The Gerontologist
Vol. 41, No. 5, 612–622

Analysis of Key Decision-Making Incidents in the Life of a Nursing Home Resident

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Purpose: This study examined change in the decision-making autonomy of a single nursing facility resident. ***Design and Methods:*** This case analysis was part of a larger 3-year ethnographic investigation of decision-making events in four nursing facilities. In this case analysis, the resident, her daughter, and three staff members closely associated with the resident's care were each interviewed five times over a 15-month period. ***Results:*** Analysis of interview transcripts revealed four themes in decision making. Temporal change was evident in a complex scenario regarding room changes. Spatial context reflected the need for predictability and adaptability in decisions using space. Interdependence of decisions and decision makers was most evident with medical treatment and health care decisions. Awareness, being informed, and knowing what was going on was the final theme. ***Implications:*** Despite having the best interests of the resident in mind, the process of decision making in nursing facilities may contribute to a pattern of gradual withdrawal of decisional autonomy from residents regardless of their ability to make decisions.

Key Words: Long-term care, Case study, Decision making, Progressive surrogacy

For many residents, life in a nursing facility consists of a repeated daily cycle of predictable activities occasionally punctuated by a specially scheduled social event, a visit from "outside," or the stress of a health crisis. Over weeks, months, and sometimes years of residence, the repetitive rhythm and routine of each day provides a sense of familiarity and regularity, a sense of "being in place" (Rowles, 1991, 2000).

The nature of a resident's being in place is to a significant extent a function of the decision-making environment in each setting and the degree to which the resident him- or herself is involved as an active participant in decisions that shape his or her daily life and milieu. Involvement, or lack of involvement, in everyday decisions such as those involving the placement of furniture, timing of meals, choice of seating in the dining room, and routine health care often greatly affects a resident's well-being and accommodation to the institutional setting (High & Rowles, 1995; Rowles & High, 1996, in press). There is a growing literature in the domain of decision making in nursing facilities and the degree to which residents are involved (Bradley, Peiris, & Wetle, 1998; Capitman & Sciegaj, 1995; Kayser-Jones, 1995; Ryden, 1985). For example, Bradley and associates (1998) studied the frequency with which nursing home residents and their surrogates discussed with clinicians the resident's wishes concerning future treatment. They concluded that no discussions were documented for most residents. Even for those with documented discussions, conversations occurred rarely and were narrow in scope, suggesting that residents' roles in medical decision making were limited. Ryden's nursing home study revealed that caregivers saw themselves as the predominant decision makers. Only in one-to-one and solitary activities did they prefer giving residents the primary decision-making role, possibly because they viewed most residents as incapable of making decisions. In contrast, Lantz, Buchalter, and McBee (1997) found that using a wellness group to emphasize residents' strengths and their individual coping and decision-making skills assisted in counteracting the tendency for staff to control much of resident behavior. Placing decision making within a broader conceptual framework, Capitman and Sciegaj (1995) proposed a contextual autonomy model that focuses on relationships and the context of decision making involving the individual, other persons, and the social institution.

For all its sameness, the routine of institutional life is dynamic, and so are the decisions that determine

A version of this article was presented at the 52nd Annual Meeting of The Gerontological Society of America, San Francisco, CA, November 21, 1999. University of Kentucky Institutional Review Board Approval No. 99-22099.

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this routine. Regular patterns of daily behavior are gradually and progressively modified as the individual's health status and life circumstances change. With increasing physical frailty and/or cognitive impairment, decisions pertaining to the pattern of daily life evolve through a complex process of "progressive surrogacy" as control over activities and decision-making responsibility for those activities gradually shifts away from the resident toward family members and staff (High & Rowles, 1995). Individual residents may fluctuate through alternative phases of decline and recovery of decision-making capacity in various domains but, for the majority, the overall trajectory is one of reduced involvement in decisions affecting their lives.

In this article, we document aspects of change in the decision-making autonomy of a single nursing facility resident through interpretation of what are, for her, and for those who surround her, key *decision-making incidents*. In this context, an incident is liberally defined as a specific episode requiring a decision, for example, the determination of where to sit in the dining room. Such a decision may involve a series of separate interactions among the resident, family members, and staff over a number of days, weeks, or, in some cases, months.

Our objective is threefold. First, insight is provided into the manner in which an individual's life in a nursing facility is shaped by a constantly evolving decision-making milieu involving the self, family members, institutional personnel, and implicit, often taken-for-granted, institutional rules, norms, and expectations. Second, using a case study approach (Barlow & Hersen, 1984; Davis, 1991; Fielding, 1994; Meier & Pugh, 1986; Stake, 2000), we illustrate the importance of understanding decision-making processes in institutions, as they are uniquely manifest in the life experience of individual residents and their families. Finally, we present the argument that detailed understanding of decision making as it pertains to transitions in a single resident's life provides a dynamic holistic perspective on the nature of their being in place in the world of the nursing facility.

Methods

Design

The subject of the analysis was a participant in a 3-year study funded by the National Institute on Aging (Grant AG-08475; Everard, Rowles & High, 1994; High & Rowles, 1995; Rowles, Concotelli, & High, 1996; Rowles & High, 1996). Protection of subject rights in the 3-year study and in this case analysis was approved by the University of Kentucky Institutional Review Board. This longitudinal ethnographic investigation in four nursing facilities involved participant observation, event analysis, and repeated in-depth tape-recorded interviews with 64 nursing home residents older than 75 years of age and with members of the constellation of actors involved in their daily lives. For each resident, a *decision-making constellation* was defined operationally as including the resident, the resident's physician, the nursing home administrator, the nurse, the certified nursing assistant (CNA) having the most daily contact with the resident, and two members of the resident's family (including the self-identified primary caregiver). In some cases, other actors such as a social worker, minister, or lawyer judged to be involved in decision making pertaining to the resident were included.

The objective was to explore the changing dynamic of family involvement in decision making as the institutionalized relative became increasingly frail and, in the case of cognitively impaired persons, progressively less able to make decisions. Five waves of interviews (approximately 3 months apart) were conducted with the residents and the members of their decision-making constellation (see Appendix, Note 1). As interaction with participants occurred over a 3-year period of time, interviews ranged in length from 30 min to over 4 hr. In some cases, due to the participant's health condition or other special circumstances, interviews were brief. In others, where the participant became highly involved in the discussion, interviews extended over a considerable time period. In some cases, including those conducted with family members in their homes, the interviews extended to 4 hr.

Individual decisions affecting each resident's life were explored within the framework of eight categories of decisions. These categories were identified on the basis of a pilot study of two complete constellations. A series of meetings, involving all six researchers involved in the larger study (see Appendix, Note 2), were held in which information from the pilot interviews and material developed from extensive review of extant decision-making and nursing facility literature were used to develop a comprehensive listing of decision categories. The 87 different types of decisions identified through this process were then grouped into eight levels of decisions, which remained fixed throughout the study.

According to our *a priori* criteria, *crisis and life-and-death decisions* included foregoing or avoiding life-sustaining treatment, cardiopulmonary resuscitation, do not resuscitate orders, and intravenous or tube feeding. *Mental competence* was defined as including guardianship, durable power of attorney, confusion, and decision-making capacity. *Transfer decisions* were defined as including hospitalization, discharge, or room changes within the facility. *Financial decisions* were defined as including payment to the nursing facility, "spend-down," and management of income or assets. *Medical treatment and health care* were defined as surgery, medication, physical therapy, occupational therapy, use of assistive devices, and routine health maintenance. Decisions regarding the *social environment* were defined to include selection of roommates, resolution of roommate problems, participation in social activities, dining arrangements, relationships with other residents and staff members, and recreational activi-

ties. Decisions regarding the *physical environment* were defined as those involving arrangement of furniture in a resident's room; temperature control; display of personal items; ownership and placement of a television, radio, or telephone; and room maintenance and cleaning. Finally, *daily living decisions* were defined as the timing of activities, access to facility resources (e.g., the telephone), food choices, selection of clothing, bathing schedule, hair care, maintenance of privacy, smoking, kitchen privileges, and other everyday choices affecting residents' quality of life.

Sample components of the protocol provide an indication of the types of questions posed. The first component involved identification of decisions in the previous 3 months for each level of decision making. Acknowledging concerns about the long-term recall of everyday mundane decisions, such as decisions about the physical environment and daily living, participants were asked to recall decisions made in the previous month.

Once a decision had been identified, the interviewer used a second component of the protocol to explore the characteristics and circumstances surrounding the decision and the level of involvement of each member of the constellation. Probe questions included: (a) "What decision was made?" (b) "When did this occur?" (c) "What were the circumstances that led to this decision?" (d) "Who was involved in making this decision?" and (e) "How much were you involved in the decision?" In addition, participants were asked to describe the process (sequence of events/meetings) by which the decision was made. Particular attention was given to the role of family and friends. Probes here included: (a) "How much were family members or friends of the resident involved in the decision-making process?" (b) "Which family member(s) or friend(s) were involved?" and (c) "How were they involved?"

The next section of the protocol addressed the involvement of staff. Participants were asked, "Did any member of the staff who was unrelated to the resident act like a family member?" They were also asked to comment on how they felt about the decision and the degree to which family members were involved. The same overall protocol was used for each participant with only minor and necessary word changes to make the protocol appropriate for each person interviewed.

Analyses of the complete data set are reported elsewhere (see Everard et al., 1994; High & Rowles, 1995; Rowles & High, 1996, in press). At this point, we have begun in-depth review and analyses of the decision-making experiences of individual residents to provide a holistic perspective on their immersion within the nursing home milieu. Edna is one of these residents (see Appendix, Note 3). Our study of Edna was undertaken in order to investigate and understand, in detail, the life of one resident viewed within the context of her decision-making constellation. In studying a single nursing home resident, we were concerned with the "confluence" rather than the "influence" of variables (Sandelowski, 1996, p. 526). "In the rush to find core variables, recurring themes, and transferable concepts, analysts of qualitative data too often miss the idiosyncratic, unique, and non-fungible features of cases that give them their integrity, and make them so valuable for study" (Sandelowski, 1996, p. 525). This perspective is more contextually sensitive and discriminating in revealing nuances of an individual's institutional life than are most sample- and population-based studies. Indeed, we suggest that detailed study of an individual resident's life can provide a mirror of broader concerns regarding the conduct of institutional life (Hunter, 1989; Tanner, Benner, Chesla, & Gordon, 1993): It facilitates the translation and representation of personal troubles as societal concerns (Mills, 1959).

We selected an individual rather than a particular facility location or time period as the unit of analysis because we were concerned with viewing decision-making processes surrounding and involving individual residents within a holistic context. The life of a nursing home resident, such as Edna, tends to be focused on the limited number of individuals with whom he or she comes into routine daily contact. In contrast with community-dwelling elders, nursing facility residents tend to inhabit a naturally bounded behavioral and social world that can be both conceptually and operationally defined. Hence, we determined that it was appropriate not only methodologically but also substantively to focus on the individual.

Edna was selected because she was cognitively intact and was particularly articulate throughout the entire study. There were five interviews with Edna herself, as well as a complete set of interviews with several members of her decision-making constellation over the 15 months of data collection. Many residents were cognitively impaired at the beginning of the study or developed memory difficulties or physical ailments that prevented them from completing five interviews. We now turn our attention to Edna and to the decisions affecting her life in a nursing facility.

Case Study: Edna

Edna Wishart was born in rural Fenton County and lived there for nearly 60 of her 88 years. She taught school for 34 years. Married for 58 years, she had one daughter, Joyce, a son-in-law, and a granddaughter. As Edna entered her 80s, her health and that of her husband, Albert, declined. Following several acute illness episodes resulting in hospitalization, the couple moved together into a nursing facility in Gloucester, the county seat.

This arrangement worked well until Albert's health began to decline more rapidly and he needed cancer treatment that could not be provided by the facility. At this point, Joyce arranged for her parents to move to Concord (Joyce's hometown, about 1.5 hr from Gloucester), where Albert entered a nursing facility providing a higher level of care. Edna moved

in with her daughter. This arrangement was a temporary solution, allowing time for Joyce to arrange for her parents to be in a room together in another Concord nursing facility, Elizabeth Manor. "We closed up everything in Gloucester (their lifetime home), auctioned it, kind of closed that chapter for her."

Shortly after the couple moved to Elizabeth Manor, Albert died. Edna left the facility, once again spent a few months living with her daughter, and subsequently moved to an assisted living facility. After an acute episode with a bleeding ulcer, she returned to Elizabeth Manor where, at the commencement of our study, she had been in residence for almost 2 years. Against the backdrop of this profile of Edna's personal history and life circumstances, we offer an analysis of the institutional decision-making context and processes of decision making that shaped her life in Elizabeth Manor.

Analyzing the Data

Data collected on Edna comprised a total of 28 interviews: 5 each with Edna and her daughter and 6 with the nurse, the CNA (see Appendix, Note 4), and the administrator/social worker. Each interview was transcribed verbatim. First, Edna's transcripts and those of each member of her decision-making constellation were read. An initial line-by-line coding generated many categories. These categories served to inform our subsequent analysis of interviews and transcripts. Then coding was completed for each actor in the constellation to characterize that person's role in decision making involving Edna. A second phase of analysis involved organizing and reading the transcripts in chronological sequence (Wolcott, 1994) in order to obtain a sense of the unfolding of decision-making events during Edna's residence as they occurred over time. Again, line-by-line coding was used to identify categories and retrieve chunks of data pertaining to specific emerging themes. Third, the conceptual framework of the eight decision-making categories provided a guide to analyze the data. Worksheets were developed to summarize the data concerning each of the eight main categories of decision making. However, we were also attentive and sensitive to additional themes that emerged in addition to those revealed within the rubric of the eight decision-making categories. A final phase in data analysis involved detailed discussion among us about the data and emergent categories and themes. Efforts were made to progressively move the analysis from description to more abstract and higher levels of understanding and insight. Table 1 provides examples of the progression of coding and theme identification from participant statements, through the detection of themes, to higher and more abstract levels of revealed meaning.

Findings

Overview

Overall, the pattern of decisions made affecting Edna reflected the partial and ephemeral involvement of diverse members of her constellation in different decision-making incidents at different points during her tenure at Elizabeth Manor. The nursing home administrator was involved in few of the everyday decisions directly affecting Edna's quality of life. Pat, the social worker, was involved in some categories of decisions and was a significant participant in the decision-making process surrounding Edna's desire for a room change. Joyce was more fully and continuously involved in multiple categories of decision making regarding Edna, although she seemed to have a "snapshot" view of her mother's life in the nursing home derived from visits of about 1 hr two or three times a week. More intimately involved on an ongoing basis were the nurse and especially the CNA, who spent the most time in direct contact with Edna. Finally, as was revealed through the series of interviews, Edna herself felt ambivalent and progressively less involved in decisions affecting her life as time passed. In the initial interview, she clearly indicated her active role in the decision to enter the facility.

> I didn't want to stay with my daughter . . . . They both work and I just feel like they have their friends and they're just as good to me. I stayed down there 3 months. I just felt like I was kind a fifth wheel.

But by the final interview, her growing ambivalence and passivity were evident from an equivocal and pensive response to the question of the degree to which she had been adequately involved in decisions. "I guess I have. If it had been left up to me? If I'd have made the same decisions that have been made or not? . . . I've accepted them. Let's just say I've accepted them."

As our analysis proceeded, themes of *temporal change, spatial context, interdependency,* and *awareness* in decision making emerged as major compo-

Table 1. Coding

First Level: Participant Statements	Second Level: Themes	Third Level: Revealed Meaning
"I just want to move."	Temporal	Honor my preferences while I can express them.
"Somebody's sitting in my seat."	Spatial	I need my own personal space, especially at mealtimes.
"They just came and told me . . . . They don't ask you nothing. They just come and tell you what you are going to do."	Interdependence	My involvement in decision making is slipping away.
"I'd rather know what is going on."	Awareness	I'd rather know what is going on.

nents of the decision-making trajectory that shaped Edna's life in Elizabeth Manor. All four decision-making foci serve as exemplars of more general themes posited to underlie the process of progressive surrogacy in nursing facility decision making.

Honor My Preferences While I Can Express Them: Temporal Theme

"I just want to move."—The scenario began with a simple request from Edna, "I just want to move," reported by Pat, the social worker (November 20, 1991). Pat talked with Edna and probed to find the rationale for her request to move to Room 16 (from a private to a semiprivate room). Aware of Edna's financial situation, Pat thought money might be the reason. Pat then talked with Joyce and explained that she thought there would be conflict with the current resident of the room.

Joyce added another dimension to this picture. In an interview approximately 2 months (January 29, 1992) after her initial discussion with Pat, she reported, "Mom decided a private room was too costly so she started scouting around looking for openings, rooms, semiprivates. She initiated the discussion with Pat." During this interview, Joyce reiterated that her mother was "private pay" and was aware she needed to make her money last as long as possible. Joyce confirmed that Edna did, indeed, find a room—Room 16—which happened to be where she and Albert had resided when they first entered the facility, and the room where he had died. Joyce reported,

> Pat was a little bit concerned about the person she'd be in the room with, but Pat did not say, "Don't do it." She just said, "Let's think about it a little bit longer and let's see, you know, what comes, what happens, what develops." Pat and I talked and Pat expressed the concerns that she had also expressed to Mom about the lady who's in the room not being coherent and not being, perhaps, a suitable roommate for Mom. I also reminded her that Mom likes the privacy of her bathroom and that she would have to share a bath if she went to another room. (January 29, 1992)

Following this conversation, Pat and Joyce talked Edna out of moving to Room 16.

> The three of us never sat down and talked. Pat talked with Mom quite a bit and then I talked with both of them, but we did not sit down as a threesome. So Mom decided that she would wait and Pat's concern was that if all of the rooms become Medicare approved, if Mom's money, since she's on spend-down now, that she would not have to move. That was what Pat was hoping, you know, that she'd be able to stay in the room she's in.

Several months after this interview, Joyce confirmed her mother's continuing concern about moving to a semiprivate room to perhaps save money. "She's had this idea some time that if she moved to [a] semiprivate room it would be half the cost" (August 17, 1992). (In fact, moving to a semiprivate room would not have halved the cost, but differing interpretations of this issue confounded and complicated the decision-making process for Edna, Joyce, and Pat.)

Nearly 1 year after Edna's initial request, she was finally transferred from her private room to a semiprivate room after she reached her spend-down limit and became a Medicaid recipient. Pat shows in an interview conducted about this time:

> The major decision in the last 3 months? To transfer from one room to another, from a private to a semiprivate. You probably have this, what's funny, well, it's not funny but what's interesting is you probably have the same interview information way back when, when she wanted to move and we didn't think she should and now I wish we would have let her move . . . . I've learned my lesson to listen to the residents (November 13, 1992).

Three weeks later, Joyce also expressed regret about not listening to her mother's initial request and the missed opportunity for autonomous decision making and respect for Edna's self-determination.

> Now she's a Medicaid patient . . . . I think it would have been better if she'd gone ahead and moved at that time [initial request] . . . . Pat told me she learned a lot from this experience . . . and the fact that she needed to listen to residents more . . . . It was hard to figure out her thinking on that [financial], but the fact . . . is that there was a bed available. It was over by the window and it was the room she and Dad were in. Now that was my problem with the room . . . . Well, she'd be in the bed where Dad was . . . . I think it would have been [hard on her] and Pat did too, once we talked about that. She [Pat] was also concerned about her being in the room. Pat wants her to be in a room with someone who's coherent . . . . The important thing about this is that Mom made the decision. She was ready to move [initially] and we took it away from her. And that is why Pat said we both learned. We should have let her; that was very important to her and we just took it away (December 4, 1992).

Surprisingly, Edna herself provides yet another perspective on this room change decision-making process. What was critical to her about Room 16 was her knowledge of space in the room, particularly the bathroom. She also expressed her loneliness in a private room, yet staff reported how Edna seemed to like privacy and often stayed in her room. In an interview when she finally moved (as it turned out, into another private room), Edna reflected on the experience.

> The girls helped me move . . . . Oh, I just moved here [present room]. I wanted to move back over in 16, over on the other wing, and she [Pat] came in here and talked me out of it . . . . They didn't know I'd get along with the one that was in the room or not and I don't know but I would have and so she said, well,

> I'm not going to bother you anymore. She, Pat, told me that she saw where she didn't listen to the resident and made her own decision. If she had listened to me, it would have been better if I moved over there. I didn't want this high-priced room. I didn't care about being by myself. I didn't care about staying by myself. It got kinda boresome sometimes. And I'd been in that room over there [16] and I knew I could get around, how to manage, and there was just two people using the bathroom and nobody else, and it was a larger bathroom, too (December 1, 1992).

Viewed in a longitudinal context, this was a situation in which Edna tried to be proactive. She had intimate knowledge of the layout of Room 16 because she had shared it with her husband. She knew she would only have to share the bathroom with one other person. Both factors were important to her. However, Edna found that she had little say in the move. Only after the fact did Pat and Joyce realize that Edna had sound personal and practical reasons for her request.

I Need My Own Personal Space, Especially at Mealtimes: Spatial Theme

"Somebody's sitting in my seat."—Decisions in nursing facilities are made not only over time but also in space. Indeed, time and space are intimately interrelated, as was clearly revealed in the room change decision. A number of decisions pertinent to Edna's life concerned her use of space in Elizabeth Manor. Like most of Elizabeth Manor's residents, Edna was concerned with seating arrangements. Seating arrangements, especially for mealtimes, involved complex, partly implicit, and generally taken-for-granted norms and rules of behavior that were part of the ritual and culture of Elizabeth Manor. The identity of this environment as a behavior setting (Barker, 1968; Norris-Baker, 1998) depended on conformation to the established patterns.

Disruption of established territorial imperatives could occur quickly and be a source of considerable distress to residents. The nurse who worked most closely with Edna reported that, on at least one occasion, Edna had been adamant about her position at her table in the dining room. "Somebody's sitting in my seat and I've been there for 2 years. I don't like it." The CNA who spent the most time with Edna made a similar observation: "The only thing she gets upset about is, if the seating arrangements [have] been changed at her table. She outwardly seems like she likes everybody, but you can tell from her attitude and eyes she doesn't care for someone." As Edna's daughter, Joyce, explained, "You don't realize what a big deal it is of who's going to be sitting where at meals. It's a big deal, you know. I guess we're creatures of habit." As residents possess so little, the importance of predictability of places at the eating table may become critical in the daily life of nursing home residents.

Paradoxically, the interviews acknowledging territoriality also revealed flexibility and adaptability of patients and staff. Edna herself reported, "Well I just moved around. I'd go in and they'd be in the place where I sat. Someone would be there and I'd go to another place . . . . I think I moved three times." Edna's flexibility was perceived by staff as indicative of increasing sociability. As the CNA noted, "Lately she's been changing her seating. She's kind of been socializing a little bit." The nurse who worked most closely with Edna also confirmed that: "She's been a little more social. She still sits at the same place but we have a new resident who is 'with it' and she and Edna sit together and talk."

Not all the members of Edna's decision-making constellation were as perceptive regarding her spatial preferences. Pat admitted she was neither involved nor at all enlightened about the process of decision making for seating arrangements.

> I got the whole seating arrangement in the whole place mixed up. It's amazing what these sitters [CNAs] know. I'm not sure why [they sit people where they do]; they may know, but just don't tell me. Or I just don't ask the right questions.

Joyce was similarly mystified, although she acknowledged the importance of seating arrangements. "It does somehow [get decided] because they all have their space and it's just interesting."

As with decisions about room changes, there were divergent opinions about who made decisions concerning seating arrangements in the dining room at Elizabeth Manor, and the process whereby such decisions were made. On one hand, Edna felt she made her own choices about where to sit. On the other hand, as Edna's nurse stated, "We [nurses and assistants] kind of make the decisions [regarding seating for residents] between us." She explained that the nurses are concerned about the residents' food intake, thus they readjust seating arrangements to enhance food consumption: "The staff were trying to find a spot for Mary, who was not eating well. But putting Mary and Edna together did not work. Edna left the table." In this case, the defining factor is the decision-making capability of Edna herself. She is mobile in her wheelchair and her cognitive abilities are intact, so she exerts more choice in her seating arrangements than many of her fellow residents.

My Involvement in Decision Making Is Slipping Away: Interdependence Theme

"They just came and told me . . . . They don't ask you nothing. They just come and tell you what you are going to do."—A changing pattern of interdependence, both across decisions and among decision makers, in negotiating transitions in Edna's decisional autonomy is illustrated by analysis of incidents pertaining to her medical treatment and health care. Decisions about Edna's health care, medicines, and needed diagnostic procedures became increasingly prevalent over the 15 months of the study. The pattern was consistent with a trajectory of growing

decisional dependency as her health declined. The degree to which this represented a voluntary rather than an implicitly enforced trend resulting from benign concern on the part of staff is unclear. It emerged that decision making involved a progressively increasing degree of interdependency, both of actual decisions and among decision makers, in her decision-making constellation, as the various actors in Edna's life tried to adjust with sensitivity to her declining capabilities.

During the first round of interviews, Edna was relatively healthy, according to most members of her decision-making constellation. But by the fifth round of interviews, Edna had experienced a kidney infection (resolved with antibiotics), a bout of pneumonia from which she did not seem to fully recover, and a period when she was obliged to wear an incontinence protective undergarment.

One outcome of these episodes was that, after each one, it took Edna longer to return to her previous level of functioning. More important to the focus of this study was Edna's changing role in making decisions affecting her physical well-being as her illness episodes accumulated and her frailty increased. As time passed, Edna's involvement was marginalized as her autonomous daily health care decision making met with progressively less support and cooperation from other members of the decision-making constellation. This was exemplified at the time of a visit to her brother. Edna's nurse reported, "She refused her Lasix because she was going to her brother's and didn't know if she could get to the bathroom OK." Taking Lasix, being confined to a wheelchair, and getting quickly to a bathroom are not always compatible. Indeed, this presented a daily challenge for Edna. Consequently, she exerted her own decisional independence in deciding not to take the medication on this particular day. As the nurse said, "Edna flat-out refused." Had Edna still been in her own home, she most likely would have self-regulated her medication for this outing with her brother. However, in an institution in which adherence to medication orders is considered a priority, decision-making autonomy was viewed negatively as a "patient refusal" rather than an expression of independence.

As Edna became more vulnerable as a result of illness episodes, her decision-making autonomy was increasingly threatened. Her need to take large doses of Lasix made it increasingly difficult to get to the bathroom without assistance and without episodes of incontinence. On the surface, the staff and Joyce tried to respect Edna's personhood, to treat her with dignity, and to sustain her decision-making autonomy as much as possible. Indeed, there was evidence of hesitancy and discomfort on Joyce's part as she tried to sensitively negotiate this situation and make a decision for her mother and yet maintain her mother's sense of autonomy.

> Mom complained about pain in her legs, and the doctor ordered massive doses of fluid pills. Mom was trying to get to the bathroom, but we were having accidents all over and she was getting a bit frustrated. So I talked to her. I suggested that maybe she might want to start wearing Attends, *temporarily*, until she gets so much fluid out of her.

Joyce may have viewed wearing the incontinence protective undergarment as temporary. Yet, in all probability, given her declining level of cardiac functioning, Edna's ability to clear fluids was likely to become an ongoing challenge. The CNA most responsible for Edna's care also gave a supportive rendition of her role in gently negotiating this decision-making situation.

> I just tried to take care of it as professionally as possible because I know incontinence is, you know, kind of embarrassing, so . . . something to do with self-confidence . . . try to keep her from being embarrassed, you know, having to wear them. Dignity . . .

It is important to acknowledge the magnitude of a decision to wear an incontinence protective undergarment. In many respects, it represents a turning point widely recognized at Elizabeth Manor as a marker of dependency. It is significant that Edna never mentioned wearing incontinence protective undergarments although she did admit, "I had the flu. I was very sick and got IVs. I didn't remember a lot of things. The doctors and nurses told me things."

Understanding the delicate interdependence of people comprising Edna's decision-making constellation (including Edna herself) as they negotiate different situations is facilitated by viewing individual incidents within the broader context of the trajectory of her life as a resident of Elizabeth Manor. Individual decision-making incidents are part of a mosaic of interrelated changes that mark the resident's evolving status. Each decision involving Edna, in the benignly controlling cultural milieu of the nursing facility, was subtly related to every other decision because the same actors were generally involved. Moreover, each decision provides a template for framing subsequent decisions within the trajectory of a resident's life.

For example, Edna's episode of pneumonia occurred after her room change. As the nurse reported,

> First, she got very sick. She had pneumonia. She needed IV antibiotics because she was so nauseated she couldn't keep the oral medication down. She was pretty bad for about 2 weeks . . . . I think it all had to do with [her] room change and her sickness, because for a while we had to take her to the bathroom and Edna's always done that for herself. Well, now she's gotten back to where she's taking herself to the bathroom and she's not wearing Depends anymore, so I think it was a temporary thing due to her sickness and all that room change.

Another factor contributing to Edna's pneumonia and to her physical decline was identified by Joyce. "She started wearing Attends, about 1 month ago. It was soon after Mrs. Baumhover's death." Mrs.

Baumhover was a resident with whom Edna had developed a strong friendship. She had stayed at Mrs. Baumhover's bedside for days while she died. Joyce and the CNA were the only members of her decision-making constellation who reported on this experience. As Joyce expressed,

> She sat with her . . . . In those last days I think Mom spent most of the time holding her hand and talking with her. The night Mrs. Baumhover died, Mom told me they wanted her out of the room but she told them no, that she was on her side, and they had the curtains closed and she held her hand. It was really sweet, you know. I told her, I said, sometimes, Mom, we don't know where we're placed—that maybe we're there for a reason. And Mrs. Baumhover's daughter was sick and her granddaughter could not be there, so after the death she got this touching note from both the daughter and the granddaughter.

As the CNA noted, "The death of Mrs. Baumhover was very hard on Edna." She attributed Edna's decline in health and her pneumonia to difficulties coping with her room change, the stress of the last days of her relationship with Mrs. Baumhover, and associated strain on her adaptive capabilities.

I'd Rather Know What Was Going On: Awareness Theme

"I'd rather know what was going on."—Another decision-making incident associated with Edna's physical decline and change in the nature of her interdependence with those around her involved the deterioration of her eyesight. As Joyce explained,

> She started, probably in April, mentioning that she was having some trouble seeing with this, this left eye. But she was going to wait till I got out of school [Joyce is a schoolteacher] before we did something about it. Then I think the first of May she was noticing a noticeable difference. She talked to the [physician assistant] . . . and the next thing I know she had an ophthalmologist appointment for May 19.

What occurred at this appointment provides a clear illustration of the subtle, sometimes unknowing ways in which decisional autonomy is wrested from nursing facility residents as their frailty increases. Edna was very pleased with the ophthalmologist. He took lots of time to explain to her, in the presence of her daughter, what was going on with her vision. When she asked about surgery for the cataract on her "good" eye, the ophthalmologist indicated that this could wait a while. He gave Edna a chart she could look at to determine if she was experiencing further deterioration and suggested that he be called immediately if significant change was noted. This level of concern was greatly appreciated by Edna. But she had not been given the complete story. What the ophthalmologist reported separately to Joyce was that her mother was experiencing macular degeneration in the good eye, too, and in a matter of time would completely lose her sight in that eye as well. This example of withholding information was perhaps well intentioned but reflects the manner in which decisions began to be made without the involvement of the nursing home resident. This incident is especially poignant because Edna herself was aware of the degree to which decision-making autonomy was being benignly removed from her as she became more frail and vulnerable. As she noted on more than one occasion, "I'd rather know what was going on."

Discussion

In this case study, we identified features of the processes whereby decisions were made affecting the quality of life of a single nursing home resident. These decisions were made within a specific physical and cultural space—the nursing facility—that supported an implicit, often taken-for-granted decision-making milieu. Decisions affecting Edna were made in the context of a constantly evolving interdependency between Edna and those who surrounded her. Each member of Edna's decision-making constellation had a different level of awareness (or lack of awareness) of her needs and aspirations. Each, including Edna herself, held a different view of the relative importance of particular choices affecting her life. Each held a different image of her capabilities. And each was involved, to a differing degree and with a differing level of intensity over the course of time, in the various domains of her life at Elizabeth Manor.

Our strong impression is that all the people involved in Edna's life at Elizabeth Manor had her best interests at heart. Their involvement in decisions, however, sometimes more reflected of institutional, professional, and personal norms and expectations than fully informed understanding of Edna's wishes.

Within this rubric, our descriptive analysis provides insight into the manner in which decision-making processes in nursing facilities contribute to progressive surrogacy as resident frailty increases. In most cases, this process is benign. It embraces change, often a gradual and subtle movement toward increased dependency in the interdependent relationship between the resident and members of his or her decision-making constellation (Lowry, 1989). Such a transition is appropriate when the resident is cognitively impaired or becomes increasingly impaired over the course of residence. In such cases, there is generally clear evidence of an individual's inability to make decisions with respect to specific domains of life.

Our analysis of Edna, *who was not cognitively impaired* except for a brief period during an episode of pneumonia, suggests that removal from decision-making autonomy may be a generic feature of nursing facility life. In spite of increased awareness of the perils of "total institutionalization" (Goffman, 1961), it appears that an ethos of benign progressive surrogacy and the erosion of resident autonomy re-

mains ingrained in nursing home culture in ways unrelated to cognitive functioning (Agich, 1993; Kane & Caplan, 1990; Lidz, Fischer, & Arnold, 1992).

However, erosion of resident autonomy related to cognitive functioning is not ethical and must be challenged. There is realization and justification of the importance of resident autonomy in decision making. Programs to enhance caregivers' sensitivity to residents' concerns (Kelly & Lazaroff, 1993) and models to create a community of caring that is autonomy enhancing (Roth & Harrison, 1994) are examples to catalyze change. Even though respect for autonomy is realized and acknowledged, action is not always initiated. For example, Whitler (1996) reported that although nurses described specific ways to preserve and enhance personal autonomy, they did not use these strategies in their daily practice. However, bridging this gap between awareness and action is critical to preserve autonomy in elderly individuals. It is hoped that this case study about Edna will become part of this catalytic change so that institutionalized elders can remain autonomous as much as they are able for as long as possible.

There are limitations with respect to the degree to which case study findings that reflect Edna's experience can be generalized to the complete sample of 64 constellations involved in our study, or inform us about nursing facility populations in general. For example, during our interviews elderly residents may have become fatigued to the point that they were not able to give a full account of the intricacies of their decision-making experiences. Edna and the other residents, as well as the other individuals in their decision-making constellations, may not have recognized all of the decisions (both implicit and explicit) that were actually made. The data almost certainly do not capture the full array and subtle complexity of all possible decisions affecting each resident. Participants may also have felt that it was more relevant to focus on major life and death decisions than to go into everyday decisions, even though such decisions may have been important for their quality of everyday life. Further in-depth case studies of individual nursing facility residents and their involvement in decision-making situations could considerably add to the body of knowledge about decision making in a nursing facility. Such studies should also focus on those who are cognitively impaired.

Even in the absence of such studies, Edna's case provides a mirror of broad concerns regarding the conduct of institutional life by clearly demonstrating that although she was competent and cognitively intact, her decision-making autonomy was not fully acknowledged. The staff and Edna's daughter did make attempts to involve Edna, to listen to her. But Edna's voice was not heard and was not viewed as a critical element of decision making affecting her life. This is a reflection of the propensity of most nursing facilities to remain institution rather than resident centered (Happ, Williams, Strumpf, & Burger, 1996; Lustbader, 1996).

A shift in orientation toward a person-centered philosophy allows the experiences and preferences of residents with regard to decisions affecting their lives to be more widely and routinely acknowledged and integrated within the daily life of nursing facilities (Evans, 1996). Future directions in individualized care might include a willingness to more readily acknowledge the face-value legitimacy of cognitively intact residents' statements and requests. Even if residents are compromised in some aspects of their self-responsibility and decision-making capability (e.g., with regard to financial matters), they should still have a say about what they wear, where they sit at meals, and how their possessions are arranged in their rooms. It is critical to acknowledge that decisional impairment is a multilevel concept; residents may remain fully capable of making decisions in some domains of their lives although decision-making ability in other domains may be compromised. Moreover, as Capitman and Sciegaj (1995) noted, even persons with cognitive or psychiatric disabilities have life-long habits of self-care and continuing preferences about daily tasks that may make the indignities often associated with professional care even harder to endure. Such habits can be mapped and explicitly incorporated into care plans (Happ et al., 1996). Such mapping may be facilitated by consistent staff assignment to specific residents, allowing aides to develop awareness of each resident's capabilities and potential and enabling them to work out idiosyncratic ways of getting things done in a manner consistent with residents' abilities and preferences (Lustbader, 1996).

Most important is the need to assiduously work toward the creation of decision-making environments in nursing facilities that explicitly establish an ambiance of supportive and consultative interdependence. Rather than kindly paternalistic care that reinforces learned dependency, there is a need for an ethos of care focused on maximizing individual potential. Vogelpohl, Beck, Heacock, and Mercer (1996, p. 42) found in their study of dressing behaviors that "caregivers contribute to loss of functional performance and dependency in cognitively impaired persons when they 'do for,' that is dress the person instead of supporting independence in dressing." Kayser-Jones (1996) emphasized the importance of an individualized care-oriented milieu for eating.

> By educating nursing assistants on how to provide individualized care at mealtime and ensuring that an adequate number of staff are available to assist those who need help, mealtime rather than being a task oriented procedure will be an individualized, pleasant social event. (Kayser-Jones, 1996, p. 31)

Staff education initiatives that reinforce internalization of a basic orientation toward listening to residents, toward hearing what they say, and toward maximizing their decisional autonomy also offer the prospect of a more resident-centered nursing facility environment (Roberto, Wacker, Jewell, & Rickard, 1997; Smyer & Allen, 1999). However, the reality of the staffing situation must be acknowledged. The

barriers of low staffing ratios, high turnover, and diverse educational, cultural, and language backgrounds often overwhelm efforts toward education and sensitivity to decisional autonomy.

It is necessary to remain especially mindful of the fact that residents must have full say in the medical procedures and treatments that are rendered to them, except in circumstances where they are decisionally incapacitated. The most stringent criteria should be used in limiting decision-making autonomy in this domain. Thus, Edna's professed reluctance to undergo additional gastrointestinal testing or to have further surgery becomes the highest value, a value to be overridden only under extreme circumstances where the unequivocal benefit—to Edna—of such procedures can be clearly established. In contrast to such an ethos, current emphasis on the management of behavior has focused entirely on the control of disruption rather than on the promotion of resident strengths and abilities.

> When the focus is taken off of controlling residents and instead placed on empowering residents, both staff perceptions and residents' capabilities are seen in a different light. This view allows for the empowerment of the individual, who is no longer seen as helpless and needing to be controlled. (Lantz et al., 1997, p. 555)

The essence here lies in a crucial distinction between being informed and being consulted. All too often, Edna was informed about what was to happen to her in circumstances where she was clearly able to express a preference. All too rarely was she consulted and provided with the opportunity to have meaningful input into decisions affecting her life. Gradually, invidiously, and inexorably, she was rendered powerless and alienated as the ambiance of a perversely beneficent decision-making environment in which she found herself moved along the path of progressive surrogacy at a rate more rapid than was warranted by her increasing frailty.

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Received November 16, 2000
Accepted June 22, 2001
Decision Editor: Laurence G. Branch, PhD

Appendix

Notes

1. Although we did not collect information on residents whose stay was anticipated to be brief, we presume that those who were in a facility for rehabilitation and recuperation from an acute illness episode may have had more decisional autonomy. Their expected release from the nursing home and return to independent or somewhat independent living may have given them increased status and power in decision making. On the other hand, if the individual was admitted to the nursing home at the end stages of life, decision-making capacity would most likely be limited.
2. In addition to the principal investigator and co-principal investigator, four graduate assistants were involved in the derivation of decision-making categories, in conducting interviews, and in participant observation. Each graduate assistant spent 10 hr per week in the facility to which he or she was assigned over a period of 3 years. Thanks are due to Beth Adkins, James Concotelli, Kelly Everard, and Juliana McDonald for their assistance in this component of the study.
3. All identifying proper names in this article are pseudonyms.
4. A staff change during the data collection meant that we interviewed two CNAs.