8

The Head Nurse as Key Informant: How Beliefs and Institutional Pressures Can Structure Dementia Care

Athena McLean and Margaret Perkinson

INTRODUCTION

When an elderly person moves into a nursing home, she expects to face some changes in her life—a different physical setting, unfamiliar community of residents, a perpetually present staff, and perhaps less contact with family. What she may not expect are the less apparent conditions that can have a dramatic impact. Among these are the regimentation imposed by the bureaucratic organization, the interpretation and response of the staff to bureaucratic constraints, and the even less visible pressures that influence the way the staff interprets and structures its approach to caregiving.

Those residents suffering from some form of senile dementia may experience that impact even more severely because of the special nature of their problems and, some would argue, the accommodations necessitated by their illness. Dementia involves a progressive deterioration of cognitive functioning, including loss of memory of one's past and about elements of one's identity. This condition has been referred to as a progressive loss of self (Cohen and Eisdorfer 1986; Sabat and Harre 1992; and Scheibe 1989).

For those affected, a move to an unfamiliar setting occupied by strangers, separate from those with whom the elders share a meaningful history, can further contribute to their confusion and to questions about their identity. The adjustment of these residents may be particularly affected by the ways the staff accommodate to the idiosyncracies of their condition in the related context of their personal history.

Although researchers are finding encouraging evidence that accommodating to a resident (e.g., tuning in to a resident's toileting pattern to inhibit the development of incontinence) will positively alter or slow down the illness course (Kitwood and Bredin 1992), evidence is far from conclusive. The extent to which such accommodations would markedly improve the quality of a resident's life is also open to debate, despite the enormous importance many family members place on this (Bowers 1988; Schwartz and Vogel 1990; Schuttlesworth, Rubin, and Duffy 1982). The uncertainty about the impact of personalized accommodations to illness course and to quality of life allows clinical staff to exercise tremendous latitude in interpreting vital, from less vital, needs of these residents and in determining whether and how to respond to special requests from families.

Nursing home placement for elders with some form of dementia as the primary diagnosis is largely made to meet the ongoing needs of the elder, except for complications resulting from falls or medical conditions that may materialize after admission. Depending on the stage of the dementia, nursing home care consists primarily of varying degrees of assisting the elder with activities of daily living, such as dressing, bathing, and as the disease progresses, feeding and toileting as well. Many family members hope basic care in the new setting will also support a high quality of life and encourage autonomy and the preservation of their relative's personal identity.

Despite the family's hopes, the structure of care in a formal bureaucratic setting may create challenges to providing the kind of care families desire. The organization of care delivery in nursing homes, as Litwak has elaborated (1985), tends to be highly routinized, efficient, hierarchical, and impersonal, leading to dissatisfaction in those caregivers who aspire toward providing more personalized care (Bowers and Becker 1992).

While working within the constraints of bureaucratic settings, however, staff can exercise considerable flexibility in the way they organize their work and choose to respond to residents' needs. This is true both of supervisory nursing staff on the unit (the head nurse and the charge nurse) and of the nursing assistants (NAs). It is the head nurse on the floor, however, who is responsible for creating expectations with regard to quality, content, amount, and the nature of work to be peformed. If head nurses are flexible in supervisory style, NAs can exercise more freedom in carrying out their work; where head nurses are rigid, NAs are forced to conform to stricter guidelines about what they can do and how much time they can devote to a resident. The head nurse, then, is a key figure for shaping the caregiving environment of the unit and NAs' approach to their work.

Several studies have explored how the organization and management of the nursing staff shape the quality of nursing home care (Halibar 1982; Mullins et al. 1988; Stryuker 1982). In one such study it was shown that the impact of the management on the organization of care may be modified by

the impact of lower level staff on the operations of a unit (Henderson 1981). More recently, another study (Bowers and Becker 1992) explored the perspectives of NAs concerning their work, their approaches to organizing it, and their perceptions about organizational constraints on the quality of care they felt able to provide (see also Foner 1994a). However, the study revealed little about how supervisors affected the work of NAs, except indirectly in terms of supervisors' evaluations of the work style each NA had developed. Given the accountability of NAs to the head nurse on the unit and her importance as the chief organizing force for delivery of care on that unit, the lack of studies exploring the perspective of the head nurse is surprising. The way in which her beliefs about "good enough" care and care delivery are assimilated and translated by her staff into the everyday practices of caregiving are crucial to the experience of residents on the receiving end of the caregiving chain.

The purpose of this chapter is to describe how the head nurse of one dementia unit of a nursing home conceptualized her professional health care mission and to explore the multiple contextual pressures that helped to shape the management style and approach she developed to accomplish it. We found that her understanding of the basic health care requirements that the institution must provide, as well as the special needs of the residents on her unit, influenced her own beliefs about the care needs she and her staff must provide. Moreover, her particular interpretation of the bureaucratic constraints imposed by her institution in light of her own place within it affected the managerial approach she assumed in structuring care delivery on her unit. An additional intent of this chapter is to share the process of conducting an ethnography, from the initial encounter in the field through an analysis of the data.[1]

THE STUDY

Setting

The study was conducted in a 40-bed special care unit in a nonprofit 500-bed nursing home complex on the urban East Coast. The nursing home itself was designed as a large biomedical complex containing ten nursing home units, several comprehensive geriatric clinics, plus a hospital to accommodate emergency medical crises. The nursing home was recognized in the community as a strong medical resource and attracted many families because of its rich and varied biomedical facilities. Many of its staff were also associated with a nearby hospital. The elders' easy access to the latter facility was influential in attracting many families to this particular nursing home.

Staffing of the Unit

Typically, the principal staff person on the nursing home units was the head nurse, a registered nurse from the day shift (7 A.M. to 3 P.M.), also known as the "7-to-3" shift. She organized the delivery of care on the unit, was responsible for administering routine treatment and sometimes medicine, brought suspicious medical concerns to the attention of the medical staff (physicians and physician assistants), and completed all required documentation about the resident and treatment. "Treatments" are physician-ordered procedures requiring licensed skills, such as catheter care, decubiti care, or tending other lesions or wounds.

During the day shift, the care manager, a licensed practical nurse, generally administered medication and assisted the head nurse in providing treatment, managing the unit, and documenting treatment. There was no registered nurse in charge for the other two shifts (3 P.M. to 11 P.M. and 11 P.M. to 7 A.M.) or on weekends, so the care manager was solely in charge during those times. In addition, care managers from the "7-to-3" shift assumed responsibilities of the head nurse in her absence (for example, during illness, vacation, or after leaving her job). Although head nurses and care managers in charge of nursing home units each approached their work and organized the labor of their staff somewhat differently, each head nurse tended to establish rules about accommodations to care that were generally applied by all shifts in their interactions with family members.

Nursing assistants carried out all the routine patient care, such as assisting with dressing, transfer from bed to chair, basic grooming, feeding, changing bed linens, and other assistive tasks. They had the most "hands on" contact with the resident and often brought medical problems to the attention of the head or the charge nurse. Nursing assistants ranged in number from only two on the night shift to as many as six during the day. A bathing assistant was also hired for one day a week for six hours to bathe the residents. Diverse other staff who had regular contact with the residents included the activities and music therapists and staff who provided religious services. Each of these individuals worked with residents at least once per week.

Most medical problems discovered by the nursing staff were referred to the physician assistant (PA), who came to the floor daily to investigate problems, provide special treatments, write prescriptions, offer recommendations, and make referrals to specialists. Of medical providers, the PA had the greatest amount of time dealing with particular medical concerns. Also, a psychiatrist came to the unit once a week to address referrals and consider medication changes. The visit could last as long as two or three hours. Finally, a physician came to the unit at the end of the day shift to briefly review charts and sign off on the PA's recommendations. This visit rarely exceeded 30 minutes. Although the physician probably spent the least time on the unit of all medical personnel, and thus was the least familiar with

residents' problems in a comprehensive way, families usually preferred to go to her or him with requests or concerns, often to the irritation of the other staff.

The Residents on the Unit

The residents on this unit, as a whole, represented the most severely impaired dementia patients in the nursing home. Most of the residents were too cognitively impaired to be administered standardized cognitive assessments. In addition, most of these residents displayed disturbed behaviors, such as noisiness, repetitiveness, and/or inwardly or outwardly directed aggressive behaviors. Of the 40 residents, 32 were female. They ranged in age from 66 to 95, with 86.5 as the median age. Twenty-three were in their 80s, twelve in their 90s, and only five were in their 60s or 70s.

METHODOLOGY

The methodology was ethnographic, based on the approach to field work initially formalized by Malinowski (1961 [1922]), and later codified and elaborated by many others (for example, Agar 1980, 1986; Van Maanen 1988; Hammersley and Atkinson 1983; cf. Hughes 1992). It incorporated participant observation (the engagement and close observation of a supposedly different culture) (Keith 1988), a close relationship with a "key informant" (Morse 1991) who helped the ethnographer "interpret" the culture, detailed recording of observations, and both informal and semi-structured ethnographic interviewing (cf. Spradley 1979; Mischler 1986; Rubinstein 1988) of nursing staff.

Historically, participant observation was used to discover the culture of the "primitive" and nonwestern "other" (Marcus and Fischer 1986; Clifford and Marcus 1986). It has since become the hallmark of anthropological research and has expanded to the study of a wide variety of contexts in western society, including classical studies of medical institutional settings (cf. Goffman 1961; Estroff 1981; Rhodes 1991), studies of nursing home life (Shield 1988; Savishinsky 1991; Gubrium 1975), and other qualitative gerontological studies (Myerhoff 1978; Reinharz and Rowles 1988; Gubrium and Sankar 1994).

In studying these local contexts, anthropologists typically do not live among the people they study, as they did in their study of cultures far from home, but return home at the end of their work day. Similarly, the first author, who conducted the field research for this study, did not reside on the nursing home unit, but returned home at the end of her work day, which varied from evening to early morning.

The Head Nurse: The Key Informant to the Study

Since the purpose of the study was to learn the beliefs and social pressures that shaped the head nurse's approach to organizing dementia care on her unit, the head nurse was the natural choice for the "key informant" (Morse 1991). We expected that her perspective about the nature of dementia and her experience of multiple institutional, unit specific, and other pressures would further shape her supervisory style and structure for providing care.

Each unit of the nursing home was supposed to be run by a head nurse, who was a registered nurse (R.N.) and responsible for coordinating the care on the unit, with her assistant, a licensed practical nurse (L.P.N.), who managed that care. On this unit, however, the key informant "head nurse" had been occupying this position only as a "fill in" until a permanent head could be secured. She was, in fact, the "acting head nurse" and held an L.P.N. degree originally qualifying her as the unit's care manager. She was made the "acting head" after the previous head nurse resigned. This was eight months before the researcher began the study. During that time, this acting head nurse trained an R.N. for the position, but the latter left after three months. She remained the acting head for five more months until another R.N. was hired for the position. After training this new person, she resumed her previous position as the care manager. For most of the time that she was acting head nurse, another nurse, also an L.P.N., helped her out with regular nursing routines.

Families who were acquainted with the acting head nurse from the time she was the care manager regretted how the new position "tied her down" with desk work that removed her from floor contact with the residents. They liked her manner of interacting with and caring for residents and also felt that she could do a better job of supervising her staff from a perspective on the floor, rather than from behind a desk.

The acting head nurse (who will simply be identified as the "head nurse" in the remaining text) in fact expressed considerable concern and empathy for the residents on her unit. On several occasions, she referred to herself as their "advocate," sometimes even against their own families. She also expressed empathy with them for all that they had lost in leaving their homes to move into a nursing home.

Methodology

I (the first author) conducted ethnographic research over a nine-month period. I visited the unit several weeks before beginning research there to ensure that it was an appropriate research site, to become acquainted with the staff, and to learn if there were any potential problems that would interfere with research there. Subsequently, I met with a key administrator

to describe my research plan and to elicit support and suggestions for facilitating the research without overburdening the caregiving staff with research demands. The administrator then introduced me to the Assistant Director of Nursing (ADON). The ADON officially introduced me to the unit, reaffirming the administration's support and encouraging staff support.

This study, though focused on the day shift nurse and her staff, was part of a larger project in which the ethnographer was investigating behavioral disturbances of the residents and the contexts in which they occurred, evolved, and/or subsided. Families of residents on the unit were all informed of the study by letter, including information for contacting the researcher about any questions.

The approval from the administration allowed entry to conduct the research. However, because of existing employee/administration tensions, it also raised some questions of the actual role of the ethnographer. In this case the strong perception by the NAs of their subordinate position within the administrative hierarchy fueled their concern about the ethnographer as a possible representative of power (the administration) who might threaten their position. It also immediately raised the important issues of the actual power differential between the researcher and subjects (cf. Tourigny 1994:178–179; Clough 1992:131–136; Clifford 1986). My earlier visit—an introductory strategy other researchers have recommended (cf. Kahana, Kahana, and Riley 1988)—served favorably to weaken suspicions about my association with the administration.

My ethnographic observations covered all shifts, although most of the time spent in the field occurred during the day (7A.M. to 3P.M.) shift and extended a couple of hours into the 3P.M. to 11P.M. shift. For several weeks, I came to the unit before the 7A.M to 3.P.M. shift to observe the early morning care routines of the nursing assistants. During this time, I also observed the transitional staff meeting between the two charge nurses from the night and day shifts and the subsequent staff meeting in which the head nurse familiarized the 7A.M. to 3P.M. staff with the status of residents, alerting them to pay special attention to unusual conditions. Many days I stayed late into the second shift, through the transitional meeting between the charge nurses on the two shifts. I also stayed through the 11 P.M. to 7 A.M. shift on three occasions. On two occasions, I spent 24 consecutive hours on the unit, napping on a lounge chair as needed, in order to experience the unit as a whole, with variations, during one complete day. This unbroken day allowed for a fuller immersion into the nursing home unit than on days when I spent only hours there.

During my nine months on the unit, I spent time talking with the entire staff (from housekeepers to professional medical staff), as well as families, companions hired by the families, and where still possible, the residents. All comments relevant to floor life, interactions with family, caregiving, and

work organization were documented in a daily journal, which constituted the field notes.

Whenever possible, notes were taken immediately after a conversation ended in order to allow for the most accurate and clear retention of details. For similar reasons, observations were documented as soon after the event as possible. If this was not possible because of the need to focus on other issues, I jotted a short (sometimes single phrase) outline of the issues I wished to elaborate on later in my written notes. These were then completed on the unit or at my office. Daily notes, however, were not conceptualized as documenting isolated events. Rather, as much continuity as possible was incorporated into the note taking process by my ongoing reflections about the linkages between current and previous observations (cf. Atkinson 1992).

During the several initial months of the study, the detailed notes that were kept in the journal were dictated and audiorecorded on a daily basis. At the same time, incomplete notes or outlines of notes I could not complete because of the need to attend to competing activities (e.g., observations of new family/staff interactions, making an introduction with a family member, catching up on a previous conversation with an NA who had a few free moments to chat) were also elaborated on during dictation for audio-recording at this time. The audiotapes were then transcribed and made available on both hard copy and computer diskettes for later review. Because of limited funding, transcription of audiorecordings was no longer possible after the first few months, and hand-written notes or occasionally typed notes became the sole recording source of observational data. In making recordings of observations, I attempted to leave nothing to the imagination. Notes were taken not as if they would be used solely by me, because that could have left implicit many contextual understandings. Rather, they were taken as much as possible from the perspective of a naive observer who assumed nothing. This was to allow a full and explicit record of my observations as I constructed the text (cf. Atkinson 1992:471) and would be usable by other researchers on the project. It also provided a concrete check on particularities of events, which often become trans-formed in memory.

In addition to this narrative data, semi-structured interviews were conducted with the NAs from all shifts to acquire a flavor for differences in the delivery and organization of care across shifts. Nevertheless, consistent with the focus of the study on the organization of care during the day shift, the primary sources of data for this paper were the head nurse and the nursing assistants from the 7 A.M. to 3 P.M. shift.

I explained to the staff and families that while the general focus of the study was on the behavioral disturbances of the residents on the unit, the research concerns went beyond these to a larger investigation of the various contexts in which residents' behavioral disturbances were observed. I explained how this meant studying everything that might possibly affect a

resident's behavior. I attempted further to describe how the research would begin with intense observations of the disturbed behavior and adjacent events, including the family's involvement or interaction with the resident, but would also explore the institutional context. As the study progressed, I tried to explain that this meant examining the institutional setting in which care was administered; the way care was organized on the unit; the perceptions, complaints and concerns families and residents voiced about that care; and the constraints the caregiving staff faced in conducting their work. Finally, I explained my interest in learning about dementia, both from the professional perspectives of the staff and from the family. While thus explaining that I would be very curious, or "nosey," I also made it clear to everyone who spoke with me that their comments would be confidential.

As part of this study, I conducted semi-structured, confidential interviews with the NAs, using an interview guide with space provided for the narrative response. The interview questions were generated from questions I developed empirically from observations and from earlier conversations with some of the NAs. The interview explored the way NAs structure their work and cooperate with each other to complete it, their priorities in caregiving, and the constraints under which they worked. They were also asked about their communication with families, the kinds of interventions they have used with disturbed residents, and their views about the most effective interventions.

Consistent with the emergent "open-ended" approach of the ethnographic interview (cf. Hughes 1992:443–444), I felt free to deviate from the guide and explore relevant issues that emerged. In fact, I often found that the interview form proved an impediment to conversation. On a few occasions as I prepared to write an informant's comments, the NA asked, "Do you have to write this on the form?" When I said "No" and put my pen down, the conversation began to flow. Later, I did note the event and related issues in my journal.

Because of the enormously busy schedule of the NAs, interviews were covered during brief periods when they found the time to take a short break. They guarded their regular break times and lunch periods because of the strenuous nature of their work, so, except on rare occasions, other periods were sought to conduct these interviews, often in piecemeal fashion. I continued to chat regularly with the NAs as they worked, or I would observe their delivery of care, possibly asking a question. At other times, they might call me over to show me something of potential interest.

The head nurse—the person responsible for organizing the unit's approach to care—was the key informant for the study. She too was assured confidentiality. Everything she said that was viewed as relevant to her approach to structuring care was elaborately documented in my daily field notes. These included information about the head nurse's priorities in caregiving, her rationale for these, communications to her staff, and con-

straints that limited care provision. Anything the head nurse said about the dementia process was also documented in detail in my notes. Finally, I noted verbal exchanges between the nurse and families over their relatives' care. Of particular interest were the nurses' assessments of families' views about their relatives' condition, and of their special requests and concerns.

For the larger study of behavioral disturbances, I would move from place to place on the unit as dictated by occurrences that caught my attention (e.g., a fight between two residents, a musical activity, or the entrance of a family member). The head nurse, however, spent much of her time behind the nurses' station, completing paper work. Thus, to gain information relevant to this study, I would spend long periods of time behind the nurses' station, reviewing chart work or conducting floor observations, as I conversed with the head nurse, the latter's time permitting. Sometimes I would ask questions that emerged from observations of a resident, the family, or the conduct of nursing assistants. At other times, I might query the nurse about official care expectations or ask more information about a comment she might have made about those expectations. At still other times, I would discuss with the head nurse points of information about the dementia process, based on the head nurse's understanding of it from years of exposure to residents with this disorder.

Although the head nurse had considerable paper work, she agreed to answer any of my questions while she completed her own work, unless she felt her participation would compromise the quality of her work. In such cases, or if the questions raised were too demanding of her available time, the head nurse offered to set aside time during a later period to elaborate on her responses. She always kept her promise to make herself available.

There were other contexts that also proved useful for gaining an understanding about the head nurse's views on dementia care. These included the weekly care conferences (cf. Shield 1988: 61–65) in which several residents were discussed on a rotating basis with the social worker, activities therapist, nutritionist, and medical professional. By open invitation, I attended these, as I did many of the staff meetings the nurse held with the NAs, and occasionally, with administrative staff. Comments by the head nurse and others during these meetings often provided the basis for further questions to the nurse. Thus, my ethnographic approach for learning about the head nurse's perspectives on care and about the institutional culture in which it was provided approximated one of student (the ethnographer) with teacher (the nurse)—one form of the informant/anthropologist relationship. Over time, I attempted to acquaint myself with all family visitors, identifying myself as a researcher and attempting to separate myself from the clinical staff. Many of them appreciated my interest in their family member and would often come up to me on their own to offer a comment, make an observation, or ask to talk privately. In this way I learned much about their views, concerns, and wishes.

Whenever a tense interaction occurred between the head nurse or other staff member and the family, I would listen and take notes about the issues. After the interaction ended, I would then approach the family, introducing myself if necessary, to learn about their concerns and the nature of the encounter.

The first time that this happened, I observed the nurse's raised eyebrows as I was approaching the family. After completing my conversation with the family, I made a point to explain to the head nurse that I was interested in learning the family's perspective as well. However, I would also talk with the head nurse about the encounter in an effort to gain her perspective about the issues, the validity of the family's response, and her views about accommodating the family.

Glitches in the Research Process

Despite considerable support from the nursing assistants, head nurse, and families, the research did have its glitches. For example, the close proximity of myself and head nurse, often seated together and talking behind the nurses' station together, initially inhibited some family members from talking openly with me. I explained that I was not part of the clinical staff and that I felt the family's perspectives about care were valuable. Only one woman remained mildly hesitant in talking openly with me. As families learned that I too had a parent with dementia, they seemed to share their thoughts with me even more openly.

For the first couple of months, the NAs wondered whether I was a spy for the administration. The relationship between NAs and the administration was becoming tense due to an impending strike, and my sudden appearance raised questions. The staff had experienced researchers before; they had even completed questionnaires for them. However, they had never experienced an anthropologist's perpetual probing. My curiosity, it seemed to them, went beyond the more limited structured research to which they were accustomed and it piqued their suspicion that I had been hired by the administration to evaluate their work. In such situations, an awareness of power differentials becomes sharpened, revealing the lack of balance within the ethnographic situation (cf. Tourigny 1994:178–179; Clough 1992:131–136; Clifford 1986).

Just as they were becoming convinced that I was indeed not working for the administration, an event occurred that once again challenged my security. One NA was asked to file a report on her involvement with a resident who had allegedly been abused. When I asked if I could see it, the NA was reluctant to share it. The sensitivity of the situation apparently had rekindled her suspicion. I was concerned that she might rally support against the research because she had seniority and enjoyed relative power among the other staff.

Despite this experience, the NAs continued to share their thoughts. By the time I was halfway into the study, one NA actually expressed appreciation for having been taken seriously and having apparently valued her perspective. She noted that being regarded as an authority of care, rather than being always at the lowest end of the medical hierarchy, was a refreshing contrast. Such an experience of reciprocal gain is extremely satisfying in field research (cf. Reinharz and Rowles 1988:8–9), where the potential for one-sided gain by the researcher looms ever too large, as the "new," or critical, ethnographers have warned (cf. Clough 1992; Marcus and Fischer 1992; Clifford and Marcus 1986).

The head nurse was the one who related the NA's renewed suspicion to me, perhaps as a way of communicating her own. In the conversation that followed and my expression of concern, however, it seemed as if the head nurse had allayed her doubts. A few days earlier, the head nurse's main assistant was also beginning to ask questions about what an anthropologist "really does." Similarly, during this time I sensed some tension with the head nurse when asking questions that did not specifically relate to a behavioral disturbance, such as a query about an administrative procedure (e.g., "How do you go about getting lost dentures replaced?"). At these times, I would reiterate the importance of the institutional context in which behaviors occur. By the time the nurse began to share her views about several administrators and their policies, several months into the study, I felt assured that the nurse indeed trusted me.

Although the tension with the head nurse diminished after this encounter, I detected some annoyance on occasions when I asked questions that challenged the nurse's belief system about dementia. These were instances when I took seriously a resident's complaint. In one case, the head nurse just smiled with raised eyebrows, noncommittedly.

In another case, the head nurse suggested I was seeing things the way families often do in attributing "unreasonable" credence to the resident's remark. I experienced this comment with particular sensitivity because I felt accused by the nurse, who knew that one of my parents resided in a special care unit. In retrospect, the head nurse's observation/allegation had disturbed me because it rang so true. I had to admit to myself that my experience as a family member enabled me, in fact, to understand families' perspectives about dementia and its care more easily than the staff's, since I experienced the families' life world myself. Such, however, is the nature of ethnographic research; there is no escaping the fact that ethnographers always bring their own life beliefs, history, and values to the field as they study others with different life experiences (cf. Silverman 1988). Our task is, in spite of our differences, to penetrate the life worlds of those others we study, as they penetrate ours.

FINDINGS

Ethnography is an ongoing process, engaging the ethnographer reflexively in a private discourse throughout, rather than waiting until "data collection" has ended (cf. Eckert 1988). Initially, I reviewed all the notes (the narrative data) to select material relevant to the study. My memory helped lead me to particular material, but I perused all field notes for possible missed insights. I then selected passages relevant to the head nurse's beliefs about dementia, her approach to organizing of care on the unit, her description about institutional and related pressures, and her perspective both on the operations of the institution and on the families' expectations. Notes taken from conversations and interviews with the nurses and NAs, from discussions with families, and about observations that might lend insight about the nurse's perspective were also pulled for review. These included the NAs' understandings about care priorities and the special requests they could or could not accommodate.

The relevant passages were then analyzed for their thematic content and consistencies (cf. Luborsky 1994). We (McLean and Perkinson) divided the data and independently reviewed and roughly categorized themes that emerged. Elaborate discussion followed, with considerable exchange in identifying key components of the head nurse's beliefs and approach to care provision. This dialectical process helped to heighten our level of agreement and to refine the categories we had initially formed.

It is important to note that an approach that uses selected data in this way, though useful to the task defined, can lend itself to a decontextualized, segmental approach (Atkinson 1992). To avoid the potential pitfalls of this approach and to preserve the holism of the enterprise (Noblit and Engel 1991), I maintained an intimate reference to the narrative data throughout this process. This helped avoid decontextualization of the narrative passages and also served to corroborate, challenge, and/or clarify findings.

The data were analyzed to determine the head nurse's beliefs about senile dementia and the related care needs of residents with this disorder. The head nurse's comments about dementia, reasoning about accommodating or not accommodating to special requests, and her criteria for judging families as "realistic" or "unrealistic" revealed some of the assumptions and conceptual frameworks that shaped her perspective about dementia care and helped her to establish care priorities.

The narrative data were examined to determine the various pressures that the nurse may have experienced in providing for her residents' care needs. Her history on the unit, her position of power within the nursing home, and the typical bureaucratic constraints she had experienced were all examined. Finally, we examined the criteria that the head nurse had identified with quality care. The analysis revealed a value hierarchy of care priorities that defined her criteria for care within the constraints of a bureaucratic economy of care.

The sections below will discuss the following sets of findings: the head nurse's beliefs, that is, her assumptions and conceptual frameworks for understanding dementia and dementia care; the nurse's peculiar professional history on her unit and position in the institution; and the bureaucratic constraints that limited the care options she could allow her staff to provide. These sets of findings identify the ideological, historical, and structural contexts—the institutional backdrop—within which the nurse organized the delivery of care on her unit. The last section will elaborate on the head nurse's value hierarchy of care as the intersection of these beliefs, experiences, and constraints.

The Head Nurse's Beliefs Concerning Dementia

From her professional training and years of experience working in different nursing homes with extremely difficult dementia residents, the nurse came to adopt a set of pessimistic assumptions about dementia through the lens of a medical model, linked to an image of a diseased brain. Her nurse's training, acquired during the 1970s, also attuned her more to acute care issues than to ongoing long term care needs.

Given this training and clinical exposure, the strong medical model under which this nursing home operated—in contrast to the social model adopted by many other homes—made sense to her and sharpened her focus on disease. The particular unit she headed housed the most extremely behaviorally disturbed residents of the nursing home—those individuals for whom a rehabilitation potential was viewed as slim. From repeated years of exposure to such severely disturbed persons, she came to adopt a fatalistic view about the general trajectory of dementia. She came to see dementia as a progressive and intractable disease that destroys the cognitive functioning of its victims—a prognosis and perspective she applied to all residents with that diagnosis. Despite her tendencies to see the residents on her unit as persons with desire and intent, her competing powerful disease lens generally led to her explaining their behavior in the reductionist, dehumanizing terms of disease process.

Yet, she revealed contradictory elements in her concern for the residents' well-being. She seemed to hover, as many nurses have in similar settings (Hyman, Bulkin, and Woog 1993), between an appreciation of their right to freedom and their right to protection. For example, she empathized that residents have given up so much in coming to the nursing home, that their wishes should be honored whenever possible, even over those of their family, if necessary. Yet at other times, she could not overcome her proclivity to protect residents even if that meant totally disregarding their preferences. This strong sense of protectiveness similarly came to dominate over her competing inclination to support autonomy in her approach to providing for dementia care.

Her comments about "unrealistic" families further elucidated her conceptual framework concerning dementia. Unrealistic families were those who saw their relative's problem as immediate and localized and thus correctable by immediate and localized environmental accommodation. These families, for example, would insist on replacing dentures in order to reduce their relative's agitation about a pureed diet which the resident considered unpalatable ("Pureed food is delicious!" insisted the nutritionist). From her view, the problem went far beyond this immediate concern. It was, in fact, beyond anything the families —or anyone else—could do to make a difference.

In addition, the nurse distrusted many families' judgments about their relatives' needs because she felt they were denying the severity of their relatives' dementia and that they based their views on their memory of how their relatives "used to be." The nurse also distrusted the view of some families concerning psychotropic medication because the family member lacked the medical training she viewed necessary to form any legitimate opinion or spent insufficient time with their relative in the nursing home environment to know how they tended to act over a prolonged period. Families, she was convinced, were also out of touch with residents' needs because they were often operating out of their own guilt, rather than out of genuine concern for, or ability to objectively judge, their needs. This was, she stated, because she was able to see residents as they are, whereas families were invested in maintaining a view of residents as they *used to be*.

On the other hand, she at times could empathize with families, and admit that she might behave similarly if she were in their shoes. The head nurse, however, insisted that she and her staff see more of the resident than does the family, so are thus in a better position to judge his needs. For example, the nurse thought the insistence of some families on replacing their relative's dentures was foolish when the resident would not cooperate with the dentist. It seemed to her also as a poor use of her staff's limited time to take him to multiple dental appointments, because of his inability to cooperate for long, just to get the mold completed. In addition, her experience was that residents with dementia often remove their dentures and lose them. To spend all the energy to get a pair made just to have them lost seemed wasteful and senseless to the head nurse.

The head nurse also regarded families' quality of life concerns, especially with the more cognitively impaired residents, as specious. She argued that these concerns, like the ones families raised about human dignity, reflected the family's notion of life quality, not the residents'. The head nurse's fatalistic disease model and pessimistic assumption about the value of environmental manipulation shaped the priorities she outlined in her hierarchy of care. Since, according to this view, so little can be done to change the trajectory of disease, "good enough" nursing care for dementia should focus on basic custodial and medical needs.

The Historical and Institutional Contexts of Her Position as "Acting Head Nurse"

Although she was charged with additional responsibilities as the "acting head nurse" of the unit, she did not perceive that the administration invested her with authority, and there were no material signs to mark her different from before. Her salary was not changed, and she was not given the additional time and clerical help that other unit heads received to complete their paper work. It seemed to other unit staff that the administration took advantage of her powerlessness and began also to transfer ("dump," in their words) behaviorally difficult residents from other floors. Many of the staff felt these residents were both atypical and "inappropriate" for the unit, given their higher level of cognitive functioning. Yet, unlike her predecessor, the head nurse accepted them without question. The head nurse accepted the additional responsibilities of her temporary position, but did not challenge, nor seemed to resent, her apparent lack of authority. She had always hoped to become an R.N. some day and did seem to enjoy her additional responsibilities, however.

The current head nurse, serving in an "acting" capacity during the study, had worked on the unit for six years. She had been trained originally as the manager by the previous head nurse—an extremely "tough" and "no nonsense" nurse. As one family member put it, "Lillian was very strong; under her, the NAs did exactly as they were told." Many families also felt that the NAs were more responsive to residents' needs when the former head nurse was heading the unit, and that things had become more lax with no one on the floor to offer "hands on" supervision. The NAs themselves remembered the former head as either "much too tough" or "tough, but fair." The former head nurse and the current "acting" head nurse had been a good management team and ran the unit as a "tight ship," bound by the institution's rules and expectations.

The acting head nurse retained Lillian's strong sense of responsibility, institutional obligation, and impatience with incompetence. However, unlike Lillian, she did not wield power with the administration or her staff. In addition, working under Lillian, she did not have to appear overtly tough with the NAs under her management, because Lillian was the "tough parent" to whom they felt accountable.

After Lillian left, this pattern was hard to break. Given her clerical support with paper work, Lillian had been able to spend considerably more time on the floor than the current head nurse, who received no assistance. Thus, floor supervision of the NAs became drastically reduced.

The current head nurse was respectful of institutional rules and policies, but critical of nursing home unit heads and NAs who were not. In addition, her style for communicating dissatisfaction was linked to her sense of institutional propriety. When one of the NAs under her supervision did something wrong, however, she did not openly challenge her, as Lillian

would have done. She either bit her lip in silent annoyance or explained to the NA, sometimes in a disdainful tone, that she was violating the expectations of "her job." Some of the NAs claimed they were offended by this approach, because it expressed a depersonalized and moralistic appeal to authority. One NA compared it unfavorably to the more personal comment from yet a different supervisor, "Oh come on, it's not that bad, now. Is it?" Another NA—the senior NA on the unit—felt singled out in being asked to extend herself more because of her seniority. She disliked the moral tone the acting head nurse invoked in saying she had expected more of her.

With her literal interpretation of the institution's rules, she sometimes came across to her staff as an apologist to the administration. For example, when staff complained they needed an additional NA on the unit to handle the work load, she immediately discounted the idea on the basis of the administration's financial crunch—invalidating the staff's own needs. She also was careful not to reveal any information with families that might jeopardize their positive views of the nursing home. Her protective stance toward the nursing home and rather rigid interpretation of its rules may have helped to overcompensate for her inexperience and perceived lack of authority in her new role.

The acting head's history of working on the unit in a different capacity made it difficult to establish herself as a strong authority in her new, temporary status. Adopting a disengaged managerial style that appealed to institutional rules and morality only served to alienate a staff who already felt considerable tensions with the administration. Her tight interpretation of institutional rules, however, lent itself to a clearly defined hierarchy of care that delineated expectations for her staff.

Bureaucratic Constraints on the Nursing Staff

The bureaucratic constraints within which the nursing staff operated imposed a very demanding economy of care on its units to ensure that the fundamental needs of its more than 500 residents would be met. These constraints made staff reluctant to respond to special requests for nonroutine care. Under such a tight economy, special care requests could be provided only if they did not threaten the completion of the more fundamental routine care needs of other residents. The additional burden of paper work, without the clerical support other head nurses enjoyed, further limited the amount of nonroutine needs the head nurse felt she could "afford" to address.

For example, the bath attendant was required to handle eight frequently immobile and/or uncooperative elderly residents within three and three-quarter hours. This included undressing them, examining their skin, bathing, and redressing them. If she should exceed that time limit in the process of responding to special requests, she could be penalized for her inefficiency

and eventually be terminated from employment. This constraint, so familiar to the head nurse yet invisible to families, drastically limited staff's ability to offer the individualized attention that families wanted.

Thus the formal organization of care delivery in the nursing home was structured, as Litwak described (1985), according to a detached division of labor that was impersonal, hierarchical, rule-governed, and instrumentally motivated (e.g., performed for payment). Although such routinization and lack of attention to individual difference could be experienced as humiliating and dehumanizing to residents, the nurse was convinced that this was not the case, since most of the residents on the unit were too impaired, in her view, to realize the difference. Rather, it was their family members, she felt, who projected their own feelings of humiliation at the situation onto their relatives. This occurred when they raised the issue of human dignity in response to staff refusal to satisfy special requests.

The Care Hierarchy: The Head Nurse's Criteria for Quality Care

In such a demanding bureaucratic system, neglecting to carry out prescribed care routines with a resident would lead to reprimand, suspension without pay, and even termination; not bothering to search for the resident's glasses, however, would not endanger the nursing assistant's job. Working within such a system required that some practical choices be made, not for the welfare of the resident, but for the protection of the caregiver.

In order to help structure care choices for 40 residents within the institutional constraints of staff and time limitations, and to avoid the system's wrath, the head nurse developed a general care hierarchy, based on her beliefs about "good enough" care. This hierarchy prioritized care needs according to their perceived importance to all residents. This was not an explicit, concrete, documented hierarchy as such. Rather it was an implicit operational one, inferred from repeated observations and extensive discussions with the nurse as to those concerns that demanded differential attention over the course of a nursing staff's day. This care hierarchy established staff's criteria for quality care delivery.

First and foremost on the hierarchy was custodial care (cleaning, feeding, toileting), protection (restraining a resident to prevent falls when unattended), and medical attention to urgent or apparent problems (e.g., trying to recover respiration, cleaning an open sore). Second was medical attention to more ambiguous, apparently less serious problems identified solely on the basis of complaints by residents whose dementia challenged their reliability. Third on this hierarchy of care was the placement, repair, and ordering of prosthetic devices such as hearing aides. Last on the staff's hierarchy were individualized nonroutine efforts to minimize agitation or respond to a nonroutine request by a resident or family member. Non-

routine requests were concerned with improving the resident's quality of life (e.g., trying out a mechanical device to improve a resident's experience with bathing). The higher up the hierarchy that a care request appeared, the greater the likelihood that staff would respond to it.

In contrast to families' care emphasis on individualized quality of life (cf. Bowers 1988), the nurse and her staff were most concerned with the pragmatic routine care of the body. This had been inscribed in the very definition of their work. Each nursing assistant was responsible for completing a list of *bodywork* tasks, which they referred to as activities of daily living (the ADLs) for the residents in her group, and was required to document each task on the patient/resident's chart as she completed it. Starkly absent from this list was any reference to feelings or affective well-being [see Henderson, this volume].

Several behavioral dynamics were involved in operationalizing the care hierarchy. The head nurse spoke about care priorities during daily staff meetings, especially when someone in her staff had used poor judgment in ordering her care. Any time a family member requested something that was not routine, she informed the NA to refer the person directly to her, so she could explain to them what her staff could and could not do. Finally, she communicated her annoyance to NAs who failed to operationalize her hierarchy as she conceptualized it. In these ways, the NAs were socialized to the expectations of the care hierarchy.

Staffing patterns also reinforce the care hierarchy. During the day shift, only five nursing assistants were available to meet the care needs of 40 residents. Even fewer were available on other shifts. A unit-specific nonformalized protocol had been developed to implement the principles of the care hierarchy. This enabled the staff to more effectively economize their time to finish the required ADLs and to guide nursing assistants in deciding how and when to help residents and their families. For example, it prohibited responding to requests during meal times—even for toileting—until all residents had already been fed.

The rules of this informal protocol extended to families as well. For example, families were supposed to request help only from their attending NA. Also, by restricting dressing to once daily, it prohibited families from making such requests as well. Families learned about this operational protocol the first time they transgressed it. Whenever a family made a nonroutine request (e.g., to try a new dress on their family member), the nursing assistant informed them of the rule and referred them to the head nurse. She reinforced this practice, often agreeing to accommodate the family "just this once" as long as they understood this was an exception.

DISCUSSION

Working within a bureaucratic system that imposed objective staffing and time constraints on care provision, the head nurse felt she could ensure

the completion of only the minimal routine care requirements of her residents. In dementia care, tremendous variation exists from facility to facility, and from unit to unit, in considerations given to residents' needs beyond the custodial. Institutions differ in their philosophies from the most radical social model to the heaviest medical approach, like the facility in the study.

This study focused on the way in which care delivery on a dementia unit is further mediated by the head nurse, who is responsible for organizing it. In studying this process, I examined the nurse's beliefs about dementia as they entered into her construction of good care, her work history on the unit as that affected her supervisory approach, and the institutional constraints within which she had to structure the delivery of care.

The amount of flexibility a head nurse allows herself in interpreting institutional rules to organize care delivery, however, is by no means uniform. The rigidity the head nurse adopted in interpreting, and becoming constrained by, institutional pressures was related to her inexperience as a head, the temporary and uncertain nature of the position, and the pattern of her prior relationship with her staff as the "easy" parent. Adopting a rigid reliance on regulation and authority allowed her to safeguard her own uncertain position and provided a basis, no matter how alienating, for dealing with her staff. Her hierarchy of care provided the basis for "good enough" dementia care, based on her understanding about dementia and its needs, within a care economy based on her interpretation of the constraints imposed by the institution. This hierarchy helped assure her that none of the residents' most fundamental needs would be neglected.

This is necessarily a partial description, based on partial considerations of the head nurse's clinical beliefs and interpretation of, and response to, institutional pressures (cf. Clifford 1986). It is also partial in being based upon field notes that were restricted to the institutional context and produced as the text of a single ethnographer, who described and interpreted her observations from a uniquely personal and historical lens. Moreover, it is partial because it is based on my unique intersubjectivities with each of my informants, with the various self-representations each brings to a discourse (Ewing 1990; see also Rosenwald and Ochberg 1992:1), and the unique emergent narrative productions those intersubjectivities afford.

It is this complex character of human engagement that allows—or disallows/hinders—productive discourse, while always constraining it as partial. This is not to discount, invalidate, or minimize it. It is simply to insist on qualifying the limits of ethnographic investigation.

Many issues emerged, or were suggestive, in the ethnographic data and my subjective experience that reflected the complex interplay between the work setting and events outside the work setting, such as personal history and current life events. For example, how did the head nurse's life at home, church, or other noninstitutional contexts help shape her belief systems that penetrated into the nursing home context, like her respect for and literal

interpretation of institutional rules and her appeal to morality and institutional authority in supervising her staff?

What other ideologies, beyond those that affected her beliefs about dementia, affected her provision for its care? For example, the head nurse maintained a strong egalitarian ethic in the way she parceled out the provision of care. She found family members who demanded special treatment for their relative particularly offensive. Yet, some of their concerns may have been valid, rather than based on desire or privilege. Was she able to make these distinctions within her powerful egalitarian practice ethic?

How did the particular ethnic differences between the head nurse, who was African-American, and the residents and families, who were mainly Jewish, and the strength of their ethnic identities intersect to further influence the nurse's willingness to accommodate their out-of-the-ordinary requests?

How did my experience as a family member of a close relative with senile dementia limit—or extend—my ability to understand the perspective of the nurse, who assumed a different care ideology than mine? While some researchers would call this "bias," it is of course a particular, but different, bias from that of another researcher who might have shared the nurse's dementia care perspective. Again, the relevant issue is how this particular bias worked to reveal the care hierarchy described. For example, did my rigidity in reading from the field notes about the nurse's interpretation of rules come from the way I perceived the nurse's personality, given our different life experiences? Probably not, since despite those differences, I really listened to and respected the nurse's comments.

Describing such a bare-bones hierarchy of care runs the risk of seeming somewhat demeaning of the head nurse, and minimizing her enormous job of providing care for the 40 residents on her floor. This is certainly not the intent here. Her work, like that of her NAs, is extremely difficult and demanding. It requires resourcefulness, energy, and intelligence, and it is undervalued. To concretize and generalize her values in dementia care within a hierarchy can be seen in her response to her perceived pressures. She was not fixedly committed to following her value hierarchy, but it captured her overall approach to coping with the multiple constraints of a long term care economy.

The head nurse's fatalistic view about dementia resulted in a standard care practice that relegated some care needs (person preserving, quality of life related) less important than others (those involving body work). Working as she was in a heavily medicalized nursing home setting, this approach was philosophically and economically compatible with the home's. Her inability to exercise administrative authority, however, resulted in the admission of more cognitively intact residents to her unit. Yet, care was organized on this unit in a way that special accommodations were mini-

mized. The unit's inability to address the personal needs of these more intact residents limited their quality of life.

Perhaps, however, the concern about not meeting residents' special needs should be even greater when the dementia process is well under way. Perhaps it is then that the most energy should be extended to preserve personhood, especially when the body may still be in good health (Kitwood and Bredin 1992). But, perhaps this approach represents the ethnographer's bias.