirement Facility

At the retirement facility, the residency classifications form a hierarchy. Hierarchies establish the relationship between individuals through a system of ranking or ordering based on some criteria of evaluation accepted as relevant within the system. There is usually agreement, or at least acceptance, of the criteria used as a basis for changing one's rank or position within the social structure. At Rolling Meadows, it is primarily the residents' level of mental and physical functioning that determines their "rank" or where they are initially located, and subsequently relocated, within the residential structure. Residents and staff at the retirement facility agree, in principle, that certain levels of health are necessary to live in certain residency

classifications. Therefore, location is used by residents to form expectations about others they may encounter at the facility. In this sense, one's health status and residency location form the basis of a general status which affects all other aspects of one's social life at the facility.

At Rolling Meadows, the residency classifications form a status hierarchy where residents "on top" enjoy greater privileges and the esteem of others without having power over those of lesser status. This status hierarchy is organized with Semi-Independent Living residents at the top, Intermediate Care residents in the middle, and Nursing Center patients at the bottom.

After relocation, residents experience a shift in status when they are subsequently viewed and treated as if they are less capable and less competent. Two residents relocated to the IC floor expressed this in the following quotes:

> The residents fight being moved to the fourth floor. It has the implication of you not being what you once were. When I was moved to this floor, I felt demeaned because they were seeming to tell me I was less capable mentally. (woman, 84)
>
> The people up here are somewhat different. I feel I was put into third class. I feel like I'm a third rate citizen. Less freedom and privileges. (woman, 86)

This diminished status is also revealed by the negative stereo-types that residents hold about those in the more regimented sections of the facility. Those on the IC floor are referred to as "those confused people", "those people who make no sense", and "those with their minds all gone". The patients in the nursing section are referred to as: "the slowly dying", "the living dead", "the crazies", or the "feeble-minded".

Hierarchies can be classified according to the type of movement of individuals within a particular social system. Open hierarchies, the focus of this discussion, can be classified as "ascending" or "descending" depending on whether the movement is predominantly upward or downward (Fisher, 1987; Fisher and Tryban, 1985). There is movement along a career path with provision for movement from one level to another. Such careers

generally form a pattern of existence peculiar to the particular requirements of a given institution.

The social structure at Rolling Meadows exemplifies the idea of the "descending" hierarchy. A resident's illness career and movement at the retirement facility are almost exclusively downward.[3] There is occasional upward movement of residents, but this is usually from the Nursing Center to the IC floor. Upward mobility usually occurs for those entering directly into the Nursing Center due to temporarily severe health problems. When their health improves, they may be moved up to the next level. Residents who have been relocated downward are rarely moved back to their prior residency classification.[4]

One's position when one enters the descending hierarchy is substantially different from one's position on entering an ascending hierarchy. One usually enters an ascending hierarchy at the bottom of the ladder. At this point, one's possession of desired attributes is viewed as low in comparison to future expectations. By contrast, when one enters a descending hierarchy, one's possession of desired attributes (e.g., health and functional mobility) is viewed as high relative to the expectation that they will decline thereafter. While individuals in ascending hierarchies usually start at the bottom and try to move up, in the descending hierarchy, most start at the top and struggle to remain there.

In ascending hierarchies, exit is viewed as a promotion or a graduation to a future promising higher *achieved* status. Progress through one's career is associated with feelings of accomplishment, mastery and success. There is reason for hope and congratulations. The nature of this exit is markedly dissimilar for those moving through the hierarchy at the retirement facility. Progress through one's career is progress down through continually lower *ascribed* statuses. Movement and exit at Rolling Meadows is mourned, not celebrated,[5] and is usually anticipated with dread and sadness.

In contrast to ascending hierarchies, where progress represents improvement and is pursued as actively as possible, progress through a "descending" hierarchy is avoided and delayed as long as possible. Downward mobility within the structure at Rolling Meadows is much more than a residen-

tial relocation. It also symbolizes an irreversible lessening of control, the stigma of being seen as less competent and less capable, and one's increasing disability and proximity to death (Fisher, in press). The resident's goal is to slow down the pace of the career timetable. This lack of progress through their illness careers is the residents' mark of success.

Illness Career Descent from the Residents' Perspective

Most of the residents at Rolling Meadows suffer from chronic illnesses and expect to experience further declines in health. This is coupled with the discomforting realization that there is no "getting better". Residents readily recognize the pattern of health deterioration followed by relocation within Rolling Meadows. This is illustrated by the following quotes from two SIL residents:

> It was hard to understand the changes when people were moved up to the 4th floor. It's awful to see people coming and going. You have to get a crust on you. Sometimes it's more than you can take. It isn't easy. (woman, 79)
>
> That's the worst thing about being here . . . seeing others going down. They come and they go. (woman, 87)

Watching the deteriorating health of other residents and their subsequent relocation sensitizes residents to the fact that this represents their own likely future:

> When I first moved here, it was hard to see people that seemed in good health and watch them slowly deteriorate and wind up on the 4th floor. You begin to wonder then how long you have before you wind up like that. (woman, 88)

The threats of health deterioration and relocation downward continually hang over the residents' heads. This fear is reinforced by an awareness that Rolling Meadows is designed to accomodate declining health or, as one SIL resident put it: "This is a place where people go and slowly get worse. A place to go and die. We're just trying to hold on to what we've got left." (woman, 78) Relocation to the IC floor is a fate that most SIL

residents wish to avoid, a fate that some perceive as worse than death as the following quote indicates: "It's the end of the road. I would never want to be moved to the 4th floor. You're almost incarcerated there. I don't think I could accept it. I'd rather be dead." (man, 82) There is even greater fear about being moved to the Nursing Center since it is associated with severe disability and the loss of dignity. "You lose all dignity there. I'd rather die a quick death than the slow death you have there." (SIL, woman, 85) The general sentiment is that the Nursing Center is *not* a place one goes to live, but to die.

Prior to relocation, residents have usually been approached by staff on specific behavioral of physical problems. Semi-Independent Living residents are aware that they are being observed and evaluated.

> They've talked to me before so I try and keep active and do a lot of things. I'm hoping that they'll see that as a sign that I'm OK. I just don't want to be moved to that floor. I couldn't stand it. I'd go crazy for sure. (woman, 79)

Knowing that one is at risk of relocation and being told one is to be relocated create very different responses. Residents at risk attempt to postpone the move by changing or hiding undesirable behavior. The threat of relocation is minimized as long as one's disabilities are not readily apparent. Impression management is crucial for residents attempting to slow down the pace of illness career descent.

> They don't move you to tho 4th [IC] floor unless it becomes visible. I don't think I'll be moved because I'm seen around a lot and am still physically mobile. (woman, 85)
>
> I don't have any physical problems but I do have emotional ones. I have to contribute to this place because I don't want them to see that I have emotional problems. Things like that get spread around and the next thing they're wisking you off to the 4th floor. (woman, 83)

Favorably presenting oneself in public is one way to prevent downward mobility, but it is not the only way. Maintaining

one's privacy is another protective strategy to avoid supplying others with information which could be used as criteria for relocation.

Resident and Staff Interactions

When people enter the retirement complex, their ability to manage daily responsibilities is assessed and then used to determine their initial placement within the facility. Residents are aware that staff members are responsible for monitoring, reporting on, and evaluating the residents' behaviors and ability to function within their residency classifications. As one SIL resident put it: "You feel like you're being judged all the time for being moved to the 4th floor. I don't like that." (woman, 82) Staff observations and evaluations, taken collectively, form the rationale for moving a resident from one classification to the next. The residents' desire to maintain privacy as a strategy for avoiding relocation downward suggests one aspect of the strain which is ever present in resident and staff interactions.

If a staff member sees a resident displaying inappropriate behavior, seeming to be ill, or acting in any way out of the ordinary, he or she is obligated to report this information to the nurses. One staff member commented on this information network:

> Any time we notice a change in behavior, or unusual behavior, we are asked to write it down. I would report an incident of something strange that had happened or at least when I notice something going on. I'll go talk to the nurses and they'll put it right in the nurses' notes to keep an eye on a particular resident.

Private information or behavior a resident may wish to keep concealed has the potential of becoming general staff knowledge. A resident's conduct at one activity or in one setting can affect how staff interact with him or her in other settings, i.e., there is a desegregation of the spheres of life (Goffman, 1961).

Residents know they are being evaluated and most recognize this as a *good* thing so the proper regimen of health-care can be provided. On the other hand, residents are also aware

that such evaluations form the basis of staff decisions to relocate residents to more regimented parts of the facility. Residents are placed in the dilemma of how much to share with staff members whom they view as friends. Staff members are in a similar dilemma. They know they must report information on the residents' conditions, but friendship with residents requires that they maintain confidences even when it overrides set facility policy.

Another aspect of staff and resident interactions in the regulation of the residents' daily activities to guarantee the smooth and efficient management of various operations at the facility. This need to control the residents' daily lives for the sake of efficiency necessarily results in a more supervised and regimented environment. Residents are aware they can no longer exert the same control they once enjoyed while living in their own homes (Fisher, 1989).

The emphasis on social control creates the potential for conflict between staff goals and the residents' wishes. Brody (1977) notes that residents who try to exert control over their lives get labeled by staff as "bad residents." Compliant residents make it easier for staff to run the facility in a smooth and efficient manner. Becoming a "complainer" results in undesirable consequences for the residents' relationships with staff as the following quotes illustrate:

> One of the nurses made a sarcastic remark about me to another nurse. I wanted to say something but I've learned to be careful. The nurses don't come around as quickly when you need them if you complain a lot. (IC, woman, 92)
>
> If they [the staff] do something I don't like, I don't say anything. They're my lifeline. I depend on them for almost everything. They're awfully good to me around here and I don't want that to change. (SIL, woman, 87)

The interactions between staff and residents are usually cordial, but are subject to periodic strains resulting primarily from the observational and evaluative responsibilities of the staff. While staff members maintain a sharp watch for inappropriate behavior among the residents, the residents seek to avoid

negative evaluations which can result in relocation to a more regimented part of the facility.

Relocation Downward and the Effect on Self-Concept

Throughout the process of illness career descent, the individual is confronted with the task of incorporating a series of life changes into his or her self-concept. Negotiating one's identity during illness career descent depends on how rapidly one's health declines. If there are long periods of stability in the illness trajectory, then it is easier for individuals to accept whatever limitations are placed on their lives. The individual has time to reflect and assess what has changed and what remains the same. If health declines more rapidly, the disruptions may be too frequent and too great for the individual to successfully integrate these changes into his or her self-concept (Strauss et al., 1985). This is illustrated by the following comment of an IC resident:

> I feel like whole bites have been taken out of me. No time to brace myself or to prepare for this. I wasn't prepared for the emotional impact. I had my world pretty well set up. It's a readjustment to go through this and I'm finding it very hard. I'm so disgusted with myself. (woman, 92)

Kaufman (1987) noted that stroke patients mentioned three major problems when discussing recovery: 1) discontinuity of life patterns, 2) the failure to return to normal, and 3) the redefined self. Illness career descent involves similar problems for relocated residents at the retirement facility. Relocated residents are confronted with the reality that their daily lives have been seriously disrupted and that resuming their previous "normal" lifestyle is no longer possible. The following comments of IC residents illustrate such an awareness:

> You can recover but you can never go back to what you were. (woman, 88)
>
> The hardest part of this illness is knowing I'm never going to get any better. I can expect to be this way or worse for the rest of my life. (woman, 90)

Residents experiencing illness career descent know their lives have been permanently altered. This poses a serious challenge to residents as they attempt to integrate declining health and resulting life changes into their self-concepts. The challenge is to build linkages between the old self and the self now reflected in their new social surroundings. Relocation downward threatens the resident's self-concept by disrupting social networks, subjecting the resident to negative stereotypes, and by eroding his or her sense of control and independence. The following quotes from IC residents illustrate this:

> My old friends don't seem to want to bother and come up and see me. Maybe they don't think I'm as with it anymore. I'm not the person I used to be. (man, 91)
>
> All you have to do is say to people here that you're on the fourth floor and they think your mind is all gone. They think everyone up here is senile. That hurts. (woman, 84)
>
> They treat us like children sometimes up here. They tell us when to eat and how to dress. I know my health isn't as good as it once was, but I like to think I can still do those things for myself. (woman, 84)

The IC residents are aware of who they were and that their lives have changed as a result of deteriorating health and relocation.

> It's terrible to be at this age and feel I have no value. I'm just useless. A dead weight. (woman, 83)
>
> I feel inadequate. That means I have nothing to contribute, that I'm not worth anything anymore. I just hate myself. (woman, 79)

Relocated residents feel they are viewed differently by staff and other residents and initially come to see themselves as somehow changed. Viewing themselves as "dead weight" or "worthless" suggests how relocation can negatively affect self-concept and self-worth.

Summary and Implications

It is the responsibility of the health professionals at Rolling Meadows to meet the ever changing health and long-term care needs of the residents. The staff members continually monitor the residents to ensure they receive proper care and to make appropriate relocations when circumstances mandate such action. Despite the fact that the residents' medical needs are well cared for, this study suggests that being in a retirement facility can have a detrimental effect on the residents' sense of self and social well-being.

Clearly there is a need for living environments which can accomodate the older individual's increasing health-care needs, but should this take priority over his or her nonmedical needs? Retirement facilities like Rolling Meadows are organized primarily to manage residents' physical health with a less concentrated focus on preserving the older person's social relationships, life activities, and general sense of social worth. At Rolling Meadows, this imbalance in priorities was reflected, in part, by the presence of only one social worker to serve the needs of approximately 300 individuals.[6]

In handling the needs of the residents, the staff members seem to adopt a crisis intervention strategy. Crisis intervention endorses an approach which is highly controlling and invasive of privacy. This is an appropriate response to a crisis which is temporally limited and is required to stabilize the individual's condition. Such an approach is inappropriate for most of the residents, however, who experience the slower more subtle, deterioration of chronic diseases. These illness careers are generally marked by gradual decline including plateaus with relative stability. During these plateaus, the individual may be able to resume a relatively normal lifestyle. To adopt a crisis intervention approach toward chronic disease unnecessarily undermines the individual's sense of personal control and disrupts his or her social activities and relationships.

In one sense, this reflects how staff and residents are both constrained by the organizational structure in which they work and live respectively. Regulations and ethics require that staff members monitor the changing health-care needs of the residents and, in some ways intrude upon their privacy. Residents,

wanting to hold on to their independence and personal control, will try to conceal health problems that may threaten autonomy. Staff members must make judgements in order to initially place and relocate residents in appropriate levels within the facility to accomodate the residents' functional capabilities. The residents, on the other hand, do not enjoy being under staff scrutiny and fear relocation and view it as a threat to their daily routine and sense of self.

Much of the problem arises out of an imbalance between the emphasis on physical health and the need for social health. Many residents perceived a lengthy illness career descent as a slow social death characterized by friends pulling away, a shrinkage of activities, and the growing stigma of incompetence. This social death undermines their sense of personal control and their ability to age and die with dignity. The impact of the organizational structure on the residents results less from the actual relocation and more from the subsequent social consequences of relocation. The key appears to be maintaining the residents' sense of personal control and keeping them *socially* as well as physically alive.

Special training would enhance staff members' sensitivity to the concerns and fears of the residents. For example, the staff could help preserve the residents' personal control by maintaining the residents' privacy to whatever extent possible and by more actively including them in decision making processes. Residents could participate in deciding when their relocation takes place rather than the usual two week notification prior to relocation. In addition, more advance notice would permit residents to prepare for the move and to develop a more positive attitude about their new residency setting. In other words, the resident should be a team member and not a mere consumer of the services provided.

Overall, this suggests a need for staff trained to help the residents adjust. In addition, staff should recognize the residents' needs not as a matter of managing crises, but as a long-term plan into which the resident will have significant input. Understanding that the residents are concerned about social well-being and physical well-being suggests that the staff should also emphasize preserving as many of the older person's life activities and

friendship networks as possible. This promotes a sense of continuity in the older person's life throughout the process of health deterioration and relocation. Residents must also participate in the restructuring of the social environment within the facility. Rather than engaging in negative stereotyping, residents can build a greater sense of community and empathy. Increased social interaction between residency levels should help reduce the sense of social isolation after relocation. Residents can also be encouraged to organize and participate in awareness groups that deal with effective coping strategies. Again, this involves the residents and gives them a sense of control over what often confronts them as a seemingly "uncontrollable" future.

As with any study based on interviews or case studies, care chould be used when generalizing these results to other retirement facilities. Further research is needed to assess the extent to which other retirement facilities have similar organizational structures and the impact these have on residents' self-concepts and social well-being. Clearly, there is a need for facilities like Rolling Meadows to develop and implement programs to help reduce the stigma and trauma of living within what will likely be the residents' "last home".

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Notes

1. The name of this retirement facility is fictitious.
2. This residency situation is actually referred to as Independent Living which mnore accurately reflects a marketing strategy. Residents are required to take three meals a day in a central dining area and depend on staff to provide them with a variety of services (e.g. distribution of medicine, transportation, etc.).
3. During my three years at the facility, there have been only two occasions where residents were moved from a lower to a higher residency classification (i.e., from the Nursing Center to the IC floor).
4. This policy is supported by staff who would rather relocate a resident once rather than moving the resident back up a level and then have the resident's health deteriorate and subject him or her to the trauma of another relocation.
5. There are rare instances where residents in the more regimented sec-

tions move upward in the facility or exit from the facility to what is perceived as a better situation. This movement upward or outward is cause for celebration.

6. This social worker was also the director of health services and spent most of her time fulfilling adminstrative duties and handling the problems of 70 patients in the nursing center. She had virtually no time to devote to the problems of the other 230 residents.