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## **Family Involvement in Nursing Home Facilities**

### *A Decision-Making Perspective*

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Efforts to enhance both the quality of care and the quality of life in nursing facilities have increasingly acknowledged that residents must be recognized and treated as “lives in process” instead of merely patients with functional disorders or persons to be managed. There is growing awareness that, first, an individual’s life in a nursing facility should be framed within the context of his or her experienced world, with an understanding of his or her “horizons of meaning” and personal history (Gubrium 1993). Second, it is becoming increasingly accepted that each nursing facility engenders and sustains a distinctive culture, which determines whether, and to what degree, these horizons of meaning and personal histories are recognized (Gubrium 1975; Henderson and Vesperi 1995; Savishinsky 1991; Shield 1988; Thomas 1996). Third, there is growing recognition of the need to link the world within the nursing facility (the “inside”) to the world beyond (the “outside”) by increasing institutional permeability (the exchange of people, services, and communication) (Rowles, Concotelli, and High 1996). Fourth, maximizing resident autonomy, the degree to which residents are enabled and empowered to exercise choice, is

increasingly accepted as essential for quality of life (Agich 1993; High and Rowles 1995; Kane et al. 1997; Kapp 1994; Lidz, Fischer, and Arnold 1992).

One outcome of this emergent consciousness has been an array of initiatives to humanize the nursing facility home experience: advocacy for pioneering strategies involving residents and families in the operation of facilities (Berdes 1987; Kari and Michels 1991; Thomas 1996), programs that encourage rather than deter reminiscence (Burnside 1996; Cook 1984; Haight, Michel, and Hendrix 1998; Taft and Nehrke 1990), design innovations that include the construction of shared facilities, such as swimming pools and restaurants, that can be entered both from the facility and from the community, enabling nursing facilities to interface directly with the communities in which they are located (Regnier 1994), and efforts to develop an ethos of individualized care (Burger and Williams 1996). All these reflect attempts to create an environment that sustains a sense of “being in the world” and a sense of continuity with the past and with the contemporary world beyond the facility.

Unfortunately, more than half of all nursing facility residents are cognitively impaired (Strahan and Burns 1991). They are unable to communicate effectively with staff. Cognitive incapacity often limits the value of innovative programmatic options as mechanisms for residents’ sustaining and sharing the richness and meaning of their life. As a result, individuals may become “faces without stories,” their personal histories, values, and preferences inaccessible to staff (Gubrium 1993:1). Yet, each nursing home resident has a personal history, each (to a greater or lesser degree) retains vestiges of a former identity, and each has values and preferences.

As already mentioned in this book, residents’ family members often play a key role in ensuring that residents are treated in a manner consistent with their former lifestyle or a best estimate of what they would have wanted (High and Rowles 1995). We suggest that one approach to humanizing care lies in more explicitly recognizing and reinforcing the role of family members in processes of decision making in nursing facilities.<sup>1</sup> There are many possible definitions of family (Gubrium and Holstein 1990). In this context, family is considered to comprise primarily kin. Significant others are incorporated into this

category when clear evidence of a family-like relationship exists (for example, two elderly widows who have resided together for many years). A family often involves subgroups or factions, each having a different viewpoint and level of involvement in the resident's life.

It is well known that families have an important role in the decision to admit frail, older adults to long-term care facilities (Groger 1994; McFall and Miller 1992). However, the continuing role of the family and the involvement of individual family members in decisions affecting the care and life experiences of residents have not been researched. Little is known about the natural history (the pattern of lived events over time) of family involvement in nursing facility decision making and the effects of this involvement on the quality of life of both the resident and his or her family members. This gap in knowledge is of concern, given continuing ambiguity regarding the appropriate role of family members in the lives of relatives in a nursing facility. There is the dilemma of deciding whether to defer to the authority and expertise of the facility or to maintain full involvement. Within the family, this dilemma may extend to determination of which family member assumes primary responsibility for liaison with the facility.

The purpose of the ethnographic research reported in this chapter was to investigate family involvement in the decision-making environment of the contemporary nursing facility, with particular emphasis on everyday decisions that profoundly affect the quality of life of residents. We describe an array of overlapping decision-making processes and roles assumed by family members. We argue that these manifest themselves in the nursing facility decision-making culture in ways that take into account the lifestyle and preferences of the resident before admission to the facility. Central to this thesis is a contextual understanding of the nursing facility as a decision-making environment.

### **THE NURSING FACILITY AS A DECISION-MAKING ENVIRONMENT**

The contemporary nursing facility has evolved over the past 150 years as a response to the problem of caring for ever-growing numbers of frail elders who can no longer be looked after by their families or within community-based settings. (For review of the history of the nursing facility as a feature of American society, see Haber 1983; Johnson

and Grant 1985.) As a socially created institution, the nursing facility reflects and projects cultural values and expectations regarding the role and treatment of frail elders in, or more frequently outside, society (Henderson and Vesperi 1995). As Stafford notes in his discussion of “double burial” (see the introduction and Chapter 5), the nursing facility has come to represent a netherworld, a kind of purgatory between life and death, in which discordant ambiguity and ambivalence exist in a tension between straining toward life (the Hippocratic obligation) and accepting the inevitability of death (the removal from society and palliative treatment of those soon to die).

As both a physical space and a social institution, the nursing facility has become a manifestation of these seemingly contradictory imperatives. Indeed, the designation *nursing home*—accepted terminology before passage of the Nursing Home Reform Act incorporated into the Omnibus Budget Reconciliation Act of 1987 (OBRA)—embraces the contradiction between a medical (*nursing*) facility and a residence (*home*). In the past few years, new residential options for frail elders have included assisted living alternatives (Mitchell and Kemp 2000; Regnier 1994; Zimmerman, Sloane, and Eckert 2002) and public policy that focuses on keeping people out of institutional care and reducing long-term care costs. As a result, nursing facilities have become increasingly “medicalized” because they provide ever-higher levels of skilled care.

In spite of this intensifying medical focus, the nursing facility remains a place where people “live.” It is especially important to understand those aspects of this environment that provide the best possible quality of life for residents. In this context, we seek to advance such understanding by considering the nursing facility as a decision-making environment. Our premise is that the institutional culture of each nursing facility is defined by a plethora of decisions—historical and contemporary, permanent and ephemeral—that, ultimately, determine each resident’s daily lifestyle and quality of life. Decisions are made on many levels and are of many types. Some decisions are remote from the resident, even though they may significantly impinge on his or her quality of life. Federal and local government regulatory decisions, corporate policy decisions, architectural decisions made in designing the physical space, and other exogenous decisions are criti-

cal determinants of the resident's lifestyle because they define and place constraints on what is possible. Other decisions are more immediate and perhaps less immutable. The institutional routine and the rules and procedures (some explicit and some implicit) governing daily life characteristically reflect the working styles and preferences of the administrator and staff. Finally, myriad small but very important decisions are made every day in a facility. A nursing assistant decides to give a resident an extra helping of dessert. A social worker schedules a birthday party, or a family member decides to decorate a resident's room for the holiday season. The confluence of these multiple levels of decisions defines the milieu within which each resident lives out his or her life.

Within this rubric, it is useful to distinguish types of decisions: authoritative, given, negotiated, and reflexive. *Authoritative* decisions are relatively immutable decisions externally imposed by governmental or legal fiat or determined by corporate or facility administrative policy. An array of federal and state regulations impose de jure guidelines and constraints on the facility with respect to the nature and quality of care provided to each resident. Such decisions include regulations regarding staffing patterns, room assignments, access to a telephone, routine resident evaluation, and resident rights. Individual residents and their families generally have very little direct input into such decisions.

A set of taken-for-granted, or *given*, decisions defines the cultural environment of each nursing home and sustains norms and expectations regarding the conduct of everyday life in the facility. Evolving over the life history of each facility, these unspoken decisions set the parameters of life in the nursing facility. For example, our research has suggested that variation among facilities in the prevalence of room changes reflects different philosophies regarding the desirability of room changes and the process by which room change decisions are made (Everard, Rowles, and High 1994). Thus, a social worker with primary responsibility for room assignments in one facility may determine that disputes among roommates should be handled by mediation instead of separation of the protagonists through reassignment. In another facility, a room change may be the option first considered. The outcome may be one facility with a high level of internal residential stability and another where frequent room changes create an

atmosphere of “musical chairs” and a more fragmented ambiance of institutional life. Similarly, each facility, over time, evolves its own pattern of use of space, time/space rhythm, and routine of activity, which imbues the nursing home with a given-ness as a behavior setting (Shawler, Rowles, and High 2001). New residents are required to adapt to essentially a priori decisions regarding the functioning of the facility. At the time residents enter the social world of the nursing home, they and their families have little input into such decisions.

A third type of decision is *negotiated*. These decisions result from interaction among various actors. Interaction between a nurse and a resident’s physician results in a decision to increase a medication dosage. Conversation between a nursing assistant and a resident results in a decision to attend a concert to be given by local high school students in the dining room and to wear a favorite blue dress to this event. A more formal conference involving the social worker, the dietitian, and a family member results in a decision to reduce a resident’s caffeine intake or to eat on a different time schedule. A decision may be made involving the night staff and a resident that will allow her to stay up later than usual to watch a favorite late night movie and to be awakened last the morning after. To a significant degree, these individualistic, negotiated decisions determine the ambiance of each nursing home environment, creating the mores and culture of the setting.

Finally, and perhaps most important from the perspective of this chapter, many decisions affecting the lives of individual residents in nursing homes are *reflexive*. These are autonomous decisions made by individuals through a process of self-deliberation. For example, a resident may decide to spend the morning in the solarium. A nursing assistant may decide to linger at the end of her shift with a resident whose family is unable to make its customary visit. A family member may decide to rearrange a resident’s pictures, clean out her closet, or take her out to a restaurant. These decisions, too, become critical determinants of the social ambiance of the nursing home. They are particularly important for cognitively impaired residents because they help to define the level of expected resident autonomy that characterizes each facility. There is a delicate balance between sustaining the freedom of each resident to act in the manner he or she chooses—to wander around the facility at will, to move behind the nurses’ station, to sing

at the top of her lungs—and maintaining an environment wherein the needs and wishes of all participants are reconciled and respected.

The four types of decisions (authoritative, given, negotiated, and reflexive) are by no means mutually exclusive. Rather, they embrace an array of ways in which a nursing facility may be viewed as a decision-making environment. Into this setting, with established norms and rules of behavior, each new resident and his or her family enter at a time when they are particularly vulnerable. Generally, the resident is vulnerable because of the health condition that has necessitated nursing facility entry. Vulnerability from the perspective of the family results from entering an unfamiliar environment at a very stressful time. Family members must make numerous decisions. In this chapter, we explore how family members operate within the nursing home environment in their attempt to serve the best interests of their relative. They must assume various roles in a setting defined by authoritative and given decisions over which they have little say, and they must make negotiated and reflexive decisions that significantly affect their relative's quality of life.

## THE STUDY

A three-year ethnographic study of family involvement in decision-making in four contrasting nursing facilities was undertaken. Facilities were chosen to represent a diversity of characteristics, including size, levels of care provided, proportion of private pay residents, nonprofit versus proprietary status, and location. Three of the facilities are located in an urban center (population 225,000).

Kensington Place is a spacious, 100-bed, proprietary facility.<sup>2</sup> The design is modern and the decor “plush.” Approximately 85 percent of the residents are private pay. More than 95 percent of the residents have family members, many of whom live nearby in affluent neighborhoods. Residents' family members tend to visit frequently and to be actively involved in the life of the facility.

Greenhaven Manor is a single-story, modern, proprietary facility with 32 skilled nursing beds and 128 intermediate-care beds. The facility includes a 20-bed special care unit for Alzheimer's disease patients. Crowded corridors and constant activity characterize this more “institutional” setting, which during our fieldwork seemed to be

perpetually undergoing redecoration. This busy facility is functioning at full capacity. Here, the presence of family members is less pervasive than at Kensington Place.

The atmosphere at the third facility seems less frenetic. Elizabeth Manor is a recently constructed, two-story, nonprofit nursing home located in a suburban area. There are two intermediate-care wings with 50 beds each and a skilled wing with 50 beds. In contrast to Greenhaven Manor, the design of this facility conveys a calm aura of spaciousness and light. The decor is simple and tasteful, incorporating carefully chosen and matched pastel blue, green, and plum color schemes. There are few private-pay residents at Elizabeth Manor, and the majority of residents are from modest- or low-income backgrounds. The level of family involvement ranges widely, with some residents receiving frequent visits and much family attention and others receiving limited family support.

The fourth facility, Mountain View, is a single-story building on the outskirts of a somewhat isolated, rural community of 2,795 persons, located in Baden County (population 11,700) in the foothills of southern Appalachia. The decor is utilitarian and institutional, in contrast to the attractive interior design at the other facilities. There are few private-pay residents in this proprietary facility. The majority of residents are from the county or adjacent counties, and the facility is strongly integrated into the local community—historically, economically, socially, and psychologically (Rowles, Concotelli, and High 1996). There is a high level of family involvement in this facility.

Considering the individual as the unit of analysis, *decision-making* was defined as an act of making a choice, reaching a conclusion, or making a judgment. The decision-making process was conceptualized as potentially involving a constellation of actors surrounding, and including, each resident. Operationally, this constellation was defined to include the resident (if cognitively capable), the nursing home administrator, the nursing staff member most closely involved with the individual's care, the nonmedical staff member (generally a nursing assistant) most closely involved with the resident's care, the resident's physician, other actors, such as lawyers and clergy with whom the resident might come into contact, and, most important, two significantly involved family members. Depending on the nature of the decision,



**TABLE 7.1**

*A typology of resident-related nursing facility decisions*

<i>Type of Decision</i>	<i>Examples</i>	<i>Number of Subtypes</i>
Daily living decisions	Timing of activities (breakfast, bedtime, etc.), food choices, bathing, access to a telephone, snacks, spending money	20
Physical environment decisions	Room arrangement, use of furniture, personal belongings, radio or TV	11
Social environment decisions	Room assignment, choice of roommates, where to sit at meals, social activities	10
Treatment and health care decisions	Medication, restraints, physical therapy, surgery, diet, wheelchair, geri-chair	16
Major financial decisions	Payment to nursing facility, spend down, Medicaid, selling of property, insurance	9
Transfer decisions	Hospitalization, discharge, transfer within facility, transfer to another facility	6
Competency decisions	Guardianship, durable power of attorney, confusion, decision-making capacity	7
Crisis or life-and-death decisions	CPR, DNR, Living Will, artificial nutrition and hydration, funeral arrangements	9

different individual actors or subsets of these actors were involved.

The research focused on a typology of eight decision-making categories developed during the pilot phase of the project: crisis or life-and-death decisions, decisions regarding competence, financial decisions, transfer decisions, treatment and health care decisions, decisions regarding the social environment, decisions about the physical environment, and daily living decisions. Within these categories, eighty-seven subtypes of decisions were identified. Table 7.1 provides examples.

Three principal methods of data collection were employed. First, extensive participant observation over the entire three-year period enabled us to develop a sense of the ambience and culture of decision-making in each facility. We learned about many of the authoritative

decisions defining and constraining the operation of each environment. Participant observation also enabled us to experience, and thereby gain a firsthand understanding of, given decisions, the norms and expectations for particular behaviors in particular situations that defined the social ambiance and culture of each facility.

Second, a series of in-depth, semistructured interviews were conducted, centered around ten residents (per facility) who were seventy-five years of age or older. Participating in the interviews were the resident (if cognitively capable) and potential decision-makers for that resident. These interviews were repeated five times (once every three months), providing a longitudinal perspective over a fifteen-month period. Finally, event analysis, involving ongoing monitoring of individual decision situations as they were in progress, was undertaken. Data were gathered by four research assistants, one assigned to each nursing facility. The outcome included 1,084 tape-recorded, in-depth interviews (each was transcribed), extensive dossiers on the decision-making constellations of sixty-one nursing facility residents,<sup>3</sup> and more than 1,400 printed pages of single-spaced field notes.

An important finding emerged early in the fieldwork. Most families remain fully involved in the lives of their institutionalized relative throughout the relative's stay. Our interviews revealed a high level of reflexive decision making on the part of family members as, particularly in the case of cognitively impaired residents, they proactively took charge of many aspects of their relative's daily life and, within the constraints of the institutional environment, acted with a high level of decisional autonomy. Family members frequently play key roles in negotiated decision making pertaining to their relative. Family members provided information on 661 decisions during the course of the in-depth interviews. They had participated "fully" or "somewhat" in 90 percent of the 38 crisis decisions reported, 85 percent of the 34 financial decisions, 76 percent of the 136 daily living decisions, 67 percent of the 9 competency decisions, 65 percent of the 49 physical environment decisions, 61 percent of the 271 treatment decisions, 60 percent of the 52 transfer decisions, and 40 percent of the 67 social environment decisions they reported. As already stated, this high level of involvement persisted throughout the resident's stay. Family members were involved in 60 percent of the decisions they reported for residents

with less than one year of residence, 70 percent for residents with one to two years of residence, and 63 percent for residents with two to four years of residence. Only for residents with length of residence in excess of four years does the level of family involvement appear to drop significantly (only six residents in the study population had resided in the nursing facility for more than four years).

### CASE STUDIES

Acknowledging the consistently high level of family involvement in decision making, we now turn to the nature of this involvement and the way in which it manifests the propensity of family members to engage in various types of decisions and to assume an array of decision-making roles. We begin with three case studies, compiled from transcriptions of the in-depth interviews and from field notes.

#### **Vicky Dorsey**

Vicky Dorsey, an elegant, well-dressed woman with a silvery gray wig and tasteful jewelry, was ninety-six years old when she was admitted to Kensington Place. Her daughter, Andrea, visited her frequently and usually brought cookies (reflexive decision):<sup>4</sup>

Well, I always bring her cookies. She has to have cookies.... She likes chocolate ones, chocolate chip usually, so she always has those...and I know she's getting heavy. Some of the summer clothes, I've had to take two home because they've just gotten too tight for her across the stomach. I think it's from all those cookies.... Used to be I'd buy her cookies once a week or once every ten to twelve days, but now it's twice a week. I try to let her go without them for a while, but she really complains about it if she doesn't have it. And she'd been without them for two or three days and say, "I haven't had any cookies for two weeks." So she really does like them. Who cares if she gets fat? She'll be ninety-eight next month.

Although she might acquiesce to Vicky's dietary wishes, Andrea was extremely vigilant regarding other aspects of her mother's well-being. She closely monitored her care and frequently intervened with staff

when she perceived that something was amiss (negotiated decision). At one point, she became particularly concerned about her mother's foot care. A member of the nursing staff recounted this:

Now, the decision has been made for her for Dr. Virgo to do her care—he is the podiatrist—to do her foot care every month because her toenails grow real fast and her daughter's real concerned about that. Well, she was, too. Mrs. Dorsey was too. Vicky was, too.... Okay, well, her daughter discussed it in Care Plan, and the charge nurse, you know, consulted with Dr. Virgo, who is our house podiatrist, and he agreed to do it. I wasn't here when that meeting went on, but she [Andrea] has approached me several times to find out when he was coming.

Andrea also initiated and mediated the decision-making process that resulted in her mother's going to the dining room for only one meal and taking the remainder of her meals in her room (negotiated decision). Andrea explained to the staff that her mother had always been something of a loner. In addition, Andrea played a major role in setting up her mother's room to make it home-like (reflexive decision). She arranged Vicky's pictures on the wall. She brought a radio and set it to her mother's favorite station so that Vicky could listen to classical music while she dined, something she had done at home.

As Vicky's stay at Kensington Place lengthened, Andrea came to know the staff better. She was able to share information on her mother's history and preferences. She educated the staff about "trigger" words that would involve her mother in conversation. As Vicky became increasingly confused, Andrea was able to explain some of her mother's behaviors to the staff. For example, when Vicky began to wander down to the nurses' station in the middle of the afternoon and ask to be put to bed, Andrea was able to explain that her mother's typical response to stress throughout her life had been to "take to her bed." As one of the nurses explained,

You know, she was...just one of those people that couldn't stand for anything to be wrong. She had to go to bed. So it's nothing new to her daughter, but it's just showing up lately over here.

When Andrea was unable to visit for a few days, Vicky would sometimes become very upset. On these occasions, Andrea would inform the staff and work with them to minimize the trauma occasioned by her absence. She would make sure that she told her mother of her impending absence and arranged with the staff to be especially sensitive to Vicky's mood during the time she was away. On occasion, working with the staff involved benign collusion. A nurse reported:

I did talk with her daughter last week about Mrs. Dorsey was complaining about her mattress being too hard, but her daughter said a month ago it was too soft and they put a hard one on it, so she just said leave it. That way, in a week from now she will forget it. (negotiated decision)

In some ways, Vicky's life in the nursing facility is controlled by her daughter. With respect to her influence on the arrangement of her mother's room, this can sometimes have unanticipated consequences. The administrator explained:

We recently had all of the rooms, put new wallpaper...and when that was put in the room, we asked that they not hang pictures back on the new wallpaper [authoritative decision]. So, therefore, her daughter rearranged her pictures, and for about two weeks it threw her [Vicky] into an awful tizzy. I was called to her room by Carol Wilmore, the three-to-eleven nurse, who said that she was just very upset and kept saying, "Why did my daughter do this to me? Why did my daughter do this to me?" And after talking to her for a while, I finally figured out about the pictures being rearranged. We tried to talk to her and tell her about the new wallpaper, and she just wasn't processing what we were saying. She was just upset that her daughter had moved everything around without telling her.

### **Albert Fry**

A similar level of devotion to enriching a resident's life is demonstrated by Eulalah, the seventy-five-year-old spouse of Albert Fry. A very thin, always well-dressed, seventy-five-year-old with both Parkinson's disease and Alzheimer's disease, Albert lives down the hallway from

Vicky Dorsey at Kensington Place. Eulalah visits every day and is often seen sitting with Albert, holding his hand.

The first thing I do, I walk in and open his closet and start putting away his clothes that he had wore the day before [reflexive decision]. And then I get his clothes that he is to wear the next day, and then I get him an outfit put together, and then I take his dirty clothes, you know, find his dirty clothes. And I've been brushing his teeth, cut his toenails, his fingernails, and the hair in his nose and his ears. Honey, I do it all.

In addition, Eulalah diligently monitors his condition. During one span of a few weeks, she informed the nursing staff that the color and odor of his urine had changed (prompting a urine analysis), brought the deteriorating circulation in his feet to their attention (this had not been noticed previously), and intervened when he seemed to have been overmedicated (negotiated decision).

He was agitated.... The third shift called the doctor at 4 a.m., and he was still out that afternoon when we arrived. My son and I took him to the bathroom, and, honey, he was just like somebody drugged, on this drug, and he couldn't put one foot in front of the other. Al is a small man, you know what I mean. He doesn't need a lot of medication. They overmedicated in giving him something that, you know, what they give a two-hundred-pound man. That's when I started calling the doctor, too.... And I didn't want them to give him any more. I don't care what the doctor said.

Eulalah's efforts transcend merely a concern with the quality of her husband's care. She explicitly tries to empathize with his experience. There is a gentle poignancy in her comments:

Well, other than sleep, he just rattles. He don't know what he's saying. He's working. He's fired everybody and he [says], "That hole wasn't right!" I listen to him and then, finally, I [say], "Now Al, you're retired. You don't have to worry about things like that any more. Just forget it."

She also works assiduously to engage his mind. She brings photographs and family albums and encourages him to associate these pictures with the places and people in their life together (reflexive decision). She takes him outside the facility once or twice a week, often for lunch (reflexive decision).

Now, Tuesday I picked him up, and I had an errand to run out on the beltline, to get some bags for my sweeper. And the weather, you know, halfway decent. So I picked him up, and we drove out there.... Things like that, you know, just to get him out and away.

Such excursions are no small feat for Eulalah: "Them wheelchairs is heavy to put in and out of the trunk of a car for a seventy-five-year-old woman." But the outings appear to rejuvenate Albert, as is apparent from her account of a trip to attend a family fiftieth wedding anniversary (reflexive decision):

My intentions were, we would take Al to the dinner and then bring him back, and we would go...back to the party, dance—it was a dance. And so, after the dinner, we were lingering, talking with part of his family, and, uh, someone, and I can't think of who, someone came in and said, "There are some friends and that in the other room," where they were having the dance, "that heard that Al was here, and they want to see him. Bring him on in here." So we did. And everybody would just come over, his family and cousins... that he hadn't seen for some time. Of course, he couldn't remember it, but anyway we kept staying and staying.... Well, we were still staying, see, and we were sitting at this table, and it was about 9:30 and Al said, "I want to dance." Well, it kind of caught me, and I said, "Okay, let's go." So we got him out of the wheelchair, and everybody started hollering, "Oh, look, look, look!" And Al, poor thing, he was so weak—it looked like two drunks. And Grace, his sister, came over and I said, "Al wants to dance." She said, "I'll dance with you." And he said, "I'll dance with Eulalah, and then I'll dance with you." And I want you to know, we danced. It was

a slow dance, and then when it was over, he did dance with his sister.

### **Emma Wise**

Eighty-four-year-old Emma Wise, a resident of Mountain View nursing home, does not speak, because of her advanced dementia. Her abundant gray-white hair is often matted to one side from leaning her head on the geri-chair, where she sits with her feet up and knees bent—but her hair is all that is disheveled. She is usually dressed in clean nightgowns or dresses that her daughter, Betty, brings from home, and her room is well decorated by an attentive family. Betty visits every other day for two or three hours, often arriving around lunchtime to help with feeding Emma.

And then I always bring her something to eat. If I come in the afternoon, I bring her a strawberry sundae. I always bring her something to eat. I never come without bringing her something to eat.

Sometimes Betty stays for the evening meal. Like Andrea and Eulalah, she is involved in a variety of decisions and activities that serve to individualize her mother's care. She does her laundry, changes her bed when the CNAs are busy, and straightens up her room (reflexive decision). She also provides personal care, fixing her mother's hair, putting lotion on her dry skin, and cutting her nails (reflexive decision). She spends many hours holding her mother's hand, comforting her, and talking to her, even though her mother's only response is a pursing of the lips and utterance of guttural, sucking noises with her mouth and tongue.

Betty intervenes on her mother's behalf with the nursing home staff. As one of the nurses remarked, "Betty's really good about if there's any kind of problem. She always comes to the desk and talks to you about it." Thus, when she discovered that Emma was allergic to the soap the facility was using, she requested that they bathe her mother using a different soap, which she provided (negotiated decision). When the soap was changed, the rash disappeared. As Betty remarked on one occasion, "Yes, the longer you're here, the more you know what you can do" (given decision).



Betty spends the most time at the nursing home, but other family members also provide support and involve themselves in decisions that enhance her mother's care. Emma has four children (including a son who has durable power of attorney for her affairs), twelve grandchildren, and nine great-grandchildren. Remembering how she had always enjoyed her garden, Emma's son hung a bird feeder outside her window at the nursing home (reflexive decision). At Christmas, several family members decorated her room. Each year, the nursing home holds a contest to elect a Valentine King and Queen, and the winners are feted at a celebration. Votes for each resident are pennies placed in jars named for each candidate, with the proceeds donated to Alzheimer's disease research. Under normal circumstances, the nursing home administrator prefers that a cognitively capable, ambulatory resident win the competition (given decision). Indeed, generally, only cognitively capable residents are nominated. However, in Emma's case, the family was so enthusiastic about the contest that they made sure she was one of the nominees (negotiated decision). They saved pennies to donate all year, with the result that Emma won.

#### **FAMILY ROLES IN DECISION MAKING**

Andrea, Eulalah, and Betty provide examples of the way an individual family member's involvement in everyday decision making in a nursing home profoundly affects the quality of a resident's life. Family involvement personalizes and humanizes the life of a relative. It gives the resident a continuing link to his or her life history and the world outside that might otherwise be eliminated by the process of institutionalization. Similar scenarios could be presented for each of the sixty-one residents involved in this study, for all had family members who remained involved in decision making that affected the residents' lives to a greater or lesser extent.<sup>5</sup> In our review of the transcripts, consistent patterns emerged that enabled us to develop a typology of family decision-making roles:

- Caregiving
- Pampering
- Comforting
- Engaging
- Educating

- Monitoring
- Mediating
- Colluding
- Controlling

A major decision-making role involves direct *caregiving*. Family members frequently engage in reflexive decisions concerning their relative's activities, ranging from personal care, to determining daily attire and laundering clothes, to arranging the relative's room and daily activities. An essential feature of such caregiving is the ability to provide care in a manner consistent with the resident's former lifestyle. In all four facilities, it was apparent that reflexive decision making by family members with respect to caregiving was not only accepted but also appreciated by busy staff, who were relieved of time-consuming activities. In a number of cases, it was clear that family members had assumed a role of supplementary staff. As Betty remarked, regarding her mother, "I change her bed sometimes when the girls are busy," and on another occasion, "I try to stay and feed her supper.... I usually change her before I leave, and that gives the girls a [break], you know. They don't have to rush right on in and do it after supper." In a few cases, it appeared that by taking on such a caregiving role, conscientious family members experienced increased stress because staff essentially ceded responsibility for care during the times when the family member was in the facility.<sup>6</sup>

Beyond instrumental caregiving roles, family members make multiple reflexive decisions that personalize care by *pampering* residents. Family members often bring in residents' favorite foods: Vicky receives her chocolates, and Betty plies Emma with ice cream sundaes. In addition, family members facilitate the continuation of favorite activities, from listening to classical music to watching the birds outside the window.

The research also revealed a key socioemotional role in *comforting* residents, particularly those who were cognitively impaired, by sitting with them, talking with them, listening to their ramblings, and trying to re-establish or reaffirm connections to people and places in their past. This process often involved much hand holding, an indulgent

empathy, and considerable patience. However, family members' decisions to sit with residents often reduced the residents' anxiety and agitation. Thus, Andrea's calming and reassuring presence was particularly missed when she was unable to visit Vicky for a few days. In many respects, assuming the comforter's role involves given decisions. There is generally no conscious decision to provide such comfort. Rather, such actions reflect implicit, taken-for-granted choices that are accepted, indeed, often expected, as part of the assumed responsibility of being a family member in our culture.

Efforts to comfort residents were complemented, in many cases, by conscious decisions of family members to introduce activities oriented toward *engaging* or reengaging their relatives in familiar aspects of their lives. By reviewing photographs and scrapbooks, taking them on trips to see former friends or familiar haunts, family members actively sought to sustain vestiges of their relative's identity and past. For Eulalah, such efforts, in addition to enriching her husband's life, served to affirm her own identity. Continual reminders of the meaning of the life they had shared provided a kind of catharsis.

A major family role in nursing-home decision making consists of representing the resident in interactions with nursing home staff. Family members may play a key role in *educating* staff to characteristics of residents—personal quirks, whims, and idiosyncrasies that could be gleaned from no other source but that explain seemingly incongruous behavior. In Gubrium's terminology, through active involvement in negotiated decision making, families are able to transform residents into "faces with stories" and, as in the case of Andrea's explanation of Vicky's afternoon wandering behavior, to make their behavior understandable to otherwise puzzled staff.

Such education often stems from vigilant *monitoring* of residents' status by family members. Knowledge of the resident and a keen, focused, caring family eye sometimes reveal critical concerns before they become apparent to staff members, whose attention may be diffused by their responsibility for multiple residents. Thus, Eulalah's vigilance resulted in a more timely response to the circulation problem in Albert's feet, hastened a needed urine analysis, and resulted in intervention when he had been overmedicated. Monitoring may also

involve efforts to ensure that a resident's daily lifestyle is as consistent as possible with his or her past. Thus, Betty is especially concerned with her mother's clothing and closely monitors to ensure that Emma is dressed appropriately each day.

The girls that really know me, they know that I like her clothes on.... Because my mother, the reason that I'm like that, because my mother was always a neat dresser, and I don't like to come in and see, now she doesn't have her gown on today, and it bothers me, I guess, mentally.... It's my personal feeling because my mother was always a neat dresser. My mother had everything to match. If she put on a dress, she had the shoes and pocketbook. It's not nothing to do with the nursing home about this. It's my personal feeling.... Yes. And I don't say nothing to them, you know. I just go ahead and do it because I like to sit there and look at her with her gowns on.

Because of their focused concern for a single individual, family members become especially important and effective in a *mediating* role regarding a wide range of decisions. Our data suggest that key family members often take their responsibilities very seriously and take charge of negotiated decision-making situations. Thus, Andrea intervened and followed up, with some persistence, to ensure that her mother received appropriate foot care. She also worked with the staff in arranging for her mother to take all but one of her daily meals in her room, a decision consistent with her mother's lifestyle before entering the facility. Betty effectively mediated a decision that resulted in the successful treatment of a mysterious rash her mother had developed. As a member of the nursing personnel explained,

Emma had a rash. It was just a minor red rash, and her daughter was concerned about the rash and so she was trying to find out what they were using on Emma that might possibly have caused that. And the only thing we could figure out that was different was our periwash [anti-bacterial soap] solution. We'd gotten a new kind. So Betty looked at it

and smelled it, and she thought that maybe that might be what it was. So, at her request, we stopped using that, and we put up signs and we instructed our staff not to use that on Emma any more.

Although most aspects of the individualization of care by family members focus on satisfying the wishes, or presumed wishes, of residents, two decision-making roles emerged that did not fit neatly within this rubric. In some cases, we observed a propensity for family to become involved in *colluding* with staff in ways that appeared to contradict the stated preferences of residents. For example, collusion between Andrea and the nursing staff with respect to changing Vicky Dorsey's mattress resulted in a negotiated decision to take no action. In most cases, such collusion is benign, but on occasion, it may have more to do with the preferences of the family member. For example, Andrea was reluctant to take her mother to a recommended ophthalmologist because it meant transporting her to his office. As a member of the nursing staff explained,

It wasn't because it was the doctor, per se. It's she did not want to take her out to an office visit to anyone, you know. And her reasons were that every time she takes her mother out that she has BMs all over the place.

Finally, we observed a propensity for some family members to be involved in the lives of their institutionalized relative to the point that they became *controlling*. For example, the nurse who worked most closely with Emma at Mountain View described how Emma's daughter had terminated her foot care:

She brought these, whatever those bills are that they send out, and she came in and asked me what they were. And after I read them, it was, they specified some kind of surgery. And, at first, I couldn't figure it out. And then, it was from the podiatrist where he had trimmed her toenails. And she said she did not want him trimming her toenails, that she or we were capable of doing that. She saw no sense in paying taxpayers' money.

Again, in such cases, the intent was benign. However, on occasion, control of almost every aspect of the resident's lifestyle in the facility had negative consequences, illustrated by Vicky Dorsey's anxious response to her daughter's rearrangement of her pictures.

### **THE IMPORTANCE OF CONTEXT—LINKING INSIDE AND OUTSIDE, PAST AND PRESENT**

Our data suggest that, in the majority of cases, family involvement in nursing-home decision making becomes coordinated through a single family member who assumes responsibility as a point person for the remainder of the family. Andrea, Eulalah, and Betty have assumed this primary family member role. At one time or another, each has engaged in most of the decision-making roles we have identified. Indeed, they have made or coordinated many decisions regarding the life of their relative, from the determination of competence, financing, and medical treatment, to seemingly mundane everyday decisions, such as the choice of clothes to wear or the provision of candy. In assuming these roles, individual family members become decision makers not only for those residents who are cognitively impaired and with residents who are intact but also, implicitly, for the entire family. Indeed, the primary family member often *de facto* assumes responsibility for most aspects of the resident's life. In this role, the primary family member provides a critical link between the worlds inside and outside the facility.

Under most circumstances, primary family members attempt to make decisions (either reflexive or negotiated) that involve the resident and respect the resident's continuing autonomy. Especially in the case of cognitively impaired relatives, they engage in surrogate decision making that reflects their best effort to reconcile what they perceive the relative's preferences would be with what they perceive to be in the relative's best interest. Within this rubric—adopting a kind of Janus stance, facing both inside and outside the facility—primary family members also attempt to represent the preferences of the entire family. Sometimes they consult with other family members regarding the appropriate course of action, but in many cases, particularly regarding everyday decisions, they act autonomously.

Generally, other family members are content to leave routine decisions to the on-site primary family member. However, intra-family

tensions may arise when there is ambiguity or lack of consensus regarding the appropriate course of action. For example, there was some difference of opinion among Emma Wise's four children regarding Do Not Resuscitate (DNR) orders and use of cardiopulmonary resuscitation (CPR) on their mother. At the time of her admission, there was apparently consensus that extraordinary means should not be used to preserve their mother's life. Indeed, medical records revealed that Dr. Canter had provided a No Code order. Betty, who visited most frequently and had clearly taken on the primary family member role, assumed that this meant that her mother would not be "hooked up to machines." When she discovered that DNR orders would preclude the use of CPR, her opinion changed:

Well, when I called my sister, she said, "Well, that's what I meant. Do nothing." I said, "Esther, you mean we don't do anything for Mother?" And I said, "Do you mean that if I'm sitting with her and she just doesn't breathe any more that the nurses are not, I mean, because they told me if we sign this, they don't do anything?" And I said, "How am I going to take that?" And she said, "Well, you," she said when Mother was in their home [Esther had lived with her before admission to Mountain View], that was what they decided that they would not do. And I said, "Well, if I'm not there, that's fine. But what am I going to do if I'm there? That's my mother, and how am I going to take it? I mean, just like right now if something happened to her, I'd want them to help her." And she said, "Well," then she said, "Well, call Ronald and see what he says." Well, then I called my other brother, Damon, and he said, "Well, Betty, you know we want them to do CPR." And I said, "Well, that's what I thought, but no machines." Of course, I didn't realize that the nursing home didn't have any machines now. I'm innocent in this deal, too. And I thought when they mentioned that, that meant that they had machines here that they put her on and bring her back, and I don't see no sense in that. I don't see no sense in the machines, but I do, I feel like they could try CPR. So I called my brother [Ronald] that's power of attorney, and I told him what she had told me, that he had to

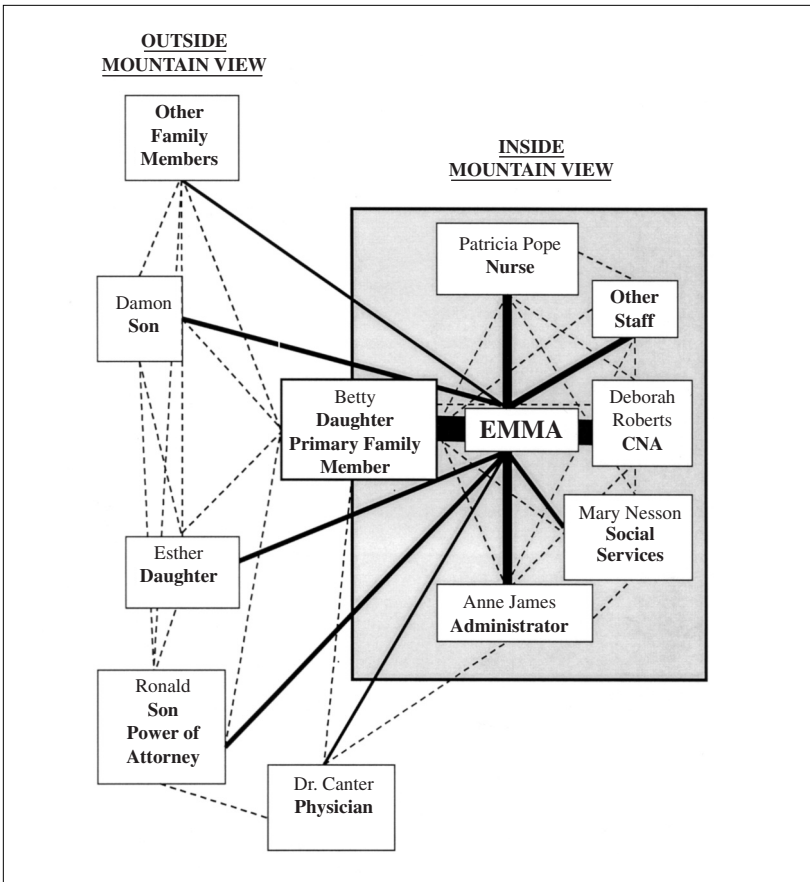
send his papers in and they have to have it authorized by Dr. Canter. That's mother's doctor. So he said, "Well, wasn't that what we decided?" And I said, "Ronald, I have to say, I guess, that's what we decided, but I put my mother in there, I didn't think my mother would live but three months, if she lived that long." And I said, "Mother has lived for a year. I go see her every other day," and I said, "The more I think about it, how can...and I said it's fine if they don't do that if I'm not there. But when I call for those nurses or those aides and they do not come to Mother, if something happened to her, I don't know what I'm going to do?" See? I mean, I had never thought of it that way. So he told me, he said, "I'll tell you what I'll do." He says, "I won't send in my power of attorney paper," because it's not valid till he sends them in.<sup>7</sup> And he said, "Each of you children write me a letter and tell me how that you want it done." And then he says, "I'll go back and change them" [the DNR orders].

For several weeks, the issue was discussed via letters and telephone calls among family members before a final decision was reached and the appropriate documents forwarded to Mountain View to rescind the DNR order.

The primary family member as decision maker also acts within the larger context of the institutional setting. It is this individual who develops relationships with nursing home staff. He or she tends to establish a strong relationship with one or two members of the nursing home staff, who become key points of contact in discussions and negotiated decisions regarding most aspects of the resident's life. Indeed, many decisions affecting residents' lives are made on the basis of communication between the primary family member and a single member of the staff. Figure 7.1 best illustrates the contextualization of family involvement in the decision-making process.

Emma Wise is the focus of a decision-making constellation involving relationships among a variety of actors both inside and outside Mountain View. Within the facility, she is cared for by a series of actors, with differing levels of involvement and knowledge of her life. The administrator, Anne James, admits, "I don't think I know her well at





**FIGURE 7.1**  
*A decision-making constellation: Emma Wise*

all.” She perceptively notes, “I know what she is now, but I don’t think I know what she used to be.” Nonetheless, she provides some hands-on care: “I sit and talk, or I feed her sometimes.” The majority of care is provided by nursing assistants. Deborah Roberts, a nursing assistant, has taken a special interest in Emma’s care. It was Deborah who noticed that Emma, who had previously spent most of her time in bed or in a chair, had an inclination to walk:

Well, when we were transferring her, she was putting her feet on the floor like she wanted to walk.... Well, then, from

there we brought her...to the dining room and got under her arms and then tried to transfer her by ambulating her to the dining room.

As Patricia Pope, the nurse most fully involved with Emma's medical care, noted, "Yes, she got hold of a good aide taking care of her who's trying to get her up and take her out." Deborah was a primary point of contact with the family, especially with Betty, who appreciated the attention given to her mother. Commenting on the return of Deborah from temporary reassignment to another part of the nursing home, she commented, "But since we got Deborah back down on our end, it's a lot better."

It is within this specific network of institutional staff/resident relationships, involving a limited number of actors, that we must view the role of family. The family interfaces with the small cadre of staff directly responsible for Emma primarily through Betty. Although Betty is the liaison with the facility, the person who inserts herself into most negotiated decision-making situations, she is very conscious that she functions in this role primarily as her mother's representative. She also represents the entire family, especially her two brothers and her sister. Betty, her sister, who lives in an adjacent state, and her two brothers (one of whom lives fifty miles away) frequently exchange telephone calls. Such calls provide a means of sharing information on Emma's condition and a forum for family discussion of issues pertaining to her care.

As the primary point of family contact with the nursing home and as the on-site decision maker, Betty is careful to maintain a relationship with staff that stops short of meddling or what she perceives as unwelcome intrusion. She is aware of a delicate balance between assuming an active decision-making role in support of enhancing her mother's quality of life and maintaining a good relationship with staff (Foner 1994:110-119). On one occasion, after she had persisted in requiring of Patricia Pope that appropriate medical attention be devoted to a cough her mother had developed, she explained,

I don't know if she was going to call that night or call the next morning, but then when I came back in two or three days, they told me she was on an antibiotic, so I just presumed that they had took care of it. Sometimes I don't like

to keep questioning them. I'm afraid that they'll think that I know more than they do, and I don't.

From the other side of the relationship, it is clear that most staff of the facilities in our study were fully aware that they did not know residents as well as did their family members. In most cases, they were very willing to receive decision-making input from family members and to adjust patterns of care accordingly. Some staff members felt that they served the families of residents as much as the residents themselves. In commenting on Emma's candidacy for selection as the Valentine's Day Queen, Anne James, the administrator of Mountain View, expressed this sentiment:

I don't really think Emma knows or cares, you know, that she's running for Queen. And, you know, I would like for the person to win who, you know, realizes what's going on and either appreciates it or says, "I'm not being in your stupid contest!" But the family enjoys it, you know. We serve the families as much as we do the patient around here, sometimes more.

## CONCLUSION

In the preceding pages, we have sought to integrate four needs of contemporary nursing home life—the need for sensitivity to individual residents' horizons of meaning and personal histories, the need for greater understanding of the distinctive culture of the nursing home, the need for deeper understanding of the ways in which nursing homes are separated from and, at the same time, a part of the community in which they are located, and the critical need for a focus on autonomy—within the framework of a study of the nursing home viewed as a decision-making environment. We have focused on the decision-making processes of family members and the roles they assume as they become part of the nursing home environment and, for the resident, the key point of contact between the facility and the family, the present and the past. In assuming this position, family members do their best to maintain their relative's autonomy against the backdrop of a decision-making environment within which they have only limited, ambiguous control. This chapter reveals the critical role of

residents' families in the culture of nursing home life and enhancing their relative's quality of life. Our study represents an initial foray into a domain of research that should be pursued in more depth as we grapple with defining appropriate roles for residents' family members in nursing-home decision making. If the perspectives we have presented are confirmed in future research, it will become important to consider their implications for the reorganization of nursing home life and routine to maximize the ability of families to support the highest possible quality of life for their relative. We may be able to develop an entirely new perspective on the nursing home as a family-focused institution.

### Notes

1. Research reported in this chapter was supported by a grant from the National Institute on Aging (AG08475). Some of the case study material incorporated in the chapter is reproduced from "Individualizing Care: Family Roles in Nursing Home Decision-Making," *Journal of Gerontological Nursing* 22:3, 1996: 20–25, with permission from the publisher, SLACK Incorporated. Views or opinions expressed in the chapter are those of the authors and do not necessarily represent the views or opinions of the funding agency. The assistance of Mary Doole and Evy Whitlatch in the review of transcripts and the development of case studies is gratefully acknowledged.

2. The names of all geographic locations, nursing homes, residents, family members, and nursing home personnel are pseudonyms.

3. This includes replacement of residents who died.

4. Throughout this section, the four types of decision—authoritative, given, negotiated, and reflexive—are identified in parentheses (or brackets, in quoted passages).

5. A focus on the nature of family involvement as the central concern of this project was such that only residents with family members were included in the study.

6. In fairness to staff, it should be pointed out that, in some cases, reliance on family to perform certain caregiving activities may provide the kind of assistance and temporary respite that enables staff to complete an excessive workload.

7. There was considerable ambiguity in this situation. From the staff's point of view, as revealed by the medical records, the physician had apparently approved a DNR order. However, Ronald, Emma's son with power of attorney, had not signed and submitted an Advance Directive. The complexity of the situa-

## FAMILY INVOLVEMENT IN NURSING HOME FACILITIES

tion was described by a somewhat exasperated Patricia Pope, the nursing staff member with primary responsibility for Emma:

She [Betty] noticed an old order on the chart that Mrs. Wise was not to be, was not to receive CPR, and she knew that we didn't have an Advance Directive from the family saying that she should not receive CPR. So she knew that there was a conflict, and she called Mary [the director of social services] and told her that, you know, we need to either get them to say, "No, we don't want her to have CPR," and we need to get Dr. Canter to say, "Yes, you can do the CPR," one or the other. So Mary called the family, and they had been, the daughter kept saying that she, that the son had legal power of attorney over here. And I think he was actually, did not want the CPR. And I think that's where Dr. Canter got that order. But you know, we did have that on the chart. So, you know, as long as there was a conflict, what we told the family was, until it was resolved, if they should walk in and she should be having trouble, they would do the CPR until it was straightened out. And she kept saying, "Well, we'll get it straightened out," but it kind of ran on for, like, three or four months, and they had never gotten it settled. So Mary called Betty and told her that we was going to have to get it straightened out.