The purpose of this study was to gain understanding of the ethical aspects of the experience of providing day care to people with dementia. Telephone interviews were conducted to elicit phenomenological narratives of satisfying and dissatisfying experiences from staff members of a state-wide random sample of dementia day care facilities. The analysis was guided by the concept of situated ethics. Findings reveal that ethical challenges of dementia day care are embodied in the everyday incidents when participants, staff, or family members "cross the line" of acceptable behavior. An ethical hierarchy of staff responses ranges from benign manipulation to termination of day care. These findings help us understand the situated ethics of dementia day care and heighten our sensitivity to the lived experience of dementia day care staff.

Key Words: Phenomenology; Alzheimer's disease; Long-term care; Ethical dilemmas

Everyday Ethics in Dementia Day Care: Narratives of Crossing the Line

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Adult day care is a relatively new form of care for people with dementia in a community setting. Adult day care centers are community-based facilities that provide daytime support to disabled elderly people and their home caregivers. The purposes of adult day care for people with dementia are generally twofold: (a) to provide a meaningful and safe daily life situation for the clients, and (b) to provide respite support for the family caregivers (Graham, 1989; Lyman, 1993; Panella, Lilliston, Brush, & McDowell, 1984; Rabinowitz, 1986; Sands & Suzuki, 1983). Programming focuses on helping the day care participant to engage in activities that are meaningful, that build on former roles and interests, that utilize remaining skills, and that foster social interchange (Mace, 1987; Zgola, 1987). A current accepted approach is to work within the experienced reality of the individual person rather than trying to impose the "real" temporal, spatial, and personal realities of the day care setting (Feil, 1990). The services provided by day care are also intended to delay institutionalization as long as possible (Lyman, 1993).

The number of day care facilities nationwide has increased dramatically during the past 15 years. Research that focuses on understanding the world of dementia day care is beginning to appear in the literature. Borell, Gustavsson, Sandman, and Kielhofner (1994) and Hasselkus (1992a, 1992b, 1994) independently conducted ethnographic studies of dementia day care programs in Sweden and the United States, respectively. In both the Swedish and the American studies, staff depended heavily on keeping most, if not all, participants physically together and engaged in group activities throughout the day. Borell et al. (1994) referred to this as the "burden of keeping order" (p. 232). Hasselkus (1992a, 1992b) couched her findings from the United States more in the domain of safety, referring to the need to keep people together in a group as a strategy to "prevent harm." In the Hasselkus study (1992a), staff also sought to provide a pleasurable and therapeutic schedule of daily activities; nevertheless, the overriding concern for safety was evident in the constant vigilance over the day care participants as staff tried to "catch trouble early" and to "keep it calm."

These and other studies on the ethics of long-term care (Collopy, 1988, 1995; Hennessy, 1989; High & Rowles, 1995; Kane & Caplan, 1990; Moody, 1992; Olson et al., 1993; Thomasma, 1984) and, more specifically, the ethics of dementia care (Ekman & Norberg, 1988; Hermann, 1984; Hofland, 1994; Howell, 1984; Lyman, 1993; Moody, 1988, 1992; Post, 1994, 1995; Roberto, 1994) suggest that the world of dementia care may be dominated by the caregivers' needs for control over the behaviors of persons with dementia (Lyman, 1993; Post, 1994, 1995). Lyman (1993) described staff concerns about losing control as related to "both the generalized uncertainty and unpredictability about what dementia is and how it will unfold, and specific daily concerns about 'managing behavior problems'" (p. 11). Moody (1988) cautioned professional caregivers to be skeptical about the paternalism of a controlling approach to care, yet he also argued...

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that paternalistic interventions can actually serve to enhance autonomy in long-term care, enabling patients to make decisions in keeping with their own values; "It is all too easy to be against paternalism and to let the matter rest there" (Moody, 1988, p. 69). Collopy (1995) urged dementia caregivers to take a more "expansive perspective" (p. 150), one that admits and accepts the risks and hazards of autonomous behaviors inherent in the human frailty of the aged.

The purpose of the study reported here was to gain understanding of the ethical dimensions of the experience of providing day care to people with dementia. Telephone interviews were conducted with staff members from a statewide random sample of dementia day care facilities. Staff respondents were asked to think back over their practices and describe especially satisfying and dissatisfying experiences. This phenomenological approach follows the thinking of Benner (1991, 1994) and Brown, Tappan, Gilligan, Miller, and Agyris (1989) that experience-based narratives provide stories that reveal meanings about the notion of good, about practical moral reasoning, and about ethical dilemmas. "Narrative accounts uncover meanings and feelings in ways that shed light on the contextual, relational, and configurational knowledge lived out in the practice" (Benner, 1991, p. 3). With narrative data, a practice-based, situated knowledge of ethics is revealed. The ultimate goal of this study was to bring into clearer view the ethical dimensions of the world of dementia day care, thereby expanding our perspective and enabling us to carry out that care with greater insight.

Methods

VanManen (1990) stated that "...the lifeworld, the world of lived experience, is both the source and the object of phenomenological research" (p. 53). Narratives, or personal stories about the lived experience, provide one salient source for understanding the nature of those experiences (Bruner, 1986, 1990; Good, 1994; Polkinghorne, 1988; Ricoeur, 1984). In this study, a narrative phenomenological approach is used to gain understanding of the nature of everyday ethics in the dementia day care staff experience.

Sample

Using a sampling strategy described by Waitzkin (1991), a random sample of 50 day care centers was generated from the membership list (N = 120) of the Wisconsin Adult Daycare Association. Letters were sent to the directors of the day care centers in the sample to explain the study and to invite each to designate a staff member to participate. Telephone interviews were successfully collected from 40 of the day care centers for a response rate of 80%. Of the 10 nonrespondents, three agencies no longer offered day care, three were still only in the planning stages for doing so, and three offered day care only rarely or to a nondementia population. The 10th nonrespondent repeatedly postponed participation, and we ultimately terminated our recruitment efforts after 3.5 months.

Two staff persons responded from two facilities; thus, the total number of respondents was 42. Forty-one respondents were women; ages of all respondents ranged from 28 to 66, with a mean age of 44 years. Years of experience working with dementia clients ranged from less than one year to 36 years. Twenty-five of the staff respondents were program coordinators or directors, and six more held the title of activity director. These and the other 11 respondents included registered nurses, social workers, nursing assistants and licensed practical nurses, recreation therapists, and one each with backgrounds in related art, music therapy, occupational therapy, and physical education. Eight of the 42 respondents had no specialized or formal training beyond high school but relied on experience and continuing education.

Data Collection

The phenomenological question for this study was, "Think back over your practice and describe an especially satisfying [dissatisfying] experience in your day care for people with dementia." Two narratives — one satisfying and one dissatisfying — were collected from each respondent. A graduate student assistant carried out the initial interviews during the months of January through May 1993. Each telephone interview lasted from 20 to 45 minutes and was tape recorded for transcribing. In the interview, probes were used to keep the staff person "in" the experience; the goal was to elicit a detailed narrative about the experience itself as it was lived through, rather than the staff person's interpretations of the experience (Riessman, 1990; VanManen, 1990). Second call-back interviews were conducted later in the analysis process with 10 respondents; these respondents were chosen on the basis of their agreement to being interviewed a second time and on their apparent articulateness during the first interview.

In the interviews for this study, we asked the respondents to remember and recall experiences from the past. Bruner (1990) stated that experiences themselves and memories of experiences are typically framed in narrative form. In other words, to remember is to create a story. The storytelling of personal experiences occurs through recall that is "loaded" (Bruner, 1990, p. 58); that is, the narrative unfolds in such a way as to "justify" actions and attitudes. In the study reported here, the dementia day care respondents created stories of practice that justified their actions and their attitudes of satisfaction and dissatisfaction. This is the primal "voice" that is being heard in these interviews.

At the same time, a phenomenological interview is by nature an active interview (Holstein & Gubrium, 1995); that is, it is one in which both actors are striving to develop a plot, to produce meaning. The goal, however, is to derive meanings that reflect relatively enduring conditions rather than continuously new formulations.
Analysis

For this study, the analysis process began with a search for the structures of experience that make up the phenomenon of providing day care to people with dementia. To do this, a detailed line-by-line reading of each day care interview was carried out (Morse, 1994). Initially, the graduate student assistant and researcher carried out parallel reading and coding for units of experience on the first six interviews. Following this, the investigators met to reflectively share and reach consensus about early interpretations. After subsequent coding of the remaining interviews, further reflective discussions led to the identification of themes within the narratives. Call-back interviews were then conducted with 10 of the respondents to obtain their feedback on emerging understandings. The iterative process of reflective conversations and call-back interviews is built into the analysis in order to stay as close as possible to the “actual” text and to bring out the experiential complexities of the phenomenon of dementia day care.

An example that illustrates this analysis process is the following: The early parallel coding of the first six interviews led to an awareness that the narratives often featured “beginnings” and “ endings” of a participant’s day care experience; a concept of stages of client participation emerged as units of experience. As the graduate assistant proceeded to conduct the remaining 34 interviews, she systematically probed for expanded detail related to this concept of stages. Ongoing examination of the narrative data about the endings of day care quickly revealed the particularly strong presence of ethical challenges at this stage, such as decisions about whether or not day care for a participant should be continued or terminated. The call-back interviews included probing questions specific to the ethical dimensions of the endings of day care.

When both initial and call-back interviews had been transcribed and coded, the data were organized by dimensions and subdimensions using a database software program for text (Diekelmann, Lam, & Schuster, 1991). The data that were coded with ethical codes were separated out and collapsed across interviews for this phase of the analysis. This article addresses the nature of these ethical dimensions of dementia day care and is based on the analysis of those narratives that described moral experiences.

Results

Crossing the Line

In the narratives in this study, the ethical dimensions of the everyday routines and activities of dementia day care were embedded in the dynamic interplay between the behaviors that the participants displayed and staff efforts to influence those behaviors. For the staff, an invisible “line” seemed to exist that defined the boundaries of acceptable behavior for staff, participants, and family. This line represented behavioral limits beyond which neither staff, participants, nor family members could venture without the staff experiencing extreme discomfort. The ethical challenges of dementia day care were embodied in those instances when staff or participants got close to or actually crossed the invisible boundary, as is illustrated in the following excerpt from an interview:

Mattie [pseudonym] had a decubitus situation on her feet, basically due to vascular disease, and so needed foot care. Because she was so desperate to maintain her independence, she would sleep with her shoes and socks on for days at a time and would become combative when the staff tried to help her or intervene or to get her to soak her feet... Even a podiatrist had great, great difficulties... Mattie was coming in here for two or three days a week, and so we tried, here, a multitude of approaches. The podiatrist would come here... and there was no way [she was going to cooperate], and we could see we were headed for that line that we didn't want to cross. So with the PRN use of this Ativan, given like an hour before she either needed her shower or before they wanted to do the foot soak every other day... or the days that the podiatrist was going to come and do a treatment, it mellowed her just enough that the cares could be accomplished... We just told her that this was something that the doctor needed her to take today and she was always very willing to take it, and was much more agreeable to it. And for her physical well being — that was one of the reasons that we gave her, the primary reason that we gave her that medication... What it did was, it prevented us from pushing her over the line. So she didn't have to strike out. So we didn't have to force her into sitting in a chair... you know, holding her arms down while we took her shoes and socks off. I mean, that's the last thing we wanted to have happened, and this allowed us to not have to do that in this situation.

In this interview excerpt, the staff person being interviewed indicates her definition of unacceptable staff and participant behaviors. Crossing “over the line” includes the participant “striking out” and the staff person having to “force her into sitting in a chair.” The concept of crossing the line as an ethical dimension of the staff experience in dementia day care is examined here in depth.

Crossing the Line: Participant — Perhaps it is obvious that, in the preceding interview, Mattie’s refusal to allow the staff to give her foot care would be considered a behavior that was a threat to her own well-being. If she did not have the foot care, other dire consequences could follow (gangrene, infection) that would be life-threatening in nature. If Mattie had struck out at the staff as they tried to carry out her foot care, that would be considered behavior potentially harmful to others. In addition, striking out at staff would be viewed as a sign that Mattie was extremely upset, and thus it would also be behavior harmful to herself.

Behaviors such as these constituted “crossing the line.” Participant behaviors that were a threat to the safety and well-being of themselves, other partici-
pants, and the staff, that required too much one-on-one attention from the staff, or that were sexual and fell outside usual accepted social behavior as understood by the staff, were in this category.

The following interview quotation illustrates a participant crossing the line in a way that threatened the safety of others. The staff person is describing an experience with a male participant who was getting increasingly agitated about wanting to "get out." Another staff member had been trying to help and had just started to walk away.

As the other staff person started to walk away...I could feel that [this man] was beginning to fall...I simply said, "He's going to go down," and with that, the other staff member turned relatively quickly and helped me...This is what was so dissatisfying about the whole situation...that that sudden movement, as you can well imagine, triggered him [the participant] to strike out...He struck out at the other staff member a few times with his fist into this other staff person's chest. The positive thing is that we didn't try to fight him. We didn't try to restrain him in any way. We just said, "It's okay." with a calm voice, "It's all right, you're going to be all right," and got eye contact with him and he stopped. And you could just feel the sigh go out of his body, and he sat down. And from there on, the experience was not escalating anymore; he had calmed down...What I felt very good about was that, even though he had struck out, there was no serious injury that was incurred to either my staff person or to [him].

In her summary of this incident, the staff person said, "What was most frustrating and dissatisfying was that it had been us that had triggered him to act out physically and the dissatisfying part, also, is that we really had no choice. The other option would have been to let him fall because I could not hold this man by myself. And so the sudden movement in order to save him from the fall and keep him safe was exactly what triggered an emotional experience for him. So that was very dissatisfying knowing that we were kind of caught in a Catch 22...we were for him. So that was very dissatisfying knowing that was exactly what triggered an emotional experience...It was just devastating to staff. We had to do a lot of counseling after that, and [also] for the other clients at the program that saw him taking off."

Participant behaviors such as these necessitated much one-on-one care by staff, and this led to other dilemmas related to fairness to other participants, staff, and family. The staff member who described the man in the busy highway intersection commented further that this "was an individual that we really needed to discharge from the program because we really could not safely manage him and care for the other clients too; but knowing the family dynamics, everybody wanted to help. You know, we wanted to be as helpful and filling [sic] the need for that family as much as possible and yet we were feeling, 'Are we being fair to other people in our program?'"

Staff members' efforts to allocate their services equitably among all participants and meet the significant support needs of the family members, as well as protect themselves from harm or burn-out, created ethical dilemmas of obvious magnitude.

A small number of the staff narratives included descriptions of participants' sexual behaviors. Sexual advances included such behaviors as asking to be touched or touching or kissing others. Staff seemed to struggle with the issues surrounding such behaviors, trying to sort out what seemed to be clearly socially unacceptable behaviors from general negative attitudes about sexuality in older people. Regarding one female participant who had made sexual advances toward a male participant, a staff member said the following:

I feel sexuality in the older adult should not be hidden and they should have a chance to express their feelings, so this does not bother me one single bit...It bothered other clients and it bothered some staff people even though we did have one of our meetings to talk about this; her feelings are OK, but the way she's doing it with an individual who is married and has a wife is inappropriate.

In another narrative, a male participant "touched" a female staff member "twice," and asked her to touch him. The staff member informed the social worker, who then "decided to call the police. [The policeman] came several days later and talked with him and told him that this wasn't right and that he can't do these kinds of things." The social worker's actions are puzzling; she seems to have reverted to a management strategy like that used with a nonmentored person, perhaps forgetting that the participant was not likely to remember either the incident of the past (the policeman came "several days later") or the admonition not to do "these kinds of things" in the future. The incident seems a classic illustration of the dementia day care staff member's dual reality — the "real" world outside of interactions with the day care participants and the contrived world of dementia care. It is in the latter context that the ideals of ethics and right and wrong are reformulated.

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These behaviors were those that were unacceptable when family members falsely accused the staff of the former or latter, a staff member was falsely accused by a participant from doing something, and it got to be too much that we would fight with her. Being "forced to use force" is being forced to force a participant to do something — sit, stand, turn around to face the toilet.

The use of restraints was another staff behavior that constituted crossing the line. Restraints were a way to prevent a participant from doing something (going out the door, striking out at another client). The use of restraints — physical or chemical — was not always unacceptable, yet it was usually described as a strategy in the extreme. In the interview quoted earlier, the staff member expressed her relief that she didn’t have to restrain Mattie, that she didn’t have to resort to "holding her arms down while we took her shoes and socks off. I mean, that’s the last thing we wanted to have happen."

Staff did seem to accept the use of medication for Mattie, saying that it "mellowed" Mattie enough so that the foot care could be performed. Yet, in the episode when the staff triggered an outburst by trying to prevent the client from falling, the staff member expressed satisfaction in not having to use either chemical or physical restraints: "He was not restrained, either chemically or physically…. I’m just very grateful that I didn’t need to do that" (emphasis added).

A combination of physical restraint and medication proved to be too much for another staff member. This staff person had been working with a doctor, trying various medications to help control the "wild" behavior of one participant. "The doctor said, let’s try this I-M [intramuscular injection] when he gets real wild…. Well, we tried it a couple times and it got [to be] too much that we would fight with him; and there was no way we were going to force an injection on a person in a day care situation…. Day care just isn’t set up for that type." It seemed that forcing an injection on the man per se was not a totally unacceptable strategy for behavior management, but it was crossing the line for staff to do that in the day care setting.

Crossing the Line: Family — Family members, too, crossed the line in two major areas: (a) in those cases in which abuse of the client by the family was suspected, and (b) those instances when family members falsely accused the staff members of unethical behaviors. As an example of the latter, a staff member was falsely accused by a wife of tying up her husband, totally ignoring him, and not "trying to help him at all." False accusations by the clients themselves (for example, blaming a staff person for causing an episode of incontinence) seemed to be accepted as part of the cognitive impairment of dementia; but false accusations by the family members were difficult to accept, perhaps because of the importance to the staff of feeling valued by the family for the services being offered.

Probably the most excruciating ethical challenges posed to the staff in dementia day care were those imbedded in situations of suspected family abuse. Staff described anguish over talking to family members about this, about the uncertainty of the demented participant’s ability to understand and discuss the situation, over fears of falsely accusing family of abuse when the evidence was unclear.

Repeated evidence of bruising was the most frequent sign of possible abuse. Family explanations were usually that the client was falling a lot at home. One staff member provided the following narrative of her struggle to handle this kind of situation:

[The participant] started getting weaker with her ambulating and her transferring… She would come in week after week with new bruises. Bruises everywhere. We were starting to document these bruises… The three of us [staff members] had many conversations about it. “Is this an abuse situation going on here?” It got to the point where I talked to the husband about it. I told him over and over and over that I did not think that there was any intentional abuse, but was he really able to continue to care for his wife alone at home?… That was very difficult, but it was also very satisfying in that we were able to work toward problem solving…. I talked with the husband about how to transfer, how does he get her on and off the toilet, showing him how to use a gait belt, talking to him about getting a wheelchair. And then he finally got a wheelchair, and then the bruising stopped! Because the transferring was so much easier after that. There wasn’t the potential for her falling on the floor while she was trying to walk…. So we were able to work through that real tough, not only physical care situation, but the whole ethical thing…. when does the day care discontinue to enable families to be in a situation that isn’t a good one?"

Suspected family abuse pulls the staff member totally off course. The day care staff is put in the untenable position of supporting abuse if they continue their services, yet to discontinue often means more or less resigning the client to nursing home placement. The day care "mandate" to continue care in all but extreme cases of unmanageable behavior is called into question. The suspected unethical behavior of the family member creates a wholly different context in which the day care staff person must focus his or her energies on bringing about change in the caregiver or must, by law, report the situation to some outside authority. In the latter case, previous loyalties extended to participant and family member as a unit are now divided, and the sense of day care worker, participant, and family caregiver working together as a team is torn asunder.
A Hierarchy of Response

Staff responses related to crossing the line form a hierarchy of ethical comportment related to the degree of ethical challenge that is perceived to be present. If the challenge is perceived to be manageable and minor, staff will respond with benign manipulation. For example, to persuade a participant who “would start yelling at you and swear” that the Ativan was “something that with him are examples of benign manipulations. For instance, the staff needed her to take today” is another example. “Bribes of cookies and candy” were used to get one “horribly obstinate” client to take part in daily activities. One staff member described a participant who “would start yelling at you and swearing at you, and because we have others in the day center, we tried everything to change the subject; we tried diverting his attention to something else, and nothing worked except to bring him into my office, close the doors, and let him cuss me out for 45 minutes. And I mean it was 45 minutes every single time. And he would do that and the rest of the day he was docile. He was fine.”

Benign manipulations are the staff’s techniques for keeping client behaviors within acceptable limits. They are similar in many ways to strategies of persuasion used in other social contexts.

Pretending. — Another strategy that worked fairly smoothly on a day-to-day basis was pretending. This strategy was used to promote general well-being of the participants and might be considered another form of benign manipulation. For example, to counteract one male client’s pattern of getting angry every day after lunch, one staff member said, “We finally realized that this man owned a factory at one time...and this is a man, that after lunch, that’s when you went back to work, you didn’t sit down and just read the paper or whatever, you went back to work. So what we tried to do is get a couple other men that were there and say we were having a board meeting. And we would proceed to sit down around the table and ask questions about businesses and so on. And that sometimes worked.” Another staff person said, “Several of our clients believe they’re coming to work every day, which is good, you know. It gives them purpose and they enjoy the people they interact with and it’s just real beneficial.”

Another kind of pretending was related to artificially creating “useful” tasks for participants to do such as messing up a bunch of towels and telling the client that they needed to be folded, or telling a client that a box of beads needed to be strung or that a pile of magazines needed to be stacked. A staff member might “go along with” a client’s confusion, such as engaging a former farmer in conversation about his crops by asking how his tomatoes were doing or if he had his peas planted.

“White Lies”. — Minor lies (referred to by one staff member as “white lies” and in the literature as “therapeutic fibs” [Hellen, 1992, p.25]) were often used by staff to respond to truly dangerous situations. Minor lies were of two types: those that fit into the reality of the demented person and those that created a different reality. One staff member’s narrative of a client’s episode of booking illustrates both types of lies. This story was about a participant who “decided that the kids needed supervision and she needed to leave the center.” The staff member described going after her and using various strategies to get her back to the center:

I tried approaches like, “The kids are in school, no one’s at home right now;” and she said, “But I have a key.” And then I tried, “You don’t have a key, you don’t have your purse with you, we have to go back to get your purse.”... That didn’t work. She said, “If I don’t have a key, I’ll go to my parents’ house.” I told her her parents were on vacation and they weren’t at home; anything that I could keep one step ahead of her. And that didn’t work. She said, “Well, then I’ll bust in a window and crawl through the basement.”

Up to this point, the staff member has used minor lies that fit in with the participant’s reality, that is, her belief that she was back in an earlier time in her life heading for her parents’ house in her home town.

After two hours of walking “probably about 4 to 5 miles,” the staff member tried a different tactic. She convinced the woman “that there was road construction up ahead and we had to turn around, that we couldn’t walk any farther because we were going to be stopped.” The staff member admitted to the interviewer that there wasn’t really any road construction; “It’s called white lies. I’ll probably go somewhere for telling these... but that was the only thing I could think of, because I had worn out everything else.” This staff member was clearly somewhat uncomfortable about the fact that she had told “white lies,” but she seemed able to rationalize their use in this situation.

Chemical Restraints. — In general, the use of chemical restraints (medications) appeared to be the next level of staff response. Their use sometimes almost took the form of accepted protocol. As one staff person said,

There have been instances when we’ve had PRN medications that we’ve used either in anticipation because of known history, or, for example, we know that they become very restless in the afternoon. And so at lunch time, or just after lunch, we may give them medication, as low a dose as we possibly can,
and that will help the individual. The primary time that we look at and really consider and agree with giving medication in order to handle a behavior is when it’s so obvious and clear that the individual is miserable. . . . It’s not that we want to completely calm them and have them sit quietly in a chair; it’s more if we can just take the edge off, so that some of our behavior management kinds of ideas and activities and ways of intervening and communicating with them have a chance of working.

The need to justify the use of medication to the interviewer, plus the comment about the low dose, appear to reflect the presence of a nagging discomfort underlying what seemed, on a superficial level, to be very like a standardized approach. Post (1995) discusses the “tremendous pressure” that exists to make drugs the matter of first choice for behavioral management of people with dementia, charging that their use for custodial reasons is a “serious problem in long-term care facilities for the elderly” (pp. 58–59).

Staff’s concern about the use of medication as a behavioral control was expressed in the following quotation: “There is [sic] always those struggles as to what will work and what you should and shouldn’t do, and at some given point you have to just kind of decide and say, ‘Well, I’ve tried everything else here today, and this is the only thing that’s calming.’”

Physical Restraints. — In rare circumstances, the staff seemed to find it acceptable to use physical restraints. As one staff member said, “Sometimes you do have to physically [restrain the person] — we had one man that was, you know, just had really gone wild and one of the staff came behind the man and put his arms around him, you know, from the back, and said, ‘Stop! You’re out of control!’ And that worked.”

It may be important to note that this staff member’s story is of someone else using physical restraint. More usual were personal and detailed descriptions of other strategies that were tried and of the ambivalence and reluctance that led up to the consideration of restraints. An experience with a very difficult male client was recounted as follows:

In our facility we have a secure care system where if you leave the building these alarms go off; and at the time, I think it was 10 exits [10 times that this client went out the exit]. Then we would take a time out, you know, I would sit with him for 10 minutes and take time out, relax and try to get back in the flow of what’s going on; and he didn’t want to calm down. His wife did not want any medication, which I really am kinda against anyway, and we went to the possibility of a restraint, a waist restraint for a 10-minute period. . . . The worst day, I had a lot of problems with him. I did restrain him for 8 minutes. He got really upset with the restraint so I thought, “Well, that’s not even going to help, you know, getting him more upset.” So we took that off . . . he would hit, swing out, push everyone away and then be incontinent and he would say, “Now look what you did to me.” . . . and this was all before noon.

This staff member was recounting an experience that took place two years prior to the research inter-
(Moody, 1983, p. 103). While there must be a presumption of the ideal, we must also remain open to redefinitions.

In the dementia day care arena, society’s ideals of everyday ethical comportment are challenged by the cognitive impairment and true dependency of the participants. It seems clear from the narratives in this study that dementia day care is a setting that is permeated with everyday ethical challenges. The central ethical question is: What is it permissible to do to influence people’s behavior? (Dworkin, 1976).

In these narratives of dementia day care, ethical distinctions are grasped through engagement in particular situations, using skilled appraisal. The dementia day care staff person, while in the situation, must make decisions about what is permissible to do to influence the demented person’s behavior. The dementia staff person, thus, must engage in an ethic of responsiveness and attentiveness, remaining open to matters of significance (Benner, 1994). Often this attentiveness stems from the need to make judgments about whether or not the client is a danger to him or herself, to the staff, or to the other participants. Hermann (1984) refers to this as a staff member’s “critical lifeline support role” (p. 655); staff must remain ever attentive to the changing nuances of the scene and to the significances of the actions.

Moody (1992) writes eloquently about the “dark side” of the ethics of dementia care. He speaks first of the “temptations of beneficence” (p. 46), discussing the subtle potential in dementia care to use beneficence as a way to demean human beings. The staff members in this study struggled with the imperative of beneficence, encountering situations in which whatever they did would potentially violate the person’s well-being (“we were darned if we did and darned if we didn’t”). Every incidence of a “booking” brought the staff person face-to-face with the dilemma of how to both protect the demented person from harm and, at the same time, not to strip the person of all rights to be self-determining. In Collopy’s (1995) discussion of this “clash of safety and independence” within long-term care, he concludes that safety is “one value among many, a value whose force shifts and modulates with circumstances, with the goals and motivations of individuals, with their willingness to bear specific burdens, to take on and struggle against specific threats” (p. 142). In the above narrative, the staff member bears the “burden” of walking 4–5 miles while trying to come up with some “logic” that will persuade the participant to turn back; this strategy is done to avoid further escalation of the incident or the use of force. But more than that, the ploy is used to elicit the participant’s own decision making, thereby resolving the immediate threat to her well-being but also affirming her personhood (Agich, 1995): its use can be said to reflect the view that the elder is still an actual agent in the world.

Moody (1992) proposes that it is the social structure of the situation that is crucial. If the staff regard strategies such as the “road construction” and the “board meeting” more as trickery to serve their own purposes than as therapeutic techniques, then the “temptations of beneficence” are evident. If, instead, such strategies arise from the shared dialogue and human relationship between the staff person and the day care participant, then they represent an appreciation for the contextual basis of the ethics. In Moody’s terms, the latter view represents an ethics of intimacy rather than an ethics of strangers (Moody, 1988).

What Moody calls the “illusions of autonomy” (1992, p. 50) were strongly evident in these narratives. “Respect, I argue, is prior to autonomy” states Moody, and “respect for others is not always accomplished by ‘truth telling’” (p. 51). Is this how we might interpret the staff member’s “white lie” about road construction, that it is an example of side-stepping the truth-telling obligation in order to support the person’s dignity, well-being, and self-respect? Because of the “white lie,” the participant decided herself to turn back to the center, thus exercising her autonomy and removing herself from the danger inherent in fleeing down the road. Her dignity was upheld in a way that contrasts markedly with the potentially shattering experience of physical restraint or police intervention. Moody calls this strategy a “face-saving deception” (p. 58), one that helps the demented person “maintain a fragile sense of self-respect and dignity.” In this kind of situation, Moody argues that the deception may be acceptable.

Moody provides no easy answers to the ethical questions surrounding the use of restraints, but says, instead, that no matter what the decision is, it is likely to be “painful and guilt-provoking” (1992, p. 58). In these data, the hierarchy of responses to crossing the line roughly represents a hierarchy from the least restrictive to the most restrictive option. Obviously, the use of restraints can easily become an exploitative expression of authority and power; to Moody, an appropriate general guideline is to use the least restrictive alternative. Dworkin (1976), too, articulates guidelines for action such as avoiding methods that rely essentially on deception and giving preference to modes of influence that are not physically intrusive. Further, Jameton (1990) lists the factors that contribute to the decision to use restraints, such as danger to others and danger to self, but rightly points out, “danger needs definition” (p. 170). If we look more closely at the narratives, we can at least see some shadows, if not the actual “dark side,” of the guiding principles. Is a client truly a danger to others “because she would stand up, walk around, touch other people, and agitate the entire group”? Is it truly a response to danger-to-self when clients are medicated “to take the edge off, so that some of our behavior management kinds of ideas and activities and ways of intervening and communicating with them have a chance of working”? Are the ethical trade-offs or compromises represented in these stories ones with which we can be comfortable (Hofland, 1988)?

Post (1995) asserts that, while the ethics of behavior control should focus on the affected person’s best interests, nevertheless, the interests of the caregivers are inevitably part of the ethical equation. Col-
These voices are inevitably “loaded” as each staff member strives to “justify” the narrative he or she creates about the client’s lived moral experiences. The narratives of nurses’ everyday ethical comportment represented in these data resemble the situated ethics of Benner (1991, 1994) and Moody (1983, 1988, 1992) more than the malignant social psychology of Kitwood (1990). It is just such dilemmas — complex, paradoxical, and ironic — that make up the everyday ethics of dementia day care.

Conclusions

A situated knowledge of ethics is employed by dementia day care staff as they seek, each day, to create satisfying experiences for themselves and for the participants. Ethical comportment within the dementia day care setting entails recontextualizing the ideals of ethics to accommodate the cognitive impairment and true dependency of the clients. Daily activity is disrupted by behaviors that challenge normative ethical guidelines for everyday social relationships, that is, by behaviors that “cross the line.” A hierarchy of staff responses to crossing the line is evident in these data, constituting a repertoire of ways to influence and control behaviors.

The ethical comportment represented in these data resembles the situated ethics of Benner (1991, 1994) and Moody (1983, 1988, 1992) more than the malignant social psychology of Kitwood (1990). It is well to remember, however, that it is the voice of the day care staff that is being heard as they recall and create narratives of past experiences in practice. These voices are inevitably “loaded” as each staff member strives to “justify” the narrative he or she has chosen to share. As Bruner (1990) so astutely says, stories “almost always portray the narrator in a good light” (p. 83). Every story is somebody’s story.

In this study, the narratives of dementia day care staff about their satisfying and dissatisfying experiences of practice provided a vehicle by which to explore the intersection of their ethical lives with those of the clients with dementia. These narratives represent each staff member’s own understanding of his or her lived moral experiences. The narratives have provided details about naturally occurring life experiences that reveal practice-based ethical concerns in action, through which heightened sensitivity to the everyday ethical dimensions of the dementia day care experience is gained.

References


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