In an influential essay on dementia care, Kitwood (1993) uses the notion of culture to orient caregivers to the communicative aspects of care on psychogeriatric wards. By talking about a “culture of dementia” he provides a new perspective on the way in which dementia sufferers are usually represented, that is, in terms of a loss of voice and of the possibility of constituting a lifeworld (Leering 1967; Chatterji 1998). He tries to think of the ward in terms of an intersubjective space that can be shared by both caregivers and patients, that offers possibilities for the development of a lifeworld. Kitwood’s work is important not only in the sphere of dementia care—he is one of the few scholars who represents dementia sufferers as intentional subjects who are responsive to community life—but also because he shows us what is at stake in achieving this sense of community. For him dementia becomes a way of problematizing the very idea of communicative sharing, for it points to the singularity of individual experience and to the fact that intersubjective relations may be built on differences rather than on commonalities. Thus, for Kitwood dementia means more than just a category of psychobiological pathology. It points to a special kind of care relationship and to a model of nonverbal communication in which there is a “heightened awareness of body language” (Kitwood 1993, 64).

In this chapter I shall use dementia as a thematic to talk about bodily disposition and the way in which it inflects the construction of ‘normal’ everyday life on a verpleeghuis (nursing home) ward in the Netherlands. A term such as the culture of dementia allows me to think of the medical institution as a local moral world and to ask what is at stake in constituting the verpleeghuis as a discursive entity (Kleinman 1988). I try to problematize dementia by using it as a lens through which to reflect on the notion of normality as a mode of standardization produced through ward routine (Goffman 1961). Problematization is itself a
somewhat tricky exercise. As Rabinow (2003) says, it means that something must have already happened to introduce uncertainty in the familiar modes of engagement with the world. In this chapter I shall describe one such event that threatened to disrupt the routine on one particular ward and that led to the transfer of one of the residents to a ward that specialized in the care of behaviorally disturbed (gedraags gestoord) persons. This allows me to destabilize dementia as a taken-for-granted category and shows how it participates in other ensembles of knowledge and practice.

To this end I juxtapose a number of different discursive sites through which the verpleeghuis is materialized. Thus I begin with a brief account of the concept that was given to the firm of architects that designed Regina Pacis by Dr. Cornelius Leering, the first medical director of the institution. I then go on to describe the ward routine and finally the case conferences that preceded the transfer of the patient that I just mentioned. In the process I hope to show how dementia offers a vantage point from which medical practitioners in the verpleeghuis can reflect on conceptions of self and normality that structure regimes of work and knowledge. The particular ward that I have chosen to focus on is a somatic ward and does not offer dementia care. I do so deliberately, as there is a fine line that separates somatic from psychogeriatric groups as far as the verpleeghuis is concerned. For the organization, such divisions often function as modes of normalization, as disciplinary regimes for the management of the verpleeghuis population. But first, a brief account of the institution is in order.

The verpleeghuis, Regina Pacis, on which my ethnography is based is a “combined” geriatric facility that offers intensive nursing and medical care to elderly persons suffering from both somatic and psychogeriatric illnesses. Dementia as a term has very little operative significance in the organization of verpleeghuis work. Instead it is subsumed within more functional categories that are able to discriminate quantitatively between different kinds of corporeal capability. Instruments that measure corporeal capability, such as the Activities of Daily Life (ADL) rating scale, and quantify the extent of nursing care that a patient requires help to disaggregate the verpleeghuis population on the basis of a differentiated set of therapeutic goals. Dementia, too, can be used to refer to a kind of corporeal capability but only in moral or evaluative terms. Thus, psychogeriatric wards are sometimes thought of as enclaves of tolerance where norms regarding bodily disposition that are crucial in sustaining the notion of a ward community can be interrogated.

The Verpleeghuis as Community: Architectural Design and Intersubjective Space

In the Netherlands, verpleeghuis medicine is premised on the idea that diseases in old age are part of life and have to be managed as such. It is also recognized
that such disabilities often make normal life in the family and community difficult to sustain. This means that the verpleeghuis defines itself in terms of two major goals. First, it must offer specialized, long-term care for old persons suffering from multiple chronic pathologies; second, it must be a “complete community” that has to cater to all dimensions of a patient’s life (Leering 1970). The fact that these two requirements can have contradictory effects is part of the problematic that I hope to address and is recognized as such by the practitioners themselves.

Cornelius Leering, a pioneering geriatrician in the Netherlands and, as noted earlier, the first medical director of Regina Pacis, tried to create a concrete structure that would fulfill both requirements. This involved restructuring the organization at several different levels—beginning with nursing activity, the coordination of different services such as medical and paramedical services, recreational services, spiritual services, and so on. It also involved a specialized architectural design—the construction of a new building whose spatial organization would reflect the primary orientation of verpleeghuis medicine, that is, a focus on the lifeworld of the individual resident.

Through a combination of fortuitous circumstances, such as the establishment of the Exceptional Sickness Costs Act in 1968, which helped finance treatment and paid for long-term stay in medical institutions such as the verpleeghuis and which in turn led to an increase in the number of verpleeghuis beds; the economic boom in the late 1960s; and new theories of architecture that tried to relate spatial design with concerns of the lifeworld; Leering was able to restructure Regina Pacis in terms of this new vision of geriatric care. Leering’s report elaborating these new ideas was submitted to the firm of architects in charge of constructing the new building in 1970. It is worth discussing here, since it not only gives a detailed account of geriatric medicine but also offers a specific representation of bodily being in old age and of invalidity as a crucial feature of this experience.

An account of Leering’s conception of invalidity, which relates the embodied being to an environment that is made palpable by the very fact of this embodiment, is necessary for an understanding of verpleeghuis culture. In the 1950s, when the first geriatric facilities were being established in the Netherlands, old-age impairments came to be seen in new ways. Active engagement with the environment came to be viewed as a form of therapy. Interestingly, this had ramifications for the treatment and nursing of patients with chronic disease as well. It was felt that such patients must learn to actively participate in societal processes and were encouraged to overcome the limitations of their disease. Bodily mobility came to be associated with well-being and became a sign of active engagement (Blommestijn 1990).

Central to the relationship between bodily movement and well-being, in Leering’s work, is a particular understanding of invalidity. Leering (1968) de-
scribes the state of being invalid as a form of damaged embodiment (*geschonden lichamelijkheid*), that is, an inability to experience one’s body as a coherent whole. This appears because the body is always other to one’s self; it is made one’s own through the process of socialization. Leering says that this form of invalidity has a particular connotation for the elderly that is not generalizable across generations. Thus a dependency on others for one’s bodily movement, “giving oneself to the gaze and practice of another,” as Leering puts it, is exacerbated in old age because it is coupled with a form of infantilization (1968, 23). In terms of bodily function this translates into a “disturbance” in the ADL, especially in those activities that are associated with personal grooming.

What is the relationship between the ADL, the mode by which one experiences one’s body as uniquely one’s own, and the experience of the verpleeghuis as a “lived environment” (*leef klimaat*)? For Leering, the experience of one’s body, the capacity to make it ones own, involves both work and learning. The ADL scheme, which has to do with the constitution of the inner space of the self, involves purposive activities that transform external bodily space into one’s private intimate space. The ADL functions are also the first step in the creation of a personalized public space. Thus, it is the responsibility of the verpleeghuis to organize its space in such a way that the potential for experiencing bodily coherence is restored. Wards are supposed to be color coded so that they can be easily recognizable by memory-impaired residents. Corridors connecting different parts of the building are broken up by points of interest and points of rest where residents can meet as if they were on a public street. Leering thought that color was an intrinsic part of the architectural design and suggested that it be used to direct movement within the building. “Light spaces,” which were supposed to be accessible to residents, for example, doctors’ examining rooms, or which were points of greater interaction, were demarcated from “dark spaces,” which were meant for introversion but also for the performance of ADL, spaces such as bedrooms and lavatories but also others where technical services were carried out and that were kept out of sight. Thus, bedrooms and lavatories were sparsely decorated, in contrast to public spaces such as the living rooms on each ward, which were marked by distinctive colors and decorations. The shopping area and the café were located near the entrance to the verpleeghuis to give the residents the sense that they could go out with their visitors even while still being inside verpleeghuis space. There were even streetlights and benches placed in the shopping area, to reinforce the impression of a public square.

In an earlier work I described how Leering was influenced by the European phenomenologists, among them Merleau-Ponty and Minkowsky, who thought of space and bodily movement as crucial aspects of intersubjectivity (Chatterji 1998). A detailed discussion of this influence is beyond the scope of this chapter. Suffice it to say that Leering was aware of the architectural debates in the Netherlands and the influence of phenomenology on some of the postwar
trends in building design. However, he was following the principles of modernist architecture when he divided the living environment into spheres for the performance of different functions (Rabinow 1996). But for him these functions were mapped onto the phenomenological body of the invalid resident.

This account is clearly oriented to the somatic patient. Leering was primarily interested in revalidation therapy, and the ADL rating scale was not just a tool for organizing the verpleeghuis population. Instead, he thought of it as a fundamental aspect of a purposive engagement with the world. Purposeless action, the repetitive gestures that are often thought to be associated with dementia sufferers, found no place in this scheme. However, he did write an article on dementia, a literary piece, in which he uses invalidity to analyze the plays of Samuel Beckett (Leering 1967). He says that the experience of dementia comes closest to describing the absurdity that Beckett sees as a part of everyday life. For Leering, dementia is a metaphor for life lived for the moment, without temporal depth, and dementia sufferers have the unique capacity to experience both intense joy and sorrow, a capacity born of an exclusive orientation to the present.

The Ward: Normality, Dependency, and Disturbed Behavior

In the previous section I dealt with the representations of the patient in terms of his or her phenomenological experiences and the manner in which there is an attempt, through the architectural design of the institution, to create a space for a potential community of residents, an alternative community in which the impaired elderly can lead “normal” lives. In this section I deal with the interactions that take place on the ward and describe the work involved in the constitution of this normality. The ward has an important role in the creation of this ideal of community. Day-to-day life on the ward is supposed to approximate normal life in the world outside the verpleeghuis.

A brief description of the organization of ward activity will demonstrate what I mean. Ward space is organized in terms of a temporal division between day and night. Thus, daytime activities are thought of as being part of what Schutz (1970) would have called the “wide awake world,” the world of purposeful social activity, and the night as the time of withdrawal into oneself. Verpleeghuis residents are encouraged to get out of bed in the morning, to dress, and to sit in the living rooms that are attached to the wards. The living rooms are thought to be spaces for socialization, but they are also places where nursing activity occurs during the daytime. I was told repeatedly that, unlike in the hospital, verpleeghuis nursing was focused on the chair and not the bed. Thus, living rooms are multifunctional spaces in which residents spend most of their waking hours. They are furnished with easy chairs and tables at which they eat their meals. They are encouraged to decorate the living rooms with some of their personal possessions, a favorite painting perhaps, ornaments, or even
greeting cards from visitors. There is an attempt to decorate the living rooms in
the style to which the residents were accustomed when they were setting up
their own homes. Considerable thought is given to the seating arrangements in
the living rooms, to encourage “contact” between residents, in keeping with
Dutch norms of sociality. Yet this sociality has to be sustained in the face of
severe impairment and dependency that at first sight seem to negate the values
of privacy and autonomy that inscribe patterns of Dutch social interaction. The
following section is a description of the nursing routine on a ward in which
there is an attempt to create a façade of normalcy that will conform to a model
of sociality, one that consciously maintains notions of autonomy, privacy, and
volition and incorporates them into the therapeutic regime of the verpleeghuis.

However, the actual “bed and body work” that makes up a significant por-
tion of the nursing routine is often at odds with the therapeutic goals of the
verpleeghuis (Gubrium 1975; Datta Chowdhury 1991; Paterniti 2003). Bed and
body work is formally organized around the ADL scheme. Patients are perceived
in terms of their ADL functions as “bodies in need,” to quote Paterniti’s evoca-
tive phrase (2003, 61; see also note 4, below). Paterniti is justifiably critical of
this way of approaching patients—in terms of their deficiencies and the time
taken to care for them. The nurses with whom I worked in Regina Pacis were
aware of this criticism. It was an aspect of their work that was frequently dis-
cussed in ward meetings. They felt that doctors and social workers did not ad-
equately understand the nature of their work. They felt that bed and body work
was often the only way they had of achieving contact with their patients. Indeed,
communication with patients is often very hard to achieve. But there is more at
stake in bed and body work, as most nurses know but are rarely able to put into
words. Given the taboo on touch in Dutch society, especially between strangers
in public places, and the valorization of personal autonomy, intimacy is ex-
pressed through bed and body work as well. Relations of care and dependency
that threaten the ideal of autonomy are framed by a professional work routine
and thereby made acceptable.

This section is divided into two parts. In the first I describe my first day as
participant observer/nursing aid on the ward and, through this, the daily nurs-
ing schedule. In the second part, I detail the spatial organization of a living room
on the ward in which patients spend most of their waking hours. Through this
description I attempt to show the contradiction between institutional ideal and
organizational practice, for it is in the space of this contradiction that dementia
emerges—not as a disease category, but as an alternate way of doing and being.

The Ward Routine

I arrived at the Peppel (Poplar) at half past seven in the morning—my first day of
fieldwork on the ward. I had been assigned to the blue unit. (Each ward is
divided into units of three with twelve patients each.) The nurse I had been
detailed to work with had already begun the distribution of medicine. I was
three minutes late that first morning, and work had already begun. The nurses
on the morning shift usually arrive ten to fifteen minutes earlier. They drink
what will be the first of innumerable cups of coffee together and smoke their
cigarettes. At 7:30 A.M. on the dot, coffee cups are drained and cigarettes stubbed
out, and one of the unit heads reads out the evening and night reports of the
previous day. The day’s roster is also read out, as well as any special appoint-
ments that a resident may have—to visit the hairdresser, go for physiotherapy,
and so on. Then the bustle begins—people must be got out of bed, washed, and
dressed, made ready to meet the day as it begins. The nurses working in the
units pick up the washbasins from the storeroom attached to the ward. There
are two for each patient, green for the upper part of the body and red for the
lower. Each nurse also takes a tray, on which are cotton wool swabs, disinfect-
ant, and nail clippers. If she is new or has no experience with the particular
patients she has to take care of, she takes the ADL cards with her. They will tell
her what functions the person can or cannot perform.

I was sent off with a student nurse to help get people out of bed. The stu-
dent nurse had a brisk and breezy air. She wasn’t experienced enough to have
developed the touches of intimacy that the more mature nurses use to soften
the work technique. She kept up a cheerful patter as we worked. She would say
to me, “Give me a hand here, catch hold of the shoulder like this . . . ” or, “This
one needs the lift . . . she’s too heavy!” She left me with a woman who had “a
light demential image” (licht dementieel beeld). We were introduced to each
other. She was lying flat on her back with her night dress rucked up. But she was
wide awake and said, “Pleased to meet you,” with great courtesy. The student
nurse, now called away, left hurriedly, saying that I could manage on my own.
Mw. Fokke (the patient) was easy to manage and would tell me what to do in
case of problems, she said. Mw. Fokke and I stared at each other rather uncer-
tainly and I began the washing routine. Mw. Fokke kept saying, “I think I can do
that myself—I do live alone, you know, so I must be able to do that on my own.”
But she spoke somewhat hesitantly and I decided to carry on. Then she said,
“Things are a little different today, aren’t they? Is there a shortage of staff?” The
nurse whom I was originally supposed to be helping came up just then, and I
asked her if Mw. Fokke could really manage on her own. She said, “Yes, that is
true, but you weren’t to know,” and she delicately covered Mw. Fokke’s chest
with a towel. I realized at that point that it had been exposed.

I saw that I had been doing everything the wrong way. Nurses take great
pains to ensure that the privacy of the body is maintained while performing
invasive activities. The private parts are covered with towels when the washing
is done—white for the upper half of the body and yellow for the lower. One starts
from the face and moves downward, in stages. After each part is washed it is
quickly covered up with the towel. Most nurses carry on a conversation with the patient while they wash and dress them. Patients are encouraged to take an interest in their appearance—to choose their own clothes, comb their own hair, and so on.

There is a conscious effort to maintain the status of patients as “normal,” as I noted earlier. Nurses are taught to “frame” invasive activities so that patients’ privacy is not violated. Officially, the relationship between patients and caregivers is supposed to be that of strangers, signaled by normal-status behavior emphasizing distance and respect.

The nurse introduced me to each patient on the unit. She told them that I was here to see things and asked them if I could watch. The patients who could talk gave varied responses. Some were genial, others confused, and some rather sarcastic. One woman said, “She can watch my face, but not here,” pointing to her genitals. The ward-in-charge took the patient to tax on this later: “Mw. We all look the same over there.” She turned to me, laughing. “She feels ashamed.” Another patient, Mw. Roosevelt, commented on the fact that there were two people beside her bed. The nurse told her that I had to learn and that I was here to write a book about the residents. Mw. Roosevelt muttered that she didn’t care if I was Sinter Klaas and was writing in my golden book. She had Parkinson’s disease and her limbs were stiff and her movements awkward. At each stage of the process of dressing she would give us instructions: “You haven’t cleaned my eyes.” “I will do it last, with this ointment,” the nurse replied. “My back hasn’t been dried properly. Do it again!” This was directed at me; I had been scared of hurting her. Mw. Roosevelt wore elasticized support stockings for the edema in her legs. She was always anxious when the stocking was fitted over the bunion on her foot. She rapped out, “Bunion!” The nurse pressed the bunion to show that the stocking was safely over it. She resisted slightly when she was told that I was to do her hair, but she did so more as a matter of form. Her instructions to us were in the same spirit, to show us that she was still in control of the situation at hand. We held out a selection of necklaces and she chose one that matched her dress. The nurse deftly sprayed her with perfume and complimented her on her dress. She unbent sufficiently to say that her son had chosen it. Then the wheelchair routine began. The nurse and I put an arm under each armpit while Mw. Roosevelt gave us rapid instructions—“Turn me to the left . . . no more . . . now move the chair closer . . . ” and so on. She wanted to visit the restroom first. We wheeled her there and left her with the calling bell in her hand. The nurse made a cross on the defecation chart under Mw. Roosevelt’s name. We rushed through the next job, breaking off for a quick cup of coffee, standing in the kitchen. It was 9:30 A.M.—the time when nurses take a five-minute break.

We got back in time to wheel some patients into the living room. Mw. Roosevelt, whom we had left in the restroom, was already ensconced in her
chair, at her place at the table. I wheeled in a rather mournful woman, Mw. Timmers, who sat at the same table. Mw. Roosevelt supervised the process. I got her breakfast from the kitchen. It was on a small plastic tray, covered with cellophane and with her name written on it. Mw. Roosevelt supervised the placing of the cup of Nutramel that she was supposed to drink: “On the right side; she can’t see from the other side.” Mw. Timmers whimpered softly. I asked her what the matter was. “She always does that!” Mw. Roosevelt said.

We broke for a fifteen-minute coffee break at 10:20 A.M. All the nurses gathered in the living rooms to drink coffee with the patients. After this we spent the rest of the morning cleaning the washbasins, the urinals, and the bedpans, as well as changing the bedsheets. As one of the nurses told me, “We give first priority to the people, the rest can come later.”

Most of the nurses take their lunch break from one to one thirty. A few stay behind to receive the lunch wagon, which comes in at about this time. Lunchtime is another period of intense activity. Many of the patients have special diets, while some are part of the eet tafel project; that is, they are served food in the “normal” way—they eat from bowls, and they can serve themselves and choose what they want to eat. The other patients eat from prepared trays. The afternoons seem more relaxed after the hectic pace of activities in the morning. Patients doze in their chairs. Some go for activities to Het Stekje (the central activities room). The nurses write their daily patient reports and drink coffee with the patients. At 4:00 P.M. the day shift ends. There are fewer nurses on the evening shift because there is less work to be done. Patients eat a brood maaltijd (bread meal) and then go to bed. Nurses prepare patients’ clothes for the next day—setting out a range of outfits from which patients can make their own selection if they are in the mood—match accessories, wash pantyhose, and so on.

The ward is very different at night. Most nurses hate the night shift because, unlike the day shift, which is filled with activity, it is monotonous. It is for this reason that it is called de wacht (the wait). There is only one nurse in the ward and she sits in the nursing station to attend to the bells that patients can ring from their beds to summon her. Most of the summonses are for bedpans. A student nurse called de zwerf, or “the rover,” rotates between the three somatic wards in the verpleeghuis and helps to lift and turn patients who are given bedpans, incontinence mats, and related items.

The nursing schedule reflects contradictions in the identity of the organization at large. Relations between nurses and patients are supposed to be modeled on the service contract so that patients are seen as clients who are recipients of a specialized service (care), the modalities of which they are, ideally, free to negotiate. However, given the extent of impairment that marks the average verpleeghuis patient, which makes it difficult for patients to enter into the details of their care contract, and the bureaucratic constraints of large organizations, which turns patients into objects to be worked on, this is not usually
possible. Doctors sometimes complained about the “medical model” that nurses on the somatic wards seemed to have internalized. The doctor in charge of the Peppel would tell the head of the ward that her nurses should spend quality time with difficult patients and worry less about the work regime. He told me that nurses were trained to be task oriented and found it difficult to shift to a people-oriented approach. However, nurses on the somatic side felt that it was only through actual bed and body work that they achieved contact with patients. They are aware that nursing often involves activities that may violate patients’ privacy. (After all, touch is usually restricted among strangers. Ideally, nurses and patients are supposed to meet as polite strangers or as service renderers and clients.) It is only by channeling all physical contact through the ADL regime that they are able to maintain the facade of a service relationship.

The work schedule creates a rationally ordered structure on the ward, a structure that is supposed to have therapeutic value for the patients because it gives them a sense of continuity with the world outside. But it is also the only mode that the staff has of communicating with patients. The daily ritual of washing, dressing, and the choosing of accessories can also become the moment of contact, of renewing ties of affection between the nursing staff and the patients. In an earlier section I said that there was a contradiction between the specialized service that the verpleeghuis is supposed to offer—long-term care for patients with chronic disease—and the aspiration for it to be a community in which patients will be able to experience themselves as normal persons. Values such as autonomy and independence are central to the constitution of self and to participation in social life in the Netherlands. Perhaps the emphasis on a task orientation among the nursing staff was a response to this dilemma. Bed and body work may be the only mode that nurses have of relating to patients while still respecting the values that make the patients persons in this society. Respect for personal privacy is also possibly the reason why the ideal of normalcy is applied only to the public spaces on the wards. Patients are dressed as if they are ready to go out, and indeed they interact with one another as polite strangers in the ward living rooms. In fact, all interactive spaces in the verpleeghuis are organized as public spaces.

The Living Room at the Peppel

In the preceding section we saw how Leering’s conception of corporeal intentionality is translated into a ward regime. Merleau-Ponty, from whom Leering borrows this idea, discusses corporeal intentionality in the context of the humdrum or routine aspects of everyday life. Institutional taxonomies, such as the ADL scheme, tend to literalize this, turning habitual routines, necessary for creating an intersubjective world, into regimented practice. In this section I move from the regime of bodily care and considerations of self that emerge from this
practice, to the ward community and to the potential of a shared lifeworld that may materialize within it. In phenomenological terms, intersubjective relations assume a notion of shared space. It is the animate or sentient body that becomes the common measure for this sharing. For Schutz (1970) there is a continuity of perspectives among actors in interactive situations based on the assumption that their bodily experiences are similar and therefore transparent to one another. He calls this the “reciprocity of perspectives,” subjunctively attributed by the self to the other. The self experiences the other through a unified field of bodily expression that reveals the other’s conscious life.

The reciprocity of perspectives is modeled on face-to-face interaction, which involves symmetry between the actors, as well as a certain spatial distance (cf. Berger and Luckmann 1967). In the verpleeghuis, a reciprocity of perspectives, as Schutz conceived it, is difficult to achieve. Intersubjectivity is made possible within the care relationship but not through the assumption of a symmetry between self and other. The care relationship is based on dependency and is therefore asymmetrical. Spatial distance is an important aspect of the self’s experience of its actions as intentional and for a sense of its autonomy. Whether or not this remains an aspect of one’s experience as a verpleeghuis patient is a question that will be explored in this section. Is the living room an intersubjective space? Do patients experience it as an aspect of their lifeworlds?

I describe the living room (woon kamer) of the blue unit of the Peppel—the interactions between patients and the spatial arrangements that configure those interactions—in an attempt to address these questions.

Let me begin with a description of the seating arrangement. There were three small dining tables that divided the room into two segments. All three tables were positioned in such a way that residents sitting at them had a clear view of the park outside; the outer wall of the living room is made of transparent glass. Mw. Roosevelt sat with her two companions, Mw. Timmers and Mw. Fokke. As mentioned earlier, Mw. Roosevelt and Mw. Timmers sat in wheelchairs, which neither was able to maneuver independently. Mw. Roosevelt was a Parkinson’s patient and was not able to perform the arm movements required for pushing a wheelchair. She had refused the offer of an electric wheelchair. Mw. Timmers had hemiplegia and suffered from chronic depression. During my time on the blue unit I never heard her speak. She would communicate through groans and whimpers and, at times, through gestures. Mw. Fokke was becoming demented, as noted previously, but her condition was not considered advanced enough for her to be moved to a psychogeriatric ward. Adjacent to Mw. Timmers and Mw. Fokke were two other women, who also sat in wheelchairs, with legs outstretched. Their limbs were so rigid and so painful for them to move that they could not be maneuvered under tables. In the other half of the room, three women sat at a rectangular table near the picture window. Two of these women, Mw. Diekema and Mw. Smit, had their backs to the round table.
Mw. Diekema was severely diabetic and had had her right leg amputated, in two procedures; Mw. Smit had a complex set of somatic problems, but over and above this she had also been diagnosed as manic depressive. The three remaining women in the room were all stroke patients. However, Mw. Van den Berg, who sat at a small square table adjacent to the rectangular table, also showed signs of Alzheimer’s disease. All attempts at fixing a daily routine for her had failed. Her food was left at her table and she picked at it intermittently. Other than the rhythmic movement of her jaw, she showed very few signs of animation. Mw. Klasen, her table companion, had a bulbar syndrome, her throat was partially paralyzed, and she was hemiplegic in her right side.

All the occupants of the room suffered from severely impaired mobility. The people whom they knew and talked to were the ones with whom they had eye contact. Mw. Smit once said to me, “I know Mw. Diekema and Mw. Guillet” (who sat opposite her at her table). “I know Adrienna Klasen and Mw. Van den Berg. I know when their birthdays are and where they used to live before coming here. But I don’t know those ladies,” and she turned her head, indicating the table behind her.

There was very little conversation in the room. Apart from the customary “Good mornings,” silence reigned. This was broken by the cheerful voices of the nurses asking, “Mw.—? Tea?” Mw. Fokke would try her best to keep the conversational ball rolling at her table by reading out gory anecdotes from the local newspaper to which she subscribed. “The body of a teenage girl found in a highly decomposed state. Tsk, tsk, I wonder what happened to her? Perhaps she didn’t get enough to eat. These young girls—always dieting!” Her comments were often rhetorical and did not require a response. The people in her vicinity would murmur something now and then. They tended to adopt a somewhat indulgent attitude toward her, because they knew that she was “confused” (in de waar). Mw. Fokke was one of the more active residents on the unit. She would go regularly for “activities” and to the gym, for physiotherapy. She participated in all the festivities that took place in Regina Pacis. Mw. Guillet, who was hard of hearing, kept herself occupied with her knitting and embroidery, but the others just sat silently at their respective tables.

Does the ward constitute an intersubjective community? At first sight it would seem not to be the case. It is only the seating plan that brought residents together into some kind of a relationship. Otherwise they all seemed to live in different worlds.

Mw. Klasen’s presence in the living room acted as some kind of catalyst for the group. She threatened to disrupt the fragile structures of normality. She was a relatively young woman—in her early sixties—and had come to the verpleeghuis as a result of repeated strokes after she received radiation treatment for a tumor in her brain.10 She had been a woman of considerable ability in her past life, a musician and a poet, and an intensely emotional person, according
to her sister. She had felt herself “disintegrating” long before she came to the verpleeghuis. Her life was a tragedy, one of the many in the ward. The difference between her and the other residents was that she had not become resigned to this loss. She could neither speak nor write. Her right side was paralyzed and her spirit too tormented for her to be able to concentrate on learning to write with her left hand. She did have a mechanical communicator when she first came but could not bring herself to use it. Her anguish expressed itself in screaming that was considered unreasonable and unbearable by residents and nurses alike. She presented a bizarre picture—saliva dribbling down her chin because she could not swallow and skirt rucked up over her knees so that her catheter tube was visible. She was very restless, fidgeting with whatever lay within her reach, wheeling herself all over the ward, even going outside. The nurses felt helpless. They could do nothing for her, could not understand what she wanted. I found that her bouts of screaming ended immediately if she was held and caressed—if she was given undivided attention by one person. But it was difficult to do this within the confines of a somatic ward. Physical gestures are restrained. The extravagant physicality that Mw. Klasen was wont to display was considered threatening. She had to be transferred finally, to a psychogeriatric ward, not because she was thought to be a psychogeriatric case but because the norms of behavior there are different.

Why was Mw. Klasen’s presence so threatening to the others on the ward? Was it because she upset their notion of spatial order? As I have shown, interactive space in the living room is largely delimited by where one sits and with whom one has eye contact. It is as if the rim of the table becomes the boundary demarcating intersubjective space. The notion of intersubjectivity assumes a conception of bodily intentionality that is based on norms regarding locomotion, object manipulation, and communication. It is largely through bodily intentionality that subjects acquire the kind of individuation required for participation in communicative relations. It is by positioning our bodies freely vis-à-vis other bodies and objects that our environment is made habitable. Thus, image schemas of the body organize the kinds of worlds in which we live (cf. Merleau-Ponty 1962). In the verpleeghuis, patients rarely conform to the bodily norms that are required for the kind of intersubjective relations that the phenomenologists describe. Norms of spatiality and motility are imposed externally, as patient’s bodies are often not capable of free and independent movement. Body images are fractured because patients are not capable of achieving the expressive unity that would give them the freedom to command the space that they require for making their own worlds.

The living room, as I have described, gives the impression of rigid spatial order, externally imposed. Patients are dependent on others for locomotion; they rarely move around the ward on their own—except Mw. Klasen. Her move-
ments, however, were not perceived as intentional. They were threatening because they were enigmatic. She did not conform to the norms required to sustain the kinds of communication that was possible on the ward. Most of the patients whom I have described did resort to gesture to communicate their wishes to the nurses; conversation was minimal other than as responses to the nursing staff. Some of the patients used words very effectively, but they tended to do so in an attempt to affirm their presence on the ward or to express their autonomy. The patient who was capable of movement and who did use speech to establish communicative relations with others in the living room was Mw. Fokke, and she was considered to be confused, though quite harmless, by the others. It was only Mw. Klasen who moved around the ward constantly—and who screamed. It was as if she breached the norms of spatial distance that people felt was necessary to sustain their own conceptions of personhood in the ward.

It was thought that a psychogeriatric ward would be more suitable for Mw. Klasen, because such wards tolerate a wider range of differences. It would also be able to provide her with a form of therapy that was difficult to find on the somatic side—that is, close physical contact. As I have already said, the loss of inhibitions caused by cognitive disturbances among psychogeriatric patients allow the nurses to communicate with them through touch. This is usually not possible on the somatic side, where the Dutch inhibitions on touch between strangers are observed. The nurses touch patients only when washing and dressing them, and this touch is kept impersonal to ensure respect for the patient’s autonomy. The self of the patient is constituted differently on the two sides of the verpleeghuis. In the case of Mw. Klasen, as we shall see, the change of residence also resulted in a change of identity.

In this section I have tried to show how selves emerge in the complex imbri- cation between institutional ideals and organizational imperatives. Public order is internalized to produce a certain conception of the disciplined self. The division between the somatic and the psychogeriatric wards does not only arise from the taxonomy of disease but also assumes different orientations to care. Theoretically, patients in somatic wards are capable of being rehabilitated. Patients in psychogeriatric wards are not. As we have seen, this division is not strictly maintained. There were at least two patients with dementia in the blue unit. They were tolerated because their presence was not overly disruptive. Mw. Albers was thought to be still aware of her surroundings and to have too much of a consciousness of self to be transferred to a psychogeriatric ward. Mw. Van den Berg’s presence on the Peppel was more difficult to justify. Her daughter insisted that she was not demented and therefore did not belong in a psychogeriatric ward.

There is a sense of fear regarding the psychogeriatric side that is shared by both nurses and patients. As will be shown in the following section, nurses
resist sending their patients to such wards. There is a fear of infantilization, of regression from the somatic ideal of rehabilitation and the hope of the recovery of a social self.

**The Remaking of the Self: Transfer to a Psychogeriatric Ward**

In organizations, entrances and exits carry a symbolic charge. They reveal the limits of organizational discipline and threaten the fragile order negotiated from day to day (Goffman 1961; Strauss et al. 1973). However, the decision to transfer Mw. Klasen to a psychogeriatric ward was not taken lightly. It took several months and many anguished meetings between the nursing staff, the doctor, and the verpleeghuis psychologist before the final decision was taken. Even then, there was a certain amount of anxiety among the nursing staff about the outcome of the transfer but also a helplessness, as if Mw. Klasen’s conduct represented an insurmountable barrier that their professional training did not allow them to cross. Here I provide an extract from the case conference.

DR. HUIJB: And now Mw. Klasen—who wants to begin?—you, you, you. (He points in turn to the two nurses from the blue unit who are present and then to me.) You, too, have something to do with her. (He does not follow the usual style of conducting a case conference. These usually begin with a brief introduction giving the patient’s medical status.)

JENNIE, THE UNIT HEAD: Her behavior has been changeable [wisselend]. There is a mental deterioration. Earlier, there was more contact with her. She responded to us more. It is not as if she doesn’t now. But then, it was as if she was actually going to say something. And now she behaves in this strange fashion—the crazy screaming, the contortions in bed—she even had her head stuck in the bed frame last week. And the weeping. It is difficult to know what is going on with her—yes, one can guess, I suppose.

DR. HUIJB: She looks better though, physically, than when she first came here.

ELIZABETH, THE WARD HEAD: When she is physically weak, she is more tranquil. Now that she is better she has become more restless.

DR. HUIJB: She sits facing Mw. Van den Berg—couldn’t be much for her there.

JENNIE: That’s why we position her wheelchair in such a way that she can look out the window.

JUDITH, A NURSE: She enjoyed the singing in the recreational therapy room last Friday.

ELIZABETH, A NURSE: We have been asked not to send her again. She started to scream and the other residents were frightened. Why she does it we don’t know.

DR. HUIJB: *(Turning to me)* You told me that she liked music.12
ANNIE, THE SOCIAL WORKER: She used to play the organ and the recorder.

DR. HUUB: This is a woman with severe cerebral injuries, but with moments of clarity. She needs individual care. She was an intelligent woman once, she made something of her life and then this . . . I know you all have too much to do. Try and get a volunteer.

(At this point there is no discussion regarding her transfer to a psychogeriatric ward. The staff is still working with a model of rehabilitation and hopes to help her acquire a social disposition that is in conformity with the normative expectations of the ward.)

Three months later at another case conference . . .

DR. HUUB: Last month, on January 6 to be precise, we had asked the psychologist to examine Mw. Klasen to consider the question of transfer [overplatsing]. (He summarizes her medical history.) She has had a meningiom and a number of CVAs. She has always been hysterical—according to her sister, that is.

MARTIJN, THE PSYCHOLOGIST: Her actions and thoughts seem unconnected. At least there is a fluctuating connection. She is easily distracted.

DR. HUUB: Is she conscious of her failings?

MARTIJN: I hope not, for her sake.

DR. HUUB: . . . and the unstoppable screaming?

MARTIJN: I don’t know what’s going on in her head. Transfer to the other side has ethical problems. It won’t help her—but it depends on the other thirty-five people. (He is referring to the other residents of the ward.)

DR. HUUB: The change has no advantages for her. She is very sensitive to atmosphere. (Turning to me) You have spent a lot of time with her. Do you want to say something?

ROMA, THE ANTHROPOLOGIST: She can’t communicate.

DR. HUUB: Yes, yes, I understand. That’s why she screams—because she can’t.

ROMA: And she isn’t demented.

MARTIJN: Yes, but there is a fluctuating chaos in her head.

DR. HUUB: (Summing up) A woman with organic injuries whose behavior is disturbing for others.

ELIZABETH: I know that she is disturbing—but we have invested so much energy in her. We have spent hours feeding her—Roma has as well. What if she gets worse? Can we get her back?

MARTIJN: No. There is a discrepancy between her pattern of expectations and that of the ward.

DR. HUUB: We don’t have any other choice. We have the whole institution to think of, not just one individual. But we have to be careful about the choice of ward.
The theme that strikes me as most significant in this discussion is the attribution of agency to the patient. Mw. Klasen’s behavioral anomalies are attributed to her communicative incapacity and to personality quirks rather than to her illness per se. Her behavior was thought to be opaque. She was not capable of internalizing a discipline that would produce a socially embodied self in alignment with institutional norms. The logical way out was to transfer her to a ward where opaque behavior was the norm, where action was not thought to be an outcome of will or intention.

As it so happens, she was much happier in the psychogeriatric ward and, as is the case with many verpleeghuis residents, she expressed this through her body. The image of her in the somatic ward had been that of a woman tottering on the edge of chaos, restrained with great difficulty. She had limp, dank hair falling from a point in the center of her head (the rest had fallen out as a result of radiation treatment). This set her apart immediately in a room full of perms and well-groomed buns. She sat in a wheelchair with a restraining belt around her, a catheter tube visible on the side. The nursing staff, in all fairness to them, did try their best to turn her out neatly, but her mental state was such that she did not care about her appearance.

After she was transferred to the new ward, the nurses began a series of normalizing experiments. They began by removing the belt. She did fall once or twice, but on the whole this experiment proved successful. She no longer sat in a wheelchair. She had already begun to walk, supported by a nurse, while on the somatic side. Now she was given a stick. (This also made her more immobile, of course.) Her hair was permed and she was encouraged to eat on her own. She was more at peace with herself and her surroundings. She developed a special friendship with a fellow resident; he gave her a new name, “Mien,” and she seemed to prefer it to her own. There was a new desire to communicate and to establish links with what she had been before. Her sister described how she had asked for her old books and the poems that she had once written. She said that she had noticed that Mw. Klasen was scribbling something with her left hand. There was a scribble, then a g, another scribble, then a d, and she suddenly realized that Mw. Klasen was writing gedichten (poems). When I visited her she would show me pictures from her childhood, the books from her nursery school, and some of the poems that she had written.

She was happy in this ward, as expressed through the new relationship she was trying to establish with the past. But there was also a dislocation from, a renunciation of, another part of it—the torment and suffering that had dominated at least a part of her adult life. I sorted out her papers with her. She would laugh at the old schoolbooks and the children’s poems that she had written, but turned her face away in distress when we came across some short poems, almost jottings, in which she had expressed her despair at the meaninglessness of passing time.
Forgetting is not always something that overtakes one. It does not just simply occur; it can also be a deliberate choice, not just a loss, but a renunciation. For Mw. Klasen, the past was in a way embodied in the family and the community from which she had to be dislocated after entering the institution. In the somatic ward, she expressed this dislocation through screaming and her disheveled appearance. After being shifted to the psychogeriatric ward, she seemed to calm herself down by bracketing away a certain part of her past and to begin inhabiting a different region, that of her childhood. The tolerance in the psychogeriatric ward of childlike behavior and the liberty to be different, since norms establishing and representing the ordered body were less strictly adhered to, allowed a temporary equilibrium.¹³

However, it is inappropriate to attribute Mw. Klasen’s transformation simply to a process of infantilization. As a result of the normalization experiments that were being tried out on her, she developed a new consciousness of self and an awareness of her presence on the ward vis-à-vis the other patients. Paradoxically, the psychogeriatric ward was able to achieve what the somatic ward could not. Mw. Klasen was redefined as a socially embodied self. As I have said, Mw. Klasen’s transfer was an acknowledgment that the goal of rehabilitation—that is, the reconstitution of social embodiment for selves who are damaged in this regard—could not be achieved in her case. It was acknowledged that it was a result of the social dislocation in the ward, a dislocation in interpersonal relations, rather than of any biological disturbance caused by her illness. The psychogeriatric ward was able to instill an inner discipline precisely by accepting her on her own terms. However, the process of resocialization did involve the sacrifice of some part of Mw. Klasen’s biography, of the passions, emotions, and intellectual concerns that marked much of her adult life.

She died a few months later. Her anguish on the Peppel had had a positive side. She had not given in to her illness completely; her restlessness had been a sign of her effort at orienting herself to her new environment in the verpleeghuis. It is as if she gave up on life after her transfer—not in despair, because she seemed happy, but as a conscious choice.

Conclusion

In recent years, dementia studies has made a significant contribution to strengthening the relational perspective on the self by describing the influence of intersubjective processes on its preservation and dissolution. Cross-cultural ethnographies have made us sensitive to the importance of culture in understanding personal and institutional responses to dementia (Sabat 2001). However, cross-cultural comparisons of institutions, especially medical institutions, are not so common. Such endeavors are complicated by the diversity of institutional arrangements that are present in any given society. Particular
institutions have cultural patterns, norms, and expectations that are specific to them, even if they all tend to conform to the general normative structures of the wider society. Cultural plurality can exist even within an institution. Thus, the two wards in the medical institution that I describe seem to embody different kinds of cultures, such that demented persons are viewed somewhat differently in each of them.

There is a danger, however, in analyzing institutions through the prism of culture, as I have done. Cultural relativity, when inscribed in self-referential bureaucratic systems such as the one I describe, can be used strategically as a justification for the perpetuation of such systems. Contradictions within the system are perpetuated, as there is no outside source to which it is accountable. Thus in the context of the verpleeghuis, the ideal of verpleeghuis medicine—individualized norms, which establish a unique relationship between the subject and the verpleeghuis environment—seems to be in a contradictory relationship to the reality of organizational functioning, which is based on “dividing practices” that classify and distribute patients in terms of externally imposed norms (cf. Rhodes 2000).

From this perspective, Leering’s references to the work of Merleau-Ponty and his discussion of the embodied self can be viewed as an attempt to “naturalize” this contradiction by locating it within the person rather than in the techniques of normalization instituted by the verpleeghuis (cf. Leering 1968, 1970). However, a careful reading of Leering’s proposal to the architects who designed the new building reveals a more complex picture. Leering took pains to define the two central concepts that he used in talking about the individual norm in relation to the environment of the verpleeghuis. One was leefbaarheid, the quality of habitability; the other was menselijke funktioneer, human functioning. Leefbaar maken—to make habitable—that is, to create an environment in the verpleeghuis that would allow the self the possibility of true embodiment, the ability to offer itself to the subject’s senses and intentions so that the patient could function as a complete human being (cf. Leering 1970, 6). This allows us to consider the dividing practices in the verpleeghuis—the division into somatic and psychogeriatric sides—as an attempt to realize this ideal.

Clearly, this division has more than a diagnostic or a therapeutic basis. As we have seen, a person’s location in a particular ward may sometimes be based on nonmedical criteria. Dividing practices also produce subjectivities. Patients become who they are in the process of interactive reflexivity with others in the ward, as well as through their sense of where they are, as we saw in the case of Mw. Klasen—a nondemented person in a ward for people suffering from dementia. Why did she accept the normalizing practices here, when she had rejected them earlier, on the somatic ward? Is it because on the psychogeriatric side, differences are accepted as the norm? Or alternatively, one could say that
both sides operate within the same disciplinary regime. They merely use different strategies.

Rhodes (2000) thinks of medical taxonomies as offering possibilities for organizing “the many forms of otherness that mark the limits of . . . manageability”—of the self and of discipline in total institutions. While the specific forms of classification in the verpleeghuis may partake of this logic, I prefer to think of the somatic and psychogeriatric sides as alternative to each other—each one representing a different kind of normality and offering a particular form of normativity (cf. Rabinow 1996). However, it is only from the vantage point of psychogeriatrics that it is possible, within the verpleeghuis, to reflect seriously on the idea of differences and to accept the challenge of constituting new norms in new environmental contexts.

NOTES

1. The term nursing home is not really a correct translation for verpleeghuis. Caregivers stress the fact that inmates reside in the verpleeghuis. It is not their home. However, until the late 1960s the designated term for such institutions was indeed verpleeghtehuis, which can be translated as “nursing home.” This was officially changed to verpleeghuis, “nursing house,” in keeping with the medical goals of the institution and an emphasis on its professional functions. However, there is also a normative dimension to this change of designation. In the Netherlands, the home is considered to be part of one’s private sphere and cannot be substituted by formal institutions of any kind.

   My ethnography is based on fieldwork in Regina Pacis, a verpleeghuis in Arnhem in 1986–1988 and again for a short period in 1989. I was able to pay a brief visit to Regina Pacis again in 2000. The fieldwork was funded by the Indo-Dutch Programme for Alternatives in Development.

2. The instrument that quantifies extent of nursing care is the Behavior Rating Scale for Old Patients (Beoordelingschaal voor Oudere Patienten [BOP]).

3. Verpleeghuis medicine is distinguished from the kind of medicine practiced in hospitals. It operates with a chronic-care model in opposition to the acute/cure model that characterizes the medical regime in Dutch hospitals.

4. Leering defines function as goal-oriented action (cf. Leering 1970). The ADL functions are as follows: bathing/washing, clothing oneself, ability to use the toilet, eating, and continence. Leering thought of the ADL in terms of activities that were concerned with the private space of one’s own body. He chose not to include walking in this scheme because it involved more than this private space. He thought of it as an activity that involved public space (cf. Leering 1968).

5. Interestingly, Leering never talks about the capabilities of patients when he discusses the need to make the verpleeghuis a personalized space. The onus is on the designers and the caregivers. This is in marked contrast to the emphasis he gives to patient initiative while discussing revalidation and the ADL (cf. Leering 1968, 1970).

6. I use the feminine form deliberately. Even though there were five male nurses in Regina Pacis at the time when I was doing my fieldwork, there were none on the Peppel.

7. The lift is a crane that is manually operated to lift up people who are very heavy from their beds on to their wheelchairs.
8. Mw. is the abbreviation for mevrouw, meaning “madam.” Verpleeghuis residents are always addressed formally by the staff as if to stress their autonomy. Since the nurse-patient relationship is often invasive, this is one of the ways in which formal distance is sought to be established.

9. Sinter Klaas is a figure of folklore who distributes gifts to children at Christmastime. He records the good deeds of children in a golden book and the bad deeds in a black book. I think Mw. Roosevelt was responding to an implicit infantilization that was taking place. She was used to the fact that she needed help with the ADL but she probably felt that more than one person helping her diminished her status as an adult with an attendant claim on privacy. Before I had started work in the ward I had circulated a note on what I proposed to do on the ward and in my discipline, cultural anthropology. In India my designation is that of a sociologist, but since I am one of the rare breed of sociologists who have studied a society other than their own, it was easier to call myself an anthropologist while I was in the Netherlands.

10. The average age of the verpleeghuis patient more than seventy years.

11. Disintegrating is the term Mw. Klasen used to describe her condition in a letter she wrote to one of her previous doctors before she was treated for the tumor in her brain. Patient records are supposed to be as complete as possible. Considerable effort is taken to collect documents from all medical institutions with which the patient has had contact. Even personal correspondence between the staff of such institutions and patients are gathered together for the patients’ dossiers.

12. On my first day on the ward, someone switched on the television while I was feeding Mw. Klasen. A recording of Vivaldi’s symphony The Four Seasons was being broadcast. She looked up immediately with an arrested expression on her face. I remembered reading in her case file that she had been an accomplished musician before her illness. I asked her, “Mw. You played an instrument, didn’t you?” She nodded and her face broke into a radiant smile.

13. Els van Dongen (1997) speaks of infantilization as a way of relating to the ungovernable body. It invites the imposition of disciplinary techniques—the imposition of external rhythms of work and patterns of bodily care—but also allows trust and intimacy between caregivers and patients. It is one way of overturning norms of autonomy and bodily discreteness.

REFERENCES


