Roma Chatterji

Medical Institutions and their Counter-Cultures

Abstract Using a mix of visual and literary storytelling as well as participant observation in the field, this chapter attempts to present the Dutch verpleeghuis (nursing home for the dependent elderly) at a particular historical juncture in the mid 1980s when it could be conceived as a public space with the potential for creativity and self-critique. At first sight, the verpleeghuis as a total institution, suggesting a particularly rigorous kind of 'disciplinary regime', seems to be an odd site on which to explore creativity. However it is precisely through its totalizing character that it is able to posit itself as being outside of society and thereby enabling it to hold up a mirror to society and also to its own working. The 1980s were a time when the humanist disciplines were very influential in gerontology in the Netherlands as they offered ways of conceiving forms of bodily intersubjectivity and individuation and enabled verpleeghuis doctors to critically reflect on their own practices. We see this happening in this chapter through cartoons and an allegorical tale written by a doctor who is reflecting on the iron cage of his own bureaucratic work place and contrasting the "should" of the ideal goals of the total institution with the "is" of bureaucratic practice. This looking back to the verpleeghuis past is contrasted with the neo-liberal present. Ironically, many of the ideas that were central to the self-critique of the verpleeghuis as a disciplinary regime, such as self-cultivation and democracy, are the very ideas that are supposed to be at the heart of the new institutional arrangements, yet have the paradoxical effect of closing off all notions of public spaces where critical voices find a space.

Keywords ADL, verpleeghuis, counter publics, cartoon, fairy tale, critique, embodiment

Introduction

"The 'agora' [the space for creative display, physical space] no longer exists within the verpleeghuis, and without that space I can no longer make cartoons." This was Dr. Jan Diekema's (MD) response to my question—did he still draw cartoons about the ambiguities of his workplace?—when I met him in June 2010 after a gap of more than twenty years. I was visiting Regina Pacis, a verpleeghuis in the city of Arnhem, where I had spent almost two years while doing fieldwork in the mid-1980s. My first fieldwork in the Netherlands was made possible by the Indo-Dutch Programme for Alternatives in Development (IDPAD), an initiative that was supposed to foster comparative research on the two countries. However, most Indian scholars who have participated in this programme have confined their work to library-based research. My research was one of the first under IDPAD to actually attempt an ethnographic study of a Dutch institution. My return visit in 2010 was made possible by the European Studies Programme that a group of teachers at the Department of Sociology, Delhi University, were involved with. The programme enabled students of the department to undertake short-term fieldwork in Europe so as to be able to put their larger concerns with Indian society in a comparative perspective.² My work on institutionalized ageing in the Netherlands was not conceived as a comparative project. It did however lead to an interest in exploring aspects of bureaucracy in India in subsequent research. Also, my doctoral research

The Dutch *verpleeghuis* is a residential medical facility meant for the long-term care and intensive nursing care for elderly people with severe chronic impairment, both somatic and psychological. Professional institutions of this kind were first started in the late 1960s and 1970s when the Exceptional Sickness Costs Act of 1967 enabled financial support for patients suffering from severe chronic disabilities. The English term "nursing home" that is used to translate verpleeghuis is misleading, especially in the Indian context where such homes are usually privatized in sharp contrast to the Dutch case. There is a long debate in the Netherlands about the substitution of the term "home" by "house" since the former conveys additional meanings of permanence that Dutch gerontology has fought hard to resist. I argue that the definition of the verpleeghuis has an inbuilt vision of itself as a system of hope—a somewhat utopian representation that has generated a culture of self-criticism. Thus, according to the official ideology, the *verpleeghuis* is a place for "reactivation" of the disabled elderly, a temporary habitation which people are encouraged to leave after regaining their health. I prefer to use the Dutch term rather than the English term "nursing home" because the connotation, especially for an Indian audience, is somewhat different.

² My visit to the Netherlands in June 2010 was under the auspices of the European Studies Programme at Delhi University, funded by a grant given by the European Commission. My earlier research project, "The Welfare State from the Outside. Aging, Social Structure and Professional Care in the Netherlands," was funded by the Indo-Dutch Programme for Alternatives in Development. Veena Das and Klaas van der Veen were the coordinators of that project, and the other members of my research team, Rajendra Pradhan and Sanjib Datta Chowdhury, conducted their fieldwork in a village in South Holland and an old age home in Amsterdam, respectively. The fieldwork period was approximately fifteen months starting in August 1986. We all spent six months learning Dutch at the University of Amsterdam in preparation for fieldwork.

on storytelling in rural India likely led me to focus attention on creative expression in the *verpleeghuis*, which is probably not common in the literature on gerontology.

What had struck me during my initial fieldwork in the 1980s was the imaginative space that seemed to exist within the *verpleeghuis*. Jan Diekema produced satirical cartoons that were displayed on the notice board in the doctor's corridor; he read out an allegorical tale instead of giving the regulation lecture at a refresher's course on nursing organized in Regina Pacis; and staff members and patients were encouraged to contribute stories, poems, and drawings to the monthly in-house magazine. Regina Pacis, as one of the first institutions of its kind in the Netherlands, was quite conscious about the kind of work environment that it wished to foster among its staff, and encouraged open discussion and self-criticism.

The inspiration for this chapter was the return visit to Arnhem in 2010 at a time when the Netherlands were reeling from the changes brought about by the rollback of the welfare state. State-funded institutions like Regina Pacis had lost much of their earlier autonomy, especially in spheres such as budgetary planning and decision making powers regarding non-medical aspects of patient care. In India, where much of this kind of care is under the purview of the family, questions around institutional autonomy may not have the same significance. Unlike the conception of the relational self that is supposed to characterize Indian society (Cohen 2000), in the Netherlands the valorization of individual autonomy has led to the professionalization of the dependency relationship (Chatterji 1991). Persons suffering from severe impairment are supposed to prefer institutionalized forms of care rather than be dependent on their relatives. An unintended consequence of this valorization of personal autonomy has been the potential for radical "totalization" of medical institutions that have come to organize all aspects of their patients' lives. The *verpleeghuis* is a "total institution" that conforms to the ideal type made famous by Erving Goffman in his classic Asylums (1961), and like all total institutions, it has a vision of itself and its role in the wider society. I will have more to say on this subject later, but let me begin with a brief account of the changes that I saw in Regina Pacis in 2010.

Architectural design and the space of habitation

When I revisited Regina Pacis in 2010 I noticed some radical changes. The *verpleeghuis* building that had been the brainchild of Cornelius Leering (MD, PhD), a pioneering geriatrician, an expert on revalidation therapy, and the first medical director of the institution, had been demolished. The structure embodied many of his radical ideas about the self of the elderly person and the way in which impairment could be viewed as an altered form of normality within an environment that was sensitive to their needs. Dr. Leering was a visionary. Inspired by the philosophy behind the science of revalidation, he believed that corporeal capability could be restored to

impaired persons by recreating their lived worlds within the *verpleeghuis* so that it could become a microcosm of the world outside. He had had a particular vision of old age "disability," which was reflected in the institution's architectural design, and it was associated with a vision of sociality that emphasized the importance of heterogeneity and intensive interaction between patients and the different professional groups working in the *verpleeghuis* environment—an interaction that Dr. Leering felt could only be possible in a kind of agora where people could meet as autonomous individuals rather than patients and caregivers. Since Regina Pacis was planned as a total institution offering full-time residential care, he decided to build the public square within the institution itself.

I argue that it was the inclusion of the idea of the public square within the physical space of the institution that fostered the kind of critical self-expression that I have mentioned, and the lack of such spaces may have something to do with the paucity of such creative voices within the *verpleeghuis* world in recent times.

For me, as an Indian, I found it extremely difficult in the early months of fieldwork to understand the careful detailing of the idea of the "public" and the attempt to bring the idea of the "public square" into an institution that is in effect closed to the outside world, as well as the silence around "the notion of the private sphere." Representations of ageing and disability in India tend to be family-centric and thus more concerned with the sphere of domesticity—an area which for gerontologists like Dr. Leering would be considered too private to be touched by the medical discourse. As I have already explained, there is a continuous attempt to expunge all references to the sphere of domesticity in the discourse around the verpleeghuis. This explains the substitution of the term verpleeghthuis (nursing home) for verpleeghuis (nursing house), as medical professionals are not supposed to encroach on the private sphere of the home or to think of creating a homelike substitute for their elderly residents. The contrast to this ideology with the representations of ageing and disability in the works of Cohen (2000) and Addlakha (2008), both of whom are concerned with medical institutions, is marked. In the works of these two scholars, the medical institution becomes available for study through the experiences of family members who are brought into the wards to share in the work of care. In my experience, it is actually easier to gain access to the experiences of disability and suffering through institutions in the Netherlands. Two colleagues from Delhi University were also doing fieldwork in the Netherlands during the same period—one in an old age home (bejaardenhuis) and the other in a village where he was trying to understand the lives of the elderly within the context of their families. It was he who found it most difficult to gain access to their lives.³ Coming back to the rather romantic idea of the "public square" that informed Leering's vision of the verpleeghuis that he had planned to construct, I was told by some of the doctors who had been at

³ See footnote 2 for details on our collaborative research project.

Regina Pacis since its inception that it was modelled on the idea of a medieval market place—a carnivalesque space of diversity and polyphony very much like the Rabelasian space celebrated by Michael Bakhtin's *Rabelais and his World* (1984). It had something of a cult status when I was doing my doctoral research in Delhi University and I was quite excited that Dutch doctors also read such works. I think that it was the literary and philosophical sensibility that informed the Dutch gerontological discourse in the 1970s and 1980s that I found most stimulating and quite different from anything that I have encountered in the literature coming out of India or England or the United States, for that matter.

With the exception of some ethnographic writings by anthropologists such as Robert Desjarlais (1997) and Lorna Rhodes (1991), organizational studies rarely focus on architectural design as a significant aspect of institutional culture. While the Foucauldian idea of the "panopticon" has been influential in shaping our understanding of the way in which selves are articulated with the disciplinary regimes of total institutions, more nuanced understandings of physical space and its role in constituting institutional culture are lacking. In this chapter, I think of architectural design as a site that embodies and helps articulate aspects of official *verpleeghuis* ideology—its modes of constituting persons with severe impairment as *verpleeghuis* residents and professional caregivers as fellow travellers who also inhabit this institutional space.

When I did my fieldwork in the 1980s, the correct designation for verpleeghuis patients was "resident." The preferred term now is "client," which reflects the new thinking on health care as a marketable commodity. Be that as it may, both terms suggest a kind of impersonality that shuns the negative connotations of passivity and dependence associated with "patient." "Resident" also carries the connotation of symmetry between different kinds of people who share institutional space, which is important in sustaining notions of personal autonomy so crucial to Dr. Leering's idea of the public square as a space for creative interaction. I will have more to say on the division into private and public space that was so central to Leering's vision for Regina Pacis in the next section. Here I want to flag the idea of an agora or public square as the site for the generation of a counter-culture within the institution.4 One expression of this counterculture that I take up for detailed discussion are the cartoons drawn by Jan Diekema, with which I began this chapter. Dr. Dikema is a medical doctor whose career in Regina Pacis spanned three decades and who therefore

⁴ I prefer the term "counter-culture" to Goffman's (1961) "underlife" because the latter is restricted to the culture produced by the "inmates" of total institutions which have the capacity to subvert the rules without being actually caught and punished by authorities. This kind of vibrant underlife occurs usually in institutions for healthy people, like prisons and boarding schools, and not in hospitals. The counter-culture suggests an active and overt critique of a dominant culture, such as the one institutionalized by the medical bureaucracy which the medical and nursing staff can counter in their everyday acts to some extent and certainly through creative expressions as I show here.

witnessed all the important developments and changes in its history—from its early attempts to institutionalize bureaucratic protocols in the name of professionalism, to the recent changes that have led to loss of institutional autonomy so that Regina Pacis is now a node in a large care network that includes many different kinds of medical care providers. His cartoons often reflect the tensions and contradictions in work practices brought on by these changes, and I shall offer a close reading of a small selection. In this way I hope to engage with the larger sociological critique of neoliberalism and the impact of its ideology on public institutions. While there are several Dutch authors (Mol 2008; The 2005) who have thrown light on the negative consequences of the market logic that has inspired the recent restructuring of medical institutions, I feel that a discussion on irony with its in-built capacity to highlight institutional bad faith may be an important addition to this.

The ideal world of the verpleeghuis

In an insightful essay on the significance of motoric intentionality in Merleau-Ponty's understanding of embodiment, Carrie Noland (2007) says that for Merleau-Ponty, the pre-personal body "cleaves" to the world even before the self assumes a conscious stance towards it. Leering, whose own thoughts on revalidation had been influenced by Merleau-Ponty, believed that corporeal capability was shaped by the social milieu (Leering 1968, 1970). Since the verpleeghuis was a chronic care facility, he felt that it had to embody the values that would make a meaningful life-world possible for persons whose mental and physical abilities were severely impaired. Thus, it should be able to embody the social values of the larger society, especially in the way that it organized the experiential categories of time and space for its disabled residents. Not only were private spaces to be marked out, spaces where one's intimate activities could be carried out in solitude—such as self-grooming—but so too were the public spaces. Public spaces were thought to be spaces of sociality, partaking of some of the qualities of the market place; a heterogeneous and polyphonic space that allowed for intense interaction between strangers. This idea was translated into a two-storied building that lay sprawling over a large and picturesque park that had once been part of the estate of Dutch aristocrat, the Duke of Palland. The doors and windows all looked out onto the park. The reception area was continuous with the public area where verpleeghuis visitors, residents, and staff could intermingle in the shop and restaurant. The hair dressing salon for residents was also adjacent to this space. A few benches and lamps in the shape of street lights reinforced the impression of a public square. All the corridors that led to the wards and to the doctor's wing radiated out from this space. The corridors were designed to be extensions of the public area with demarcated spaces for repose and intense activity. Taking Merleau-Ponty's dictum literally, that the world in a sense commands the body to move, Dr. Leering wrote that public spaces are spaces for movement, spaces that bodies come to inhabit through habitual practices producing embodied notions of selfhood. Thus, wall space was often used to display works of art in the hope that such exhibitions would help create a stimulating environment for patients with diminished capacity for sensory awareness.⁵ The notice board, as I have said, could also be used as a creative space and sometimes became a focus for intense interaction. A railing ran along the wall, marked out in a distinctive colour for the patients to hold onto for support while they walked along the corridors looking at the pictures on display. Colour and decoration were of great significance in transforming the building into a space of habitation.⁶

For Dr. Leering, the division between public and private realms was central to the organization of the *verpleeghuis* as a therapeutic space. It is supposed to provide a prosthetic environment in which severely disabled people can still function as autonomous beings. Leering had done doctoral work on the standardization of the "activities of daily life" rating scale used to judge levels of impairment and ability to carry out bodily functions. These are used routinely to classify verpleeghuis populations in terms of care requirements. For Leering, however, the activities of daily life (ADL) became existential markers, standing for fundamental human values; he said that the ADL marked out the private from the public realm as far as the verpleeghuis patient is concerned. They helped to identify the basic requirements for the maintenance of individual autonomy, for the personal intimacy that characterizes one's relationship with one's body. Consisting of activities such as bathing, dressing, eating, toilet use, and continence, the ADL was, according to Leering, the private part of human existence. But it was also the visible part so that any deficiency in this area is immediately marked and has a direct impact on one's social milieu. Bedrooms, toilets, and bathrooms had to be functional, but also had to be organized in such a way that privacy was ensured while help with bodily care and grooming was facilitated. Public spaces were for more formal activities such as reading or watching television, which he called "societal activities." Such spaces were also distinguished from the central "multi-functional" square where a variety of activities could take place, such as going to a shop or restaurant. Such space was thought to give the verpleeghuis a touch of normalcy as it allowed residents to go out with their visitors while still being within

⁵ When I did my fieldwork in the 1980s, I was told that Regina Pacis received a government subsidy for providing this exhibition space. This subsidy was considered to be part of the government's role in actively sponsoring public art projects.

The 1960s and 1970s, the period when modern *verpleeghuises* developed, was a time of great idealism. Buoyed by economic prosperity that was distributed among the population at large through welfare provisions, people were encouraged to make life style choices and to expand the range of their experiences. In 1983, when the welfare state was already in retreat, constitutional arrangements were made to reaffirm the state's obligation towards the social and cultural development of its citizens (Kossmann 1986).

the protected walls of the institutions. The ideal resident, as conceived by the architectural design of the *verpleeghuis*, was one who, although suffering from the spatial restrictions brought on by extreme disability, still had alternate spaces in which to exercise a semblance of freedom and actively engage in whatever forms of social life that were still available to them.

When I went back to Regina Pacis in 2010, it was housed in a temporary, prefabricated residential structure. As I have said earlier, the building that had been conceived by Leering had been demolished six months prior to my visit. Organizational thinking on what were considered to be the norms of sociality and efficiency had changed since Leering's time. It was felt that the use of space in the old building was inefficient and uneconomical. There were too many corridors and not enough rooms for residents. The wards in the old building had a combination of one-person and four-person rooms. Most verpleeghuises now have only single rooms as any other arrangement is considered to be a gross violation of a patient's privacy. Earlier, all wards had living rooms where residents spent the day with other members of their wards. Such spaces have now been drastically reduced, especially in somatic wards, and the only public places left are the restaurants where the resident supposedly has some choice in whom to interact with. Somatic patients are supposed to have the right to privacy, to be able to choose whom they wish to sit with, no matter that such a right may be very difficult to exercise. The model of public space in the *verpleeghuis* setting is now the café or hotel rather than the market place as Dr. Leering had once envisioned—a place for enforced sociality or where sociality is viewed as a form of public encounter. More on this subject later, but the distinction between the café and the public square as two distinct models for envisioning public space may help us understand the historical shift that has taken place in the *verpleeghuis* as an institution and the way in which its services are now organized. Thus, the name of the structure in which Regina Pacis is temporarily housed is "Café Intermezzo," deliberately chosen to reflect its temporary nature, but also to give the impression that it is an open institution where people can come and go as they wish. This, however, is far from reality, as not many patients actually leave the verpleeghuis while still alive. However the name was perhaps not intended to be a deliberate deception, but rather reflects the way health care has been commodified in the Netherlands after the functions of the welfare state have been rolled back.

The welfare state, with its vast, all-pervasive bureaucratic structures, was still in place in the mid-1980s. Trust in the ethics of care and in the bureaucratic protocols that could ensure welfare provisions formed the foundation on which the moral world of public institutions like the *verpleeghuis* were built. By the time I revisited Regina Pacis in 2010, the

⁷ A new building has now come up on the old site. It has been built on stilts to allow for more extensive parking space considered necessary for the many additional extramural services that verpleeqhuis functionaries now have to undertake.

health care sector had been radically reorganized. Cut backs in government spending on health care have led to the creation of new networks in which medical and other care facilities are coupled with private insurance companies. Regina Pacis is now part of a large network made up of several other kinds of medical and caregiving institutions. Running Regina Pacis as an independent institution had become financially unviable, and merger (fusie or fusion) with a larger care network was thought to be a way of giving it a competitive edge in a field that is increasingly being governed according to market principles.

The notion that the *verpleeghuis* could be conceptualized as a moral world whose inhabitants had an ethical duty to be responsive to the emotional demands of others emerged from a critique of the medical model in which the sick person's life is organized in terms of a disease trajectory. The recognition of a "holistic system" of care was important in thinking of the *verpleeghuis* as a "caring community" in which patients as well as staff could reach out to each other. However, the bureaucratic demands of the organizations are often at odds with the institutions' self-professed ideals. The setting up of commissions and protocols to help the process of patient emancipation and democratization within the institution is supposed to help close the gap between these contradictory aspects.

The 1960s and 1970s, the period when the first professional care institutions were being established, was a time of great optimism in the Netherlands. Social diversity and personal freedom were valorized, and there was a belief that it was possible to constitute society as a dense ethical mesh by encouraging individuals to beconscious about their distinctiveness. In this moral climate, invalidity could be viewed as a distinctive mode of being and self-expression. It was the responsibility of the *verpleeghuis*, as a total institution, to create a prosthetic environment that could enable this distinctive mode of being. In keeping with this philosophy, the *verpleeghuis* as an institution also enabled a culture of self-criticism that was quite remarkable, even in the liberal era of the 1970s. Ten Have, a *verpleeghuis* doctor, wrote a monograph based on sociological fieldwork in one such institution. Using Goffman's (1961) work on total institutions⁹ as

⁸ The "caring community" is a term that appeared in a lot of the public discourse in the 1980s. Sensitive critics like Dr. Diekema felt that this term was used in a largely rhetorical way to sugar-coat the cuts in the government's welfare budget. In the discourse of the *verpleeghuis*, the idea of the caring community reflects the institution's vision of an ideal form of neighbourly living which they try to replicate within the ward by planning patient in-take in terms of a diversity of forms of disability and ability to communicate.

⁹ The total institution ideally collapses the separation that modern societies make between spaces for work, sleep, and recreation. All activities are tightly scheduled and carried out in a single space under a single authority. The most striking feature of life in a total institution is the idea of batch living and is thought to be completely contrary to the way life is organized in normal society where privacy is a central organizing norm (Goffman 1961).

Even though the 1960s and 1970s were radical times in which there was an effort to bring about democratization in many institutions, the tolerance of

a vantage point for a critical reflection on its work culture, he came to the conclusion that patients and care providers lived in separate worlds that had no connection with each other (Ten Have 1979).

Goffman's (1961) discussion on total institutions shows us that they are based on incongruent definitions of reality (see also Emerson 2000). The reality of the *verpleeghuis* contains not only an official self-definition, but a counter-reality as well. The *verpleeghuis* ideal of "caring community" comes up against the stark reality of the patient's actual situation in which the social network around them has collapsed and they have no other source of care. In such a grim scenario, the *verpleeghuis* is often the last resort. Given this, the *verpleeghuis* identity is inherently precarious, built as it is on several contradictory definitions of reality.

The strength of Goffman's study lies in its ability to demonstrate how the total institution is not merely a bureaucratic organization, but also a social institution and thus embodies a particular moral code. Ten Have uses this aspect of Goffman's work as his point of departure and distinguishes between two aspects of the *verpleeghuis*: the organizational and institutional aspects. The organization is defined by its goals, and the institution by normative modes of action. There is always a tension between the two aspects. Ideally, the normative aspect should take precedence, but there is a real danger that organizational ends will engulf the institution as a whole. According to Ten Have, the health of the institution is dependent on the reflexive relationship between the two aspects. The verpleeghuis as an institution occupies a moral space in society, and must articulate its self-critique in terms of this reflexive relationship. Ten Have's work provided an impetus for self-reflection in the verpleeghuis world. Efforts were made to create structures that were more open-ended and responsive to criticism, and to institutionalize a more personalized system of care that could address the needs of a diverse population with vastly different forms of sensory impairment.

Discourse and its publics

In ancient Athens, the agora was the central square, open to all citizens, a space in which many different kinds of activities occurred simultaneously (Sennet 1994). The public area on the ground floor of Regina Pacis near the main entrance housed a shop, a restaurant, hair dressing salon, and a chapel where the pastor in residence held mass once a week. ¹⁰ In a small way there was an attempt to replicate the idea of a public square in the city center where people met while carrying on diverse activities. The

verpleeghuis culture is still quite remarkable and certainly not shared by other kinds of medical institutions (see Chatterji 1993).

¹⁰ This and some other cultural symbols pointed to the past history of Regina Pacis as a Catholic institution. After the Algemeine Wet Bijzondere Ziektekosten (ABWZ) came into place in 1967, admission to Regina Pacis was no longer restricted by religious denomination (Chatterji 1991).

public square is the ideal space for stranger sociability separate from and contrasted with the private space of domesticity and intimacy.¹¹ It was in this central space that Jan Diekema along with other members of the staff chose to display his satirical cartoons on bureaucratic protocols and work routine.

In the Netherlands, most "total institutions" that were built in the 1970s tried to incorporate the idea of a central square in their buildings. Thus, most old age homes (bejaardenhuis) tried to build in some idea of a public space so that the world can be brought to the doorstep of its residents who are otherwise confined to their rooms, thus enabling them to lead normal lives within the protective though restrictive walls of the institution (Datta Chowdhury 1991, 241). In Regina Pacis, more than the ideal of a normal life it was the significance of a common space where individuals could meet and where face-to-face interaction between people with different interests could occur that was considered important.

Jan Diekema was certainly referring to this common space when he spoke about the agora—the space for creative display, physical space. But was there also something more implied? More than architectural space I think Jan Diekema was referring to the presence of an audience that was implied by the existence of such a space—an audience that could form the potential addressees of his critical utterances. Michael Warner (2002) uses the term "public space" to characterize the space in which discourse circulates, a space carved out by the trajectory of this discursive circulation in which publics exist by virtue of being addressed by discourse and are organized by it.

Once we begin to consider discourse as self-reflexive and conscious in its choice of addressees, we also have to think about the form that discourse takes. The choice of genre, the style in which it is embodied, will determine its range of circulation, the interpretative frames that it can anticipate, the projected field of argument, and so on (Warner 2002, 63). *Verpleeghuis* medicine already has a well-established genre that it uses for critical reflection—"the extended case study" popularized first in the writings of Ten Have (1979), thereafter by van der Wulp (1986) and The (2003), amongst others. Why were cartoons and fairy tales the preferred modes of self-expression? The first public display of creative work was on the occasion of a board meeting held in Regina Pacis under the chairmanship of the director who took over from the charismatic Dr. Leering in 1985. Dr. Diekema had worked closely with Dr. Leering to bring in new ways of thinking into the institution. Both probably felt his absence very

¹¹ It is interesting to note that the verpleeghuis has never sought to replicate the models of private domestic space. There was some attempt to replicate the idea of living in flats where patients were allowed to stay in single rooms with small, open kitchens and attached bathrooms in the late 1990s (Miesen 2009). Nurses would serve food and beverages to the patients from these personalized kitchens. Regina Pacis hired a floor of a disused old age home to try an experiment of this sort about ten years ago. However, this arrangement was financially not sustainable, given the drastic cuts in health care budgets as mentioned earlier.

keenly when he had to retire unexpectedly after a stroke. The director who replaced him was an economist by training and had a very different style of functioning. The decision to display their artwork that had been inspired by the *verpleeghuis* environment was as much a lament of a time gone by as it was a criticism of bureaucratic procedure.

As Warner says, writing to address a public helps to make a world. From the experiences of a known world one projects a public through whom one hopes to achieve transformation (2002, 64). Jan Diekema had experienced the verpleeghuis in more optimistic times when the welfare system was in a phase of expansion, and also when institutional possibilities and their transformation were viewed through a somewhat idealistic lens. The period after Dr. Leering's resignation was one of consolidation when bureaucratic protocols were put in place to try and ensure some of the democratic procedures that the first generation of gerontologists and verpleeghuis staff had discussed. However, bureaucracies tend to become ends in themselves and the larger purposes for which bureaucratic rules are formulated are often lost sight of over time. As a form of social criticism, cartoons do not generally counter normative or moral claims with opposing claims of their own. Their aim is not so much to posit a counter argument to the one being critiqued, but rather to expose the latter's claim to the moral high ground (Willet 2008). By using a form of "quotation irony," i.e. the citation and evocation of particular organizational protocols, Jan's cartoons serve as powerful tools to expose the "bad faith" arguments used to legitimize bureaucratic procedures in the patients' interest (Todorov 1983).

The cartoons that I now describe are from a series on bureaucracy and institutional care that Jan Diekema had worked on over several years. 12 Figure 1 depicts an elderly resident in a wheelchair, alone and forlorn, facing a window overlooking the picturesque garden, next to one of the corridors described so enthusiastically by Dr. Leering as the vectors of sociality but starkly empty in the picture, and underneath the caption, "And yet it doesn't really seem like home." The image brings out the contrast between corridors used for the repetitive "ambulations of pacing" by patients and meaningful forms of journeying through varied spaces such as streets and pathways that become sites of encounter and adventure (Desiarlais 1997, 20). Figure 2 shows a nurse at a dying patient's bedside—we, the viewers, know this because the familiar figure of time, the Grim Reaper with his scythe, is waiting outside the door; but the nurse does not see him as she is busy completing her work protocols. "Be quiet! Visiting hours are over," is what she says. But to whom is this addressed—to the patient or to the figure of death? Death, an ever-present reality in the verpleeghuis, is feared by most nursing staff as it goes against the ideology of hope that is so central to their training. The bed and body work of patient care that involves so much of their time can also become a way of keeping

¹² All images are reproduced here with the permission of the artist Dr. Jan Diekema. All translations from the Dutch are my own.

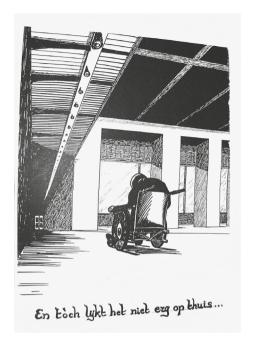


Figure 1: "And yet it doesn't really seem like home."



Figure 2: "Be quiet! Visiting hours are over ..."

this frightening possibility at bay as this cartoon shows. Dr. Diekema also drew a series of cartoons that dealt with the organizational aspects of Regina Pacis. Thus each one of them uses the image of a familiar object to speak of the institution in an ironic way. Regina Pacis is visualized as a ramshackle car without wheels and as a dilapidated truck almost invisible under the load of junk piled on top of it. Each one of the items carries the label of one of the committees responsible for bringing about reform in the verpleeghuis (Fig. 3). Figure 4 is especially interesting as it refers to protocols introduced to bring in democratic reform in the institution. It depicts a hobo filling gas balloons shaped like formally suited men (representing upper management), each with a label of a committee associated with reform. The caption below reads, "Our newest success number—the Complaints Committee for residents!" The repetition of organizational terms and their recontextualization in absurd scenarios serve as techniques to destabilize the familiar world in which such protocols are meaningful. The repeated use of quotation irony points to what Todorov calls the "inauthenticity of the initial act of enunciation"—to the spirit in which these reforms were initiated (1983, 63). Humour, as Bergson (1956) tells us, often depends on situations that can be interpreted in two entirely different ways. Thus the reduction of an institution to a machine, the sudden change in aspect, graphically represented, is the perfect tool for a genre that uses irony to communicate its message. Ridicule is inherently democratizing as it has a levelling effect, puncturing the hubris endemic to bureaucratic hierarchies.

The discussion in this chapter has so far drawn attention to the discursive regimes within which institutions operate and the way power circulates within them. Institutional enunciations, such as the organizational protocols ridiculed in Dr. Diekema's cartoons, acquire the status of truth and legitimize certain kinds of ideological apparatuses that help perpetuate the institution by not only producing certain kinds of discourses, but forms of subjecthood/subjugation as well (Foucault 1980). The concept of "interpellation" posited by Louis Althusser (1971, 121) helps us to better understand this dual operation by which ideologies are constituted by state apparatuses which then interpellate subjects through acts of naming and address. The allegorical narrative recounted below describes precisely this—the process by which the *verpleeghuis* resident is produced as a subject through bureaucratic procedures of subjugation.

Jan Diekema wrote a fairy tale (sprookje), a parody of the style of functioning of the verpleeghuis and its official rhetoric on the occasion of an in-house refresher course that had been organized for the nurses in 1987. A translation of the story is given in the Appendix. It is set in an imaginary place called potato land or more literally, Taterland. The scenario that unfolds is familiar to the verpleeghuis world. An old lady who lives on her own suddenly falls ill. Her kith and kin are far too busy with their own affairs to fathom just how critical her situation is. Before anyone realizes what is happening, she is whisked away to a mysterious, faraway place to which her little grand-daughter Piepeling journeys in search of her Grandma. Her companion on



Figure 3: "Only this one more [on top], and then we can go ..."



Figure 4: "Our newest success number—the Complaints Committee for residents!"

this journey is a wise owl who sees life as it is and passes no judgement. Piepeling finds her Grandma in a nightmarish world of frenzied activity and raucous sound presided over by a host of men clothed in white whose rank is determined by the size and brightness of the spoons that they carry. It is significant that the spoon, an essential implement for carrying out one of the basic activities of daily living, i.e. eating, should be used here to denote rank. The spoon is a sign of power, and Grandma has forgotten to bring hers and has to be fed. She is no longer able to "function" independently as a person. The much-vaunted plurality of *verpleeghuis* culture is reduced to mockery in this story. Difference implies hierarchy, and a hidebound specialism that can brook no criticism. Piepeling is told to go to the complaints commission when she dares to cross swords with one of the heads.

The story poses questions of basic existence—happiness, freedom, and loss. Piepeling's question becomes a refrain as she passes along the organizational hierarchy: "But what is Grandma actually doing here?" No one offers a proper answer. The important looking white-jacketed men can only offer platitudes in their professional jargon. Finally it is the young trainee who has taken care of Grandma who reveals the truth: "Everything has been tried but things remain the same. Perhaps they always come back to this state, they can't be really different." Yet the story ends on a note of hope. The boy weeps with Piepeling when Grandma dies. He is able to participate in her grief. It is only in the inter-subjective experience of this emotion that there can be redemption. The story, presented as a form of self-critique to young *verpleeghuis* caregivers, addresses the existential self in its singularity, stripped of all social and ideological attributes. In this way it fills the lacuna in the organizational discourse which can only speak in terms of a bureaucratically organized rationality.

Jan Diekema's fairy tale presents the critical voice in the role of witness. Piepeling, an innocent little girl, and the wise owl are both outsiders, and it is through their eyes that we view the *verpleeghuis* world. He uses this outsider perspective as a device of estrangement to highlight the moral space that the *verpleeghuis* occupies. This aspect is seen as constituting a reflexive relationship with the organizational aspect of the institution—the sphere of medical protocols and policy decisions. This relationship also brings about a heightened sensitivity to suffering and death. It posits a contradiction between illness as a perturbation in the bodily system that the *verpleeghuis* as therapeutic space will restore to equilibrium and illness as irreversible loss.

Brands and care networks

I have tried to show that the self-definition of the *verpleeghuis* simultaneously assumes contradictory counter themes which challenge the dominant definition (Emerson 2000). Jan Diekema's satirical utterances transform experiences in the institution into texts that become reflecting mirrors. It is not accidental that his choice of expressive genres emphasizes the voice

of the witness as an outsider—a device of estrangement—to destabilize common sensical definitions of reality. Thus, he turns official protocols and organizational practices into utterances that can circulate as quotations in new contexts, thereby problematizing their source and meaning.

The importance of thinking critically about the "institution" seemed to be a prerequisite to understanding the disordered lives of the people whom they cared for was, as I have tried to show, an important aspect of verpleeghuis care. Why am I using the past tense here? It is not as if the counter reality of the verpleeghuis is no longer given expression. In fact there is now a growing body of literature that uses the case study method to critique geriatric care facilities. Death, loss, and suffering lend themselves to parody and were recurrent themes for cartoonists in Dutch newspapers, though that may not still be the case (Verwey 1986, 1989). But this critique no longer finds its primary location within the verpleeghuis world. The importance of creating enclaves of "dissensus" was still recognized in the 1980s (Ranciere 2010).13 This was considered important for self-understanding so that the institution could reimagine its practices to itself. In the last two decades the symbolic imagination of the public sphere has increasingly given way to a market model in which health care institutions have to compete with each other for patients, now called clients, in an environment of diminished resources.

Still, in the Netherlands there is a strong sense of trust in public institutions and in the ethics of care. In spite of competition between different health care networks and insurance companies, the Exceptional Sickness Costs Act or Algemein Wet Bijzondere Ziektekosten (ABWZ) continues to finance continuous, systematic, long-term, multidisciplinary care. But other forms of financial support that the verpleeghuis used to receive, such as for infrastructure and building, is no longer available. The ABWZ was in the process of being reorganized and several initiatives such as financial support for household help were no longer available when I visited the Netherlands in 2010.14 In the past such institutions had much more autonomy, and therefore institutional arrangements were more malleable. Doctors, social workers, and other health care professionals organized the intake function of such institutions and would often try to make alternate arrangements which involved an interface between intramural and extramural care. It was the in-house doctors who decided whether patients should become prospective verpleeghuis inmates. The verpleeghuis no longer have this kind of independence. Institutions do not receive an annual budget from the government anymore. Instead they are paid in terms of beds occupied and the care contracts with individual patients in

¹³ The term connotes the opposite of consensus and is used by Ranciere to critique the dominant managerial culture under neoliberalism.

¹⁴ Many of these financial arrangements are fairly recent (2007–2008). Regina Pacis's financial troubles which led to its incorporation in a large care network date from the same period (see van de Rijdt-van de Ven 2009 for recent changes in the financing of old age care; also Risseeuw et al. 2005).

terms of specific nursing/care functions and medical interventions. The emphasis now is on only as much as is necessary, made-to-measure care (zorg op maat). An independent organization called the Central Indication for Care (Central Indicatiestelling Zorg, or CIZ) evaluates how much care per function is necessary for each patient and administers the ABWZ accordingly. Any change in the care contract, i.e. an addition of care functions, must be officially notified to the CIZ so that the institution can receive additional funds. The delay in payment due to procedural complications and the time lag between treatment and official accounting means that institutions are constantly scrambling for funds. Over and above this, they also receive regular directives to cut back on personnel and services.

The new managerialism in health care is client-centric, oriented to care as a commodity and to the patient as consumer. Care institutions have to become brands to survive. Brands are usually seen as drivers of revenue in a situation where there is not much difference between the products on offer. It is the function of the brand "to establish a point of competitive difference among similar products in a category" by creating symbolic meaning around the brand so that the product is transformed into something special (Franzen and Moriarty 2009, 74). Regina Pacis's recent merger with a large care corporation called Attent-Residence, Wellbeing, Care (wonen, welzijn, zorg) reflects this new approach. Its website claims to offer a broad spectrum of services, different institutions each with a distinctive culture. 16 There is now a contradiction between the ABWZ that supports CSLM care (Continuous, Systematic, Long-term, Multidisciplinary Care) offered in the verpleeghuis as a public good and the institution as a profit-making organization that has to finance itself through its own earnings. Medical institutions like Regina Pacis are now monitored for credit worthiness when they apply for bank loans for their infrastructural needs. This has led to greater corporatization as a form of brand management, cuts in staff and "nonessential" facilities for patients. There is also an emphasis on extramural services such as consultative services by doctors and so on.

According to Jan Diekema, it is precisely this new form of managerial culture based on a form of consensual politics in which one knows and accepts one's role within a bureaucratic hierarchy that disallows the idea of the agora as a space of dissensus where contestation and litigious speech is possible. His words, spoken when we had met in 2010, acquired a prophetic quality some years later when, at his retirement party, he made a PowerPoint presentation of his cartoons that depicted a humorous history of Regina Pacis in lieu of a farewell speech. In a bittersweet exchange with me via email he wrote that his presentation met with "deafening silence;" no one commented on his unusual farewell speech or asked him about

¹⁵ This is called the *zorgzwartepakket* or "weight of care package" for an individual patient.

¹⁶ https://www.attentzorgenbehandeling.nl/wonen/regina-pacis-arnhem, accessed on February 20, 2020.

his eccentric vision of the *verpleeghuis*.¹⁷ In a further exchange with Jan Diekema, we discussed the role of neoliberal ideas and their impact on institutions. One may laud the emphasis placed on individualism, autonomy, and freedom of choice but an unintended consequence of this may be that critical voices may be less threatening and therefore tolerated as individual opinion rather than as important correctives of institutional practice.

So has the vibrant expressive culture that once existed around the existential situations that were typically associated with the *verpleeghuis* vanished? Bere Miesen, a psychologist specializing in psychogeriatrics, started the initiative known as "Alzheimer Café" in Leiden in 1997 to provide opportunities for the "emancipation of the patient and his family" through counselling. The Alzheimer Café consists of a gathering that is held once a month to discuss issues relating to dementia. The term "café" is used deliberately to evoke a "non-compulsory, open-ended, non-bureaucratic tone" (Miesen 2000, 244). It has now become a franchise with branches all over the Netherlands and in countries such as Belgium and England. Miesen's intention is to spread awareness about dementia by encouraging sufferers and their families to communicate with others in similarly placed situations. This, he feels, will create greater self-reflexivity in the experience and management of the illness.

Miesen's experiment is a successful attempt at creating a new form of branded service—a rational and useful product which also has an emotional and symbolic meaning. Dementia is the one disease that is most threatening to the Dutch values of individuation and autonomy. By emphasizing the aspects of self-awareness and control over the course of the disease trajectory, he is able to package a service as a new kind of intervention. This kind of branding is happening at a time when the *verpleeghuis* is increasingly becoming subject to adverse criticism about the quality of care that they are able to offer.

In a sensitive and thought-provoking account on the "logic of care" operative in the medical field, Annemarie Mol (2008) discusses the forms of interpellation evoked by the social imagination articulated by the ideology of choice. The two dominant contexts in which the "logic of choice" is operative in the Netherlands according to Mol are the market and the sphere of democratic state apparatuses. The market interpellates the person as a customer who is able to choose the products he or she wishes to consume and state apparatuses do so by constituting the person as a citizen who is defined by their ability to control their bodies. Mol argues that the "patient" conforms to neither model of subjecthood. As Mol says, the care relationship between doctors and patients cannot be articulated as a transaction in which the former hand over clearly defined health "products" to

¹⁷ Jan Diekema started drawing cartoons again after a long hiatus soon after my last visit to Arnhem in 2010. As part of his farewell address to his colleagues in Regina Pacis, he made a PowerPoint presentation of his cartoons spanning more than two decades. His presentation however was met with a deafening silence (communication by e-mail from Jan Diekema, November 2015).

the latter. The exigencies of disease require long term and varied kinds of interaction in which the terms of engagement may shift from day-to-day (2008, 16). Similarly, it may be difficult to posit patients as citizens in the care relationship as they are rarely in the position to control their fragile bodies. The care relationship is not an on-off transaction but a social process in which neither caregivers nor receivers are seen as autonomous individuals. Instead, they form shifting collectivities whose boundaries may shift from time to time depending on the vagaries of the disease process.

The process of de-institutionalization had already started in the Netherlands when I conducted my fieldwork in the 1980s. There was talk of "economization" (bezuiniging). Hospitals were for short-term stay, and old age homes were no longer admitting healthy old people as they had in the 1960s and 1970s when such institutions were touted as ideal residences enabling old people to maintain their independence. The verpleeghuis's imagination was shaped by its residual status—as an appendage to the hospital, as a residential, chronic care facility. But its institutional autonomy did allow for the possibility of an expressive space within its walls. The contradiction between a contractual model of care and the fact that an indication for verpleeghuis admission meant that the prospective patient had no alternative mode of residence and thus no real choice in an alternative life style provide a fruitful subject for critical expression. As de Swaan (1988) shows, the transfer of responsibility to professional caregivers is a way in which dependence is made acceptable in Dutch society. The generalization of dependence helps individuals to come to terms with contradiction between the value of autonomy and old age disability. However, the acknowledgement of a counter reality—the fact that care cannot be constrained within the model of a contract but must always include a social surplus—is only possible in this critical space (van der Veen 1991). As of now the *verpleeghuis* is struggling to come to terms with the market model, and its credit ratings are often low. Staff members have many more extramural tasks such as consultancies, but many complain about the loss of voice. This is in spite of the elaborate committees that are set up to redress complaints within the verpleeghuis and so on. The increase in scale that is a by-product of corporatism means that individual voices are often difficult to hear. Sociologists like Richard Sennet (2007) have spoken about the importance of institutional stability in the creation of meaningful life narratives for those who work in them. Even highly bureaucratized organizations can provide creative outlets for their workers in the way that rules are interpreted and tasks accomplished. Staff members who are committed to the work that they do have been able to create meaning precisely by engaging with official protocols in a reflexive manner. The radical changes that have occurred in the last decade, the loss of institutional identity, have led to the shrinking of this critical space as it existed within the institution. There is no dearth of critical writing on health care in general and on dementia in particular. But it is largely by people who stand outside the medical system.

Revisiting the field is always difficult. A sense of nostalgia tends to distort one's vision, and it is hard to present an objective picture of the current situation. The decades of the 1960s and 1970s, when the verpleeghuis developed as an independent institution, were exceptional times. Unprecedented economic growth was coupled with an idealism that was translated into the social values associated with the welfare state that supported personal development and self-reflexivity regarding life style choices. The 1980s, the period of my fieldwork, were already marked with a growing anxiety about economic stagnation and the state's inability to continue with the extensive welfare measures that were in place. However, some of the radicalism of the early decades could still be seen in the way that the institution was able to look at itself critically, with self-doubt. Most people whom I've known since the 1980s now say that the reorganization of work due to the resource crunch no longer allows for the luxury of such self-reflection. Writing about the past, not as a seamless chronicle but rather as a re-presentation, allows one to select particular events and view them in the light of images and aspirations that helped shape the imagining of such an institution. I have used the image of the "agora", its rise and development and then its substitution by another image—the "café" and its franchise—to highlight a particular aspect of the institution's selfunderstanding, one that is rarely highlighted in discussions of verpleeghuis organization. Understanding the social imaginary is an important aspect of the history of modern social institutions, and creative expressions such as the ones discussed here—may be one of the ways in which it is available for study (Taylor 2004).

By way of conclusion

But what about the story from India? Such questions are inevitable when the researcher is an Indian as I learned from my interactions with Dutch colleagues during fieldwork in the Netherlands. At that time my response was that comparing geriatric institutions in India and the Netherlands was like comparing apples and oranges—they are incommensurable. But perhaps this question requires a more thoughtful response. What form does institutionalization take in India, especially in the medical field? In a comparative account of a hospital in Srinagar, Kashmir and the verpleeghuis in Arnhem, Sangeeta Chattoo, Veena Das, and I (1998) were able to show that the 'chronic care' model in which multiple pathologies are supposed to be managed in a holistic fashion that governs geriatric care in the Netherlands is rarely applied to the elderly in India where the 'acute cure' model tends to prevail so that illness episodes are treated as discrete units without a sense of long duration. Total institutions with specially designed environments to enable severely impaired patients to lead full and creative lives is possibly a utopian vision even in the Netherlands but unthinkable in a country with scarce resources such as India. But more importantly, in

India it is difficult to talk about institutions without discussing the role of intimate relations with family and kin networks. In a society where the family is still thought of as the primary unit of care, institutional boundaries are porous. Family members are an intrinsic part of hospital wards as they are the primary caregivers of the patients (Addlakha 2008). Even in cases of long-term institutionalization, scholars like Sarah Pinto (2016) describe the ebb and flow of intimacies as patients come to be folded into the web of kinship at times, while at other times they fall out when the burden of care may snap intimate ties worn thin by the very opacity of the illness experience. In a different key, Veena Das (2015) discusses the impact of new medical technologies, governmental practice and the discourse of global health on the urban poor in Delhi. Using the neighbourhood as her ethnographic site she shows how neo-liberal regimes impact the poor, generating new markets for pharmaceuticals and medical technologies while simultaneously extending the sphere of kinship obligations. By constructing people as consumers of health she shows how the burden of care and the responsibility for health increasingly falls on the individual and his/her family in situations of poor institutional delivery.

Are India and the Netherlands comparable? Given that India has still to achieve equity in health and medical provisioning it would seem that they are not. Yet in India development in the medical sphere is very uneven and cutting edge medical technology and institutions co-exist with forms of medical provisioning that border on quackery. It is the idea of medical pluralism and the range of choices that it gives to individuals that is sometimes used to justify the presence of such divergent kinds of medical provisioning while it bypasses questions of poor institutional delivery (Das and Hammer 2004). In the Netherlands radical changes in the verpleeghuis have come about in a response to a critique of the ways in which chronic dependency in the Netherlands is admitted into social life only through the mediation of total institutions such as the verpleeghuis. Such reforms attempt to align such institutions with the values of a liberal democracy in which citizens are conceived as autonomous, independent, and rational and society is an association of such individuals who have the right and the ability to make their voices heard. The model of the *verpleeghuis* that Leering envisioned was an environment that would enable severely dependent people to live with a creative vitality even in diminished circumstances. His idea of creative vitality would require a type of sociality radically different from the forms implied by the liberal ideas that govern not only Dutch society but the global health discourse today.

Acknowledgements

The staff and residents of Regina Pacis made my research possible. I returned to Arnhem with some trepidation but the welcome I received after such a long gap made me feel as if I was coming home. I am especially grateful to Cory Tromp, Jan Diekema, Dinni te Pas, Jeroen Fokke,

Ruud Lambregt, Klaas and Jenny van der Veen, Sanjib and Namrata Datta Chowdhury, and Carla Risseeuw. I would also like to thank the International Institute of Asian Studies at Leiden for hosting my visit to the Netherlands, and Christiane Brosius for inviting me to participate in the "New Approaches to Ageing in South Asia and Europe" workshop in Delhi that enabled me to revisit this material.

Figures

Fig.1-4: By courtesy of Jan Diekema. © Jan Diekema.

References

- Addlakha, Renu. 2008. *Deconstructing Mental Illness: An Ethnography of Psychiatry. Women and the Family*. Delhi: Zubaan.
- Althusser, Louis. 1971. *Lenin and Philosophy and Other Essays*. Translated by Ben Brewster. New York: Monthly Review Press.
- Bakhtin, Mikhail. 1984. *Rabelais and his World*. Translated Hélène Iswolsky. Bloomington: Indiana University Press.
- Bergson, Henri. 1956. "Laughter." Translated by Cloudsely Brereton and Fred Rothwell. In *Comedy: "Laughter" Henri Bergson, "An Essay on Comedy" by George Meredith*, edited by Wylie Sypher, 61–198. New York: Doubleday.
- Chatterji, Roma. 1991. "Regina Pacis: An Introductory Account." In *The Welfare State from the Outside: Aging, Social Structure and Professional Care in the Netherlands,* edited by Roma Chatterji, Veena Das, Sanjib Datta Chowdhury, Rajendra Pradhan, and Klaas W. van der Veen, 336–384. Indo–Dutch Programme for Alternatives in Development (IDPAD).
- ——. 1993. "The System of Hope: The Constitution of Identity in Medical Institutions." *Sociological Bulletin* 42 (1 & 2): 157–170.
- Chatterji Roma, Sangeeta Chattoo, and Veena Das. 1998. "The Death of the Clinic? Normality and Pathology in Recrafting Aging Bodies." In *Vital Signs: Feminist Reconfigurations of the Bio / logical Body,* edited by M. Shildrick and J. Price. 171–196. Edinburgh University Press.
- Cohen, Lawrence. 2000. *No Aging in India: Alzheimer's, the Bad Family and Other Modern Things*. Berkeley: University of California Press.
- Das, Veena 2015. *Affliction: Health, Disease, Poverty*. New York: Fordham University Press.
- Das, Jishnu and Jeffery Hammer 2004. "Strained Mercy: Quality of Medical Care in Delhi." *Economic and Political Weekly* 39 (9): 951–961.
- Datta Chowdhury, Sanjib. 1991. "An Introduction to the Home for the Aged." In *The Welfare State from the Outside: Aging, Social Structure and Professional Care in the Netherlands*, edited by Roma Chatterji, Veena Das, Sanjib Datta Chowdhury, Rajendra Pradhan, and Klaas W. van der Veen, 262–314. Indo-Dutch Programme for Alternatives in Development (IDPAD).

- Desjarlais, Robert. 1997. *Shelter Blues: Sanity and Selfhood among the Homeless*. Philadelphia: University of Pennsylvania Press.
- De Swaan, Abram. 1988. *In the Care of the State: Health Care, Education and Welfare in Europe and the USA in the Modern Era*. Oxford: Polity Press.
- Emerson, Joan. 2001. "Behaviour in Private Places. Sustaining Definitions of Reality in Gynaecological Examinations." In *Organizational Studies: Critical Perspectives on Business and Management. Vol II: Objectivity and its Other*, edited by Warwick Organizational Behaviour Staff, 889–901. London: Routledge.
- Foucault, Michel. 1980 [1977]. "Two Lectures." Translated by Alessandro Fontana and Pasquale Pasquino. In *Power / Knowledge: Selected Interviews and Other Writings* 1972–1977, edited by Colin Gordon, 77–108. New York: Pantheon Books.
- Franzen, Giep, and Sandra Moriarty. 2009. *The Science and Art of Branding*. Delhi: Segment.
- Goffman, Erving. 1961. Asylums: Essays in the Social Situation of Mental Patients and Other Inmates. New York: Doubleday.
- Kossmann, E.H. 1986. *De Lage Landen 1780 / 1980: Twee Eeuwen Nederland and Belgie: Deel II 1914–1980.* Amsterdam: Elsevier.
- Leering, C. 1968. *Gestoord Menselijk Functioneren: Een Onderzoeknaarnaarde Structuur van de ADL bij Patienten in Verpleeghuizen*. Nijmegen: Dekker & van der Vegt.
- ———. 1970. Omschrijving van de Fundementele Uitgangspunten: Alsmede Nadere Concrete Gegevensvoorhet Formuleren van een Programma van Eisen vooreen Nieuw Verpleeghuis"Regina Pacis." Arnhem: Regina Pacis.
- Miesen, Bere. 2000. Mijn Leed, Mijn Lief. Omgaanmet Gevoelens, Ervaringen en Emotionele Achtergrondenbij Dementie: Leidraadvoor Patienten, Familieleden, en Verzorgenden. Utrecht: Bohn Stafleu Van Loghum.
- ———. 2009. Bij Alzheimer op Schoot: Verstand van Dementie. Amsterdam: SWP.
- Miesen, Bere, Anne-Marie Streppel, and Paul Tjoa, eds. 1981. *Nog Even Blijven:*Ontmoetingenmet Oudere Mensen. Amsterdam: Van LogumSlaterus.
- Mol, Annemarie. 2008. *The Logic of Care: Health and the Problem of Patient Choice*. Abingdon: Routledge.
- Noland, Carrie. 2007. "Motor Intentionality: Gestural Meaning in Bill Viola and Merleau-Ponty." *Postmodern Culture* 17, no. 3 (Fall): 1–35.
- Pinto, Sarah. 2016. "Walking Through: Movement, Schizophrenia and the Vicissitudes of Presence." In *Living and Dying in the Contemporary World: A Compendium*. Edited by Veena Das and Clara Han, 510–524. Berkeley: University of California Press.
- Ranciere, Jacques. 2010. *Dissensus: On Politics and Aesthetics*. London: Continuum. Risseeuw, Carla, Rajni Palriwala, and Kamala Ganesh, eds. 2005. *Care, Culture and Citizenship: Revisiting the Politics of the Dutch Welfare State*. Amsterdam: Het Spinhuis.
- Rhodes, Lorna. 1991. *Emptying Beds: The Work of an Emergency Psychiatric Unit.*Berkeley: University of California Press.
- Sennet, Richard. 1994. Flesh and Stone: The Body and the City in Western Civilization.

 London: Penguin Books.
- ———. 2007. *The Culture of New Capitalism*. Delhi: Orient Longman.

- Taylor, Charles. 2004. *Modern Social Imaginaries*. Durham, NC: Duke University Press.
- Ten Have, H. 1979. *Het Verpleeghuis: Veld van Onderzoek*. Deventer: van Loghum Slaterus.
- The, Anne-Mei. 2005. *In de Wachtkamer van de Dood. Leven en Stervenmet Dementie* in een Verkleurende Samenleving. Amsterdam: Thoeris.
- Todorov, Tzvetan. 1983. *Symbolism and Interpretation*. Translated by Catherine Porter. London: Routledge.
- Van de Rijt-van de Ven, A. J. H. 2009. *Complexe Ouderenzorg in Verzorgingshuis en Huis: Handreiking, Samenhangende Zorg in de Eerste Lijn*. The Netherlands: LHV, KNMP, NHG & NVA.
- Van der Veen, Klaas W. 1991. "Who Cares and Why? A Comparative Discussion of Cultural Codes and Social Support." In *The Welfare State from the Outside.*Aging, Social Structure and Professional Care in the Netherlands, edited by Roma Chatterji, Veena Das, Sanjib Datta Chowdhury, Rajendra Pradhan, and Klaas W. van der Veen, 9–89. New Delhi/The Hague: Unpublished Report Submitted to Indo-Dutch Programme on Alternatives in Development (IDPAD).
- Van der Wulp, J. C. 1986. Verstoring en Verwerking in Verpleeghuizen: Belevingswereld en Conflicten van henen die Verdere Leven in een Verpleeghuisdoorbrengen. Nijkerk: Intro.
- Verwey, Stefan. 1986. Waar Zit de Pijn Precies? Amsterdam: De Harmonie.
- ———. 1989. Lang zullenze Leven. Amsterdam: De Harmonie.
- Warner, Michael. 2002. "Publics and Counterpublics." Public Culture 14 (1): 49-90.
- Willet, Cynthia. 2008. *Irony in the Age of Empire: Comic Perspectives on Democracy and Freedom*. Bloomington: Indiana University Press.

Abbreviations

ABWZ	Algemein Wet Bijzondere Ziektekosten (Exceptional Sickness Costs Act)
ADL	activities of daily life
CIZ	Central Indicatiestelling Zorg (Central Indication for Care)
CSLM	Continuous, Systematic, Long-term, Multidisciplinary Care
IDPAD	Indo-Dutch Programme for Alternatives in Development

Appendix: The Story of Piepeling in Pottage Land

Jan Diekema¹⁸

A long time ago and very far away there was a land called Taterland because the people who lived there cultivated them in enormous quantities. They used them in all their transactions; they gave them as birthday presents, they paid their bills with them and threw them away with their rubbish. In short, their lives revolved around these taters and everyone was happy.

In a small village in Taterland there lived a little girl called Piepeling who, along with her brothers and sisters, was also involved in all these tater happenings even if on a more modest scale. They could have carried on like this for years, uninterrupted but for the fact that one day they got a letter from Grandma. Grandma lived alone on the other side of the dark woods and it seemed from the letter that because of her age and ill health she could not manage her taters any more. Did they have a bag of taters left over for her? I am sorry to say that the letter came at a most inopportune moment—the whole family was extremely busy with their own taters and had very little time for an old lady who was sick. She would insist on living on her own they thought, and now who could they send to take care of her?

Finally little Piepeling was sent with a bagful of creamy taters so that stubborn Grandma was taken care of and everyone could say that they had done their duty.

Little Piepeling had a nice walk in the warm midday sun. She skipped up the path that led to the cottage where Grandma lived. But strangely no one answered the door when Piepeling rang the bell. The shutters were closed and no smoke came out of the chimney.

"Looking for someone?" asked a voice from above. On the roof sat a large brown owl who blinked at her with round yellow eyes.

"I am looking for Grandma," said Piepeling.

"She is not in," drawled the owl, "shifted house or something, some time ago." It seems that Grandma had been taken away by some large men in white jackets.

"Oh," said Piepeling, "but I have to give her these taters, do you know where she has gone?"

The owl closed its eyes and thought.

"You will have to walk a long way. Perhaps I should come with you."

"That would be nice," said Piepeling with relief, "but I don't have my walking shoes on."

"We shall be flying," said the owl impressively.

He swooped down from the rooftop and seemed suddenly to grow three times larger. He swept Piepeling up on his back and flew off high above the woods and fields of Taterland. Piepeling felt dizzy from looking down and closed her eyes tightly for the rest of the journey. Then, all of a sudden, there was a loud thump and Piepeling saw that they had landed on the ground. Before them was a high wall in white stone with a gate in the middle. Over the gate was written:

¹⁸ Translations from the Dutch in this appendix are my own.

POTTAGE LAND

HOUSE ANIMALS AND UNAUTHORIZED PERSONS FORBIDDEN

"We are here," said the owl—his voice very close to her ear. He seemed much smaller now and Piepeling saw that he was sitting on her shoulder. His small brown head near her ear gave her a warm and cozy feeling.

One the other side of the gate they could see a big, sunny meadow. It seemed rather bare, without any trees or bushes and they could see no flowers anywhere. Old people sat in groups on the meadow and there were several young people dressed in white who scurried around. Most of them had big white bowls in their hands which they would fill from a row of taps on one side of the meadow and then rush screaming towards the group of old people. In one corner stood a pop group that belted out an ear-splitting tune so that it looked like a scene from a carnival.

"Does Grandma live here?" asked Piepeling amazed. "What is this place and what are these people doing?"

"This is where the main pottage distribution takes place," whispered the owl in Piepeling's ear.

It took some time to find Grandma. She was sitting in the midst of a group of very old people and there was a young man in white overalls who sat near her with a white bowl on his lap. He was busy ladling thick soup into her mouth with a thick yellow spoon worn out with use. Grandma was chewing like one possessed and could barely pause to greet Piepeling.

"Can't you do that more slowly," asked Piepeling, "does it have to go so fast?"

The young man looked up briefly without stopping from what he was doing and said, "No it can't. Actually it should go much faster! I am already behind in my pottage schedule!"

The bowl was almost empty and the dirty yellow liquid dribbled down Grandma's chin.

"What are you feeding her?" asked Piepeling.

"Can't you see?", said the young man irritated, "why, pottage of course! They all get that here. It's very good for them! And I have six more to do. Now that's called overworking!" With that he spooned the last mouthful into Grandma's mouth, sprang up and disappeared into the crowd.

"Pottage distribution is not as simple as it looks," whispered the owl, "you have to be trained for it and to have followed all the refresher's courses."

"Why aren't you at home and why and what are you doing here?" asked Piepeling leaning beside Grandma.

Grandma sighed and shook her head, "I couldn't peal my taters any longer, so they have brought me here".

"I have brought some for you," said Piepeling and showed her the bag.

"Let it be child," said Grandma, "It's very kind of you to bring them but I don't think I like them any more".

"But you can always use them to buy things and distribute them," Piepeling argued.

"That's not allowed," whispered Grandma, anxious in case anyone had heard. "Only Pottagelanders with spoons can distribute things and I have left mine at home. Besides, everyone eats pottage here".

"But no one has a spoon in Taterland and no one eats this dirty pottage," said Piepeling angrily.

"But here they do," said Grandma, "and the bigger and shinier the spoon is the more you have to say. But I don't mind not having a spoon dear, you get used to it very quickly."

"That's called hospitalization," said the owl. But Piepeling wasn't listening.

"I think this pottage is tasteless," she snapped, "let's go home and then you can have some delicious taters with us."

"That's strictly forbidden," a harsh voice rang out behind them, "and that dirty bird must be removed immediately!"

Piepeling turned around and saw a tall Pottagelander with her hair screwed tightly in a bun and an iron spoon in her hand. The owl rustled its feathers nervously.

"Who are you and what business is it of yours," asked Piepeling. She was a little scared and tried to sound angry to make herself feel brave.

"If you are the boss then why don't you see that Grandma has her taters," asked Piepeling, "and do you also have to eat pottage?" She rushed off, saying over her shoulder, "Grandma must first recover, go ask the pottage magician."

Piepeling burst into tears. "This is a horrible place," she cried, "no one has the time and I know you are not comfortable here."

"Only in the beginning child and that was when I wasn't used to the pottage. But you get enough of it to eat even if you do have to wait for it and there is no one to talk to you."

"The boy was so rude," Piepeling sniffed.

"He can't help it," said Grandma, "he is only a trainee and everyone sits on his head."

Piepling blew her nose and got up. "I'm going to look for the pottage magician and take you out of here."

The owl shook his head but Piepeling ignored him.

"Do you know for certain that Grandma wants to leave," asked the owl.

"I don't care," Piepeling stamped her foot, "I think that this is a horrible place for Grandma to be in."

The pottage magician was also in a meeting. He wore a white jacket and had wrinkles on his forehead. Together with a couple of other Pottagelanders he was eating delicious golden taters with a bright copper spoon. At first Piepeling could not make herself heard over the din that the Pottagelanders were making. Everyone was talking at the same time with their mouths full and no one was listening.

"Will Grandma get better," shouted Piepeling, pushing her way in to stand next to the bowl of taters. That helped and they all stared at her while she repeated her question.

"Yes," said the pottage magician, "I am doing my best. But I have so many Pottagelanders to physic and that is a lot of work."

"She isn't here for nothing you know," said another Pottagelander, "she has to exercise a lot before she can even think of taters."

"Precisely, and her spoon has still to be measured and adjusted to suit her." 19

"And all that has to be planned, organized and coordinated," added the pottage magician, "order and regulation you know."

"Oh!" said Piepeling, looking at the chaos in the room.

"Our work is our chief concern," said the pottage magician, "this is a genuine revalidation institute."

"But in the mean time they all get pottage and far too quickly at that," said Piepeling, "why don't you go and help the trainees."

There was a deathly silence while the Pottagelanders glared at Piepeling.

"And what does Grandma do besides eating pottage all day?" she asked.

"Aha, there is a special department for that. People do pottaging and mashing there. In the corner, look, in the corner over there," said the pottage magician.

Piepeling found a Head Pottage Distributor with a silver spoon. She was also in a meeting but she seemed to have the time to explain.

"It is to do with the fact that people live here," she said, "and to make that more pleasant we offer them different kinds of pottage—radio pottage, TV pottage, even video pottage. We also have music pottage and song pottage for the more discriminating tastes. We have recently developed sleep pottage—it's the absolute end!"

"But it's pottage for all that," said Piepeling.

"If you have come here to criticize go to the complaints commission," said the Head Pottage Distributor, "good day."

Piepeling turned sadly back to the teaming crowd in the meadow.

"I told you so," said the owl, "you should have listened to Grandma."

"I don't believe that," Piepeling said, "Everyone here is busy with their own spoons and nobody cares about Grandma."

"Do you really think that child," a grave voice spoke behind her. When she turned around she saw an important looking Pottagelander holding a golden spoon. Clustered around him were a group of Pottagelanders with silver spoons.

"The Chief Pottage Distributor himself," whispered the owl.

"Oh gosh!" said Piepeling, but then taking a deep breath she asked, "Can you tell me if Grandma will get better and why she has to eat pottage?"

The Chief Pottage Distributor took a deep breath and began, "In the light of the threatened retrenchment, both in the sphere of pottage as well as spoon provisions and given the fact of the evaluation of service functions, the computerization necessary for our systems, the development of action committees, etc., the stew pot is growing steadily emptier and the spoons..."

"I don't understand a word of it," Piepeling interrupted rudely, "I just want to know how Grandma is?"

"But that is what I am talking about child," said the Chief Pottage Distributor bending over her, "We are trying out new policies to see whether less pottage can be

¹⁹ The reference is to *zorg op maat* or "made to measure care" that is part of the individual care plan of each patient.

distributed to more people so that there is still enough. A great responsibility rests on our shoulders."

"Oh!" said Piepeling as the Pottagelanders seemed to swell with pride as they listened to their leader's weighty words, "What is 'responsibility'—what does it look like?"

The owl swallowed the wrong way and broke into a fit of coughing. The Chief Pottage Distributor started to explain, waving his spoon for greater emphasis. His companions seemed suddenly to deflate.

"I think that none of you have ever distributed a spoonful of pottage," cried Piepeling, "or else you would have done something about it. I think responsibility only means being able to wave fancy spoons around and not to have to share things the way we do in Taterland. I am going to take Grandma home!"

Grandma was lying down when Piepeling reached the meadow. She recognized the trainee pottage distributor. He was kneeling besides Grandma and was holding her hand tightly in his own.

"What happened to your pottage schedule," asked Piepeling.

He looked up and Piepeling saw that he had been crying.

"I am saying goodbye to her," he said, "my duty time is over."

"I am taking Grandma home," Piepeling said, "we are leaving now."

"There is no hurry for that," said the boy, "we must get her ready first and arrange the transport for her."

"She can go with us as she is—don't you agree?" said Piepeling, turning to the owl.

"Why don't you ask her first," growled the owl softly.

But Grandma did not answer. She was lying very still.

Sometime later when Piepeling had cried her fill, and the meadow had become very dark, she saw to her surprise that the boy still stood by her. She had been using his handkerchief without knowing it and had wrung it out five times only to soak it again with her tears.

"She was actually quite happy here," said the boy but he sounded uncertain.

"I still think that there is something wrong with this place," Piepeling said, "but I have to think about it."

"Very sensible," said the owl, "who knows, perhaps you will have to take pottage yourself one day when you are old."

"Never!" cried Piepeling, "I would rather die! And anyway by then things will be better."

"Yes, you always hear them saying that," sighed the boy, "but no one has ever come up with anything better. Everything has been tried—pottage theory, pottage magic, pottage *mantel zorg*, ²⁰ unit pottage provision and lots more—but it always comes back to pottage distribution in the end."

"I am going to think of something better," said Piepeling in parting, while saying goodbye to the boy. When she was flying over the dark wood on the owl's back the thought came to her that the boy had very gentle eyes even though he wanted to become a pottage distributor.

And that was a nice thought to take home with her.

²⁰ Mantel zorg is assisted home care.